

# Effects of the TCARE<sup>®</sup> Intervention on Caregiver Burden and Depressive Symptoms: Preliminary Findings From a Randomized Controlled Study

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**Objectives.** We examined the effects of a manualized care management protocol specifically designed for care managers working with caregivers, the Tailored Caregiver Assessment and Referral<sup>®</sup> (TCARE<sup>®</sup>) protocol, on caregiver identity discrepancy, burden, and depressive symptoms.

**Methods.** Preliminary data from a longitudinal, randomized, controlled intervention study with 266 family caregivers served by 52 care managers in 4 states were analyzed using repeated measures random effects regression procedures. Caregivers in the intervention and control groups were repeatedly assessed for up to 9 months on caregiver identity discrepancy, 3 areas of caregiving burden—objective, relationship, and stress burdens; depression; and intention for nursing home placement.

**Results.** We found significant group by time interaction effects for caregiver identity discrepancy, relationship burden, stress burden, depression, and intention for nursing home placement. Caregivers in the intervention group experienced significant improvement on these measures, whereas caregivers in the control group worsened on these measures over time.

**Discussion.** The preliminary findings provide strong support for effectiveness of the TCARE<sup>®</sup> protocol on improving caregiver well-being and mental health outcomes.

**Key Words:** Caregiving—Caregiver identity theory—Care management—Intervention—TCARE<sup>®</sup>.

AN estimated 65.7 million Americans provided unpaid care to one or more disabled or ill family members or friends in 2009 (National Alliance for Caregiving & AARP, 2009). This provision of care does not come without costs. An extensive body of literature documents the link between caregiving and a variety of negative mental and physical health outcomes (Schulz & Sherwood, 2008).

Over the past two decades, considerable efforts have been made to develop and test the effectiveness of a range of support services for family caregivers (Goy, Freeman, & Kansagara, 2010). These caregiver interventions have included respite services (Zarit, Stephens, Townsend, Greene, & Leitsch, 1999), psycho-educational skills training (Bourgeois, Schulz, Burgio, & Beach, 2002; Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2003), cognitive behavioral therapy or family counseling (Gonyea, O'Connor, & Boyle, 2006; Mittelman, Haley, Clay, & Roth, 2006), or a combination of services (Belle et al., 2006). Two observations can be made about findings that have emerged from these studies. First, the most

promising findings regarding the positive impact of support services on caregivers have emerged from studies that include a relatively comprehensive set of multiple support services (Belle et al., 2006). Second, it is clear that the programs are most effective for reducing caregiver burden when the services are provided in sufficient quantities and targeted to specific needs. Unfortunately, even with this information from numerous studies of caregiver interventions, few resources exist to help guide care managers or other family specialists to formulate decisions about the correct type of services and the most appropriate time for initiating service use. As a result, there is a tendency for service providers or care managers to offer caregivers the services that are available in their communities with little knowledge about which services are most needed and most likely to be used by and benefit the caregiver at that point in time. Unfortunately, this practice creates the circumstance that many caregiver services go unused, and/or they are provided at a point in time that is too late to fully benefit the caregiver or the care receiver (Montgomery, 2002).

The Tailored Caregiver Assessment and Referral<sup>®</sup> (TCARE<sup>®</sup>) protocol is an efficient evidence-informed process that was developed to assist care managers and practitioners working with family caregivers to meet the unique needs of individual caregivers (Montgomery & Kwak, 2008). The protocol reflects current knowledge about caregivers and caregiver interventions and is grounded in the *Caregiver Identity Theory* articulated by Montgomery and Kosloski (2009). The major tenet of the *Caregiver Identity Theory* is that caregiver identity discrepancy, defined as a disparity between the care responsibilities that he or she is assuming and his or her identity standard, is a major source of caregivers' stress.

This conceptualization of the distress process builds upon the work of Burke (1991, 1996) and his colleagues who consider identity maintenance to be a continuous process in which identity standards are applied to the self in a social role. Identity standards are personal norms that serve as reference points for self-appraisal in a role. These personal norms are influenced by social, cultural, and familial norms. Consistency between an individual's identity standards and appraisal of behaviors maintains identity stability. An inconsistency between identity standards and behaviors challenges identity, resulting in stress and, at times, a transition to a different social role and new identity standard (Burke, 1991, 1996). Caregiver identity theory suggests that the caregiving role emerges out of a prior familial role, most often the role of child or spouse. As a caregiver assumes greater responsibilities for care he or she experiences an identity change in relation to the care recipient and a change in identity standards. This change process is dynamic and continues as the tasks and responsibilities of the caregiver change in response to the changing needs of the care recipient and care context. For most caregivers, the change in role identity is a slow insidious process that proceeds in stops and starts, ultimately resulting in a significant shift from one's initial role relationship to the care recipient. For example, a daughter may easily assist her mother who has some difficulty paying bills or shopping without experiencing stress. As the disease progresses, the needs of her mother and the resultant demands placed on the daughter increase. As this process unfolds, the daughter's activities gradually increase in intensity and become discrepant with the norms that the daughter has internalized with respect to her role as a daughter. Simply put, her activities are now discrepant with her previous role identity, that is, identity discrepancy.

This identity discrepancy can be manifested in at least three distinct areas of burden: objective burden, relationship burden, and stress burden, as well as depression (Savundranayagam & Montgomery, 2010). Reflecting these assumptions, the TCARE<sup>®</sup> protocol was designed to help caregivers by systematically targeting identity discrepancy, the three domains of burden, and depression (Montgomery & Kwak, 2008).

Essentially, TCARE<sup>®</sup> is a triaging mechanism that empowers family caregivers to make informed decisions by

providing them with critical information about the care context, their own strengths and needs, and resources available to address their needs. The protocol outlines a six-step process for assessing the caregiving context and caregivers needs, creating a care plan and providing care managers with a set of tools to implement the process. The six steps are to (a) conduct an assessment using a 32-item standardized form; (b) transfer key information gained from the assessment process to a summary sheet that enables care managers to calculate scores for key measures and interpret them using distributions that have been established through previous studies; (c) follow a decision algorithm to identify goals, strategies, and resources that are targeted to the caregivers needs and preferences and record these on a care consultation worksheet; (d) consult with the caregiver to review and discuss the assessment results, suggested goals, strategies, and resources and mutually agree upon a care plan; (e) create a care plan that is a written record of decisions made during the care consultation and includes detailed information for implementing the plan; and (f) conduct a follow-up assessment at three-month intervals. A computer-assisted version of the protocol is available for care managers to use.

A key feature of the TCARE<sup>®</sup> protocol is the decision algorithm that enables care managers to integrate extensive information about the caregiver and care context to create a care plan tailored to the unique needs of the caregiver. The algorithm, which is grounded in the caregiver identity theory, leads to the identification of (a) an appropriate intervention goal, (b) strategies for reaching that goal, and (c) a generic list of services that is consistent with the identified strategies. The three possible goals for a caregiver are to (a) continue in his or her current identity as a caregiver by "stretching" that identity to include current caregiving activities, (b) reduce the caregiving aspects of his or her identity to bring his or her identity into line with what he or she is actually doing, or (c) further embrace an identity as a caregiver to bring his or her identity into line with what he or she is actually doing. For many caregivers, the algorithm also identifies a health goal, which is uniquely tied to the strategy of improving health and the recommendation of medical or behavioral health evaluation. The five possible strategies for achieving the selected goal include (a) changing the caregiver's personal norms or rules pertaining to care responsibilities and interactions with the care recipient, (b) reducing the workload, (c) enhancing positive self-appraisal, (d) reducing emotional stress, and (e) improve overall health.

The 44 pathways through the decision algorithm reflect various combinations of caregivers' scores on measures of three types of burden, intention to place, depression, and identity discrepancy. When appropriate, the algorithm also incorporates additional information about the care context to enable the care manager to make professional judgments regarding the capacity of the caregiver to provide necessary care in a safe manner.

Caregiver A	Caregiver B
<b>Scores on Key Measures</b>	
Depression = low; Objective Burden =high; Relationship Burden =low; Stress Burden =low; Identity Discrepancy =low; Intention to place care receiver given current condition =no	Depression =medium; Objective Burden =high; Relationship Burden =low; Stress Burden =high; Identity Discrepancy =high; Intention to place care receiver given current condition =no
<b>Step 1: Identify map that includes algorithm for caregiver</b>	
Map D is used when Objective Burden =medium or high and Relationship Burden =low; Intention to place =yes or no	
<b>Step 2: Depression Medium or High?</b>	
No  <i>Go to Step 3</i>	Yes Goal: Improve Health Strategy E: Improve overall health Service: Medical/Behavioral Health Evaluation  <i>Go to Step 3</i>
<b>Step 3: Identity Discrepancy Medium or High?</b>	
No Goal: Maintain Current Identity Strategy A: Change personal rules for care Service: Education to learn to respond to mood and behavior change Strategy B: Reduce or minimize work load Service: Education to learn to respond to mood and behavior change Service: In-home support service (e.g. chore services)  <i>Go to Step 5</i>	Yes          <i>Go to Step 4</i>
<b>Step 4: Does caregiver accurately understand level of care receiver's need? (This is a professional judgment made by the care manager)</b>	
	No, Care receiver has lower level of need than caregiver perceives. Goal: Reduce caregiver role Strategy A: Change personal rules for care Service: Education about disease process Service: Counseling for self care  <i>Go to Step 5</i>
<b>Step 5: Stress Burden Medium or High?</b>	
No Develop care plan with local resources as outlined in Step 3	Yes Add counseling or education focused on coping skills to the care plan as outlined in Step 4
<b>Initial Care Plan: The plan is tailored by identifying specific services for which the caregiver is eligible and providers in the caregiver's community.</b>	
Goal: Maintain Current Identity Strategy A: Change personal rules for care Service: Education to learn to respond to mood and behavior changes Strategy B: Reduce or minimize work load Service: Education to learn to respond to mood and behavior changes Service: In-home support service (e.g. chore services)	Goal: Reduce Caregiver Role Strategy A: Change personal rules for care Service: Education about disease process Service: Counseling for self care Strategy E: Improve overall health Service: Medical/Behavioral Health Evaluation

Figure 1. Example of decision algorithms and care plans for two caregivers.

A step-by-step illustration of the application of the decision algorithm for two caregivers with different combinations of scores is provided in Figure 1. The figure depicts the pathways for the two caregivers leading to the goals,

strategies, and examples of the types of services that would be included on an initial care plan. The process starts on Map D, which includes the decision algorithms for caregivers who score medium or high on objective burden but low

on relationship burden. The second step is to examine the depression score. If a caregiver scores medium or high on the depression measure, as did Caregiver B, the goal to improve health is established. The third step in the process is to examine the caregivers' scores on the measure of identity discrepancy. Caregiver A has a low level of identity discrepancy and therefore the goal selected for her is to help her "maintain her current identity." Strategies and services are recommended that will help lower her level of objective burden by easing her workload. In contrast, Caregiver B has a high level of identity discrepancy, which stems from the fact that she inaccurately perceives the care receiver to be more dependent than he actually is. In this case, the caregiver is engaging in a level of care that is fostering overdependency on the part of the care receiver. Strategies and services are recommended to help her let go of caregiving tasks and thereby align her activities with an identity that is more in keeping with her primary role as a wife. The last step of the process for both caregivers is to examine stress burden to determine whether services are needed to help alleviate the caregiver's anxiety, which is the case for Caregiver B but not Caregiver A.

The generic service types listed in Figure 1 are drawn from the TCARE® *Guide for Selecting Services* which is a catalogue of over 90 types of resources grouped into 15 major categories that have been identified as potentially useful for supporting caregivers. The guide provides a cross walk between five strategies for supporting caregivers and each type of resource that could be used to support the strategy. Care managers hone and tailor the initial list of suggested services to reflect the caregiver's preferences and the availability of services within the community.

We report findings from preliminary data of the randomized controlled study of family caregivers that examined the effects of the TCARE® protocol on caregiver outcomes. We hypothesized that caregivers served by care managers using the TCARE® protocol would experience lower levels of identity discrepancy, objective burden, relationship burden, stress burden, and depressive symptoms over time when compared with caregivers served by care managers following their usual practices. We also hypothesized that there would be a difference between the two groups in the caregivers' expressed intention to place a relative in a nursing home facility.

## METHOD

### *Participants*

*Caregivers.*—The study sample included 266 family caregivers who contacted 20 social service organizations in Georgia, Michigan, Minnesota, and Washington for support services to care for their relatives with cognitive or functional impairment and met the eligibility criteria established for the study. A short standardized screening tool was used to identify potential participants. Caregivers were deemed

eligible for the study if they (a) indicated that they "probably would" or "definitely would" place their care receivers in a different type of care setting for long-term placement given their relatives' current condition or (b) scored above the cut-off score on at least one of the following major outcome measures: caregiver identity discrepancy (Savundranayagam & Montgomery, 2010), objective burden, relationship burden, stress burden (Savundranayagam, Montgomery, & Kosloski, 2011), or depressive symptoms (Andresen, Malmgren, & Cater, 1994). Prior to this study, data from a sample of informal caregivers enrolled in a caregiver registry ( $n = 431$ ) were analyzed to establish cut-off score for each measure, which was set to one standard deviation below the mean. Eligible caregivers were randomly assigned to the intervention or control group using a computer-generated algorithm and a standard protocol for transmitting randomization information to the participating organizations.

*Care managers and organizations.*—Fifty-two care managers from 20 social service organizations participated in the study. Twenty-three care managers were selected by their organizations to participate in a structured training process that included an initial two-day intensive TCARE® training session, a follow-up one-day session conducted one month later, and an in-person or web-based training session. To ensure fidelity with the protocol, all cases by intervention group care managers were submitted to the study team for review at baseline and six months. Twenty-nine care managers were assigned to the control group to serve caregivers following their normal customary practices. At least one care manager from each organization was assigned to the control group. We compared demographic and employment characteristics between the groups and found no significant differences except for mean age (53.04 [9.74] for the intervention vs. 46.55 [10.89] for control group,  $p < .05$ ).

### *Procedures*

This research project was approved by the University of Wisconsin-Milwaukee Institutional Review Board. Of the 626 caregivers who participated in the screening process, 481 caregivers were eligible for the study and randomly assigned to be served by a care manager in the intervention or the control group. At the initial meeting with their care managers, caregivers were informed about and invited to participate in the study. A total of 266 caregivers agreed to participate, 143 in the intervention group and 123 in the control group.

Data for caregivers in the intervention group were collected as part of the TCARE® protocol by care managers using the standardized TCARE® assessment form. Data for caregivers in the control group were collected by trained interviewers from the research team using the same

TCARE® standardized assessment form. Up to three follow-up interviews were conducted with caregivers at intervals of approximately three months. Participants contributed data until they dropped out from the study. Follow-up interviews were discontinued for caregivers if the care receiver died during the study period ( $n = 29$ ). We continued our follow-up data collection, however, for caregivers who placed the care recipient in a nursing home ( $n = 34$ ). Of the 266 caregivers with baseline interviews, 185 (70%) individuals completed first follow-up (three-month) interviews, 138 (52%) individuals completed second (six-month) follow-up interviews, and 94 (39%) completed third (nine-month) follow-up interviews. The final analysis included a total of 680 observations from these caregivers.

### Outcome Measures

**Identity discrepancy.**—Caregiver identity discrepancy is defined as the affective psychological state that accrues when there is a disparity between the care activities in which a caregiver is engaging and those activities that would be consistent with his or her identity standard (Montgomery & Kosloski, 2009). Identity discrepancy was measured using a 6-point six-item inventory with scores ranging 6–36 ( $\alpha = .80$ ; Savundranayagam & Montgomery, 2010). For each statement, respondents indicated the extent to which they agreed using a response set that ranged from 1 (*strongly disagree*) to 6 (*strongly agree*). Example items are “the things I am responsible for do not fit very well with what I want to do” and “it is difficult for me to accept all the responsibility for my (care recipient).”

**Caregiver burden.**—Caregiver burden was measured using the modified Montgomery Borgatta Caregiver Burden Scale (Savundranayagam et al., 2011). The caregiver burden inventory measures three domains of caregiver burden (objective burden, relationship burden, and stress burden). For all items in the inventory, respondents were asked to use a 5-point response set ranging from 1 (*not at all*) to 5 (*a great deal*) to indicate the extent to which their caregiving responsibilities changed each aspect of their life. Objective burden is defined as a negative psychological state that results from the perception that caregiving activities and responsibilities are infringing on other aspects of the caregiver’s life, such as time and energy to address other family obligations, leisure activities, and personal privacy. Scores for this measure, which comprised six items, ranged from 6 to 30 ( $\alpha = .86$ ; e.g., Have your caregiving responsibilities decreased time you have to yourself?). Relationship burden, defined as demands for care and attention over and above the level that the caregiver perceives is warranted by the care receiver’s condition, was measured with five questions (e.g., Have your caregiving responsibilities, caused conflicts with your care recipient?). Scores ranged from 5 to 25

( $\alpha = .84$ ). Stress burden is defined as a generalized form of negative affect that results from caregiving. Five items were included in this measure (e.g., Have your care responsibilities made you nervous?). Scores ranged from 5 to 25 ( $\alpha = .87$ ).

**Depressive symptoms.**—Depressive symptoms were measured using a 10-item short version of the Center for Epidemiological Studies–Depression scale (Andresen et al., 1994). Scores ranged from 0 to 30 ( $\alpha = .80$ ).

**Intention to place.**—Intention to place was defined as the caregiver’s intention to place the care receiver in an alternate care setting now or in the future. The measure is the sum of responses to two questions that used a 4-point response set that ranged from *definitely not* to *definitely would*. The first item asked caregivers whether they would place the care receiver in a nursing home or other long-term care facility, given their relatives’ current condition. The second item asked about the caregiver’s intention to place the care receiver in an alternate setting if the care receiver’s condition became worse. Scores ranged from 2 to 8, with a higher score indicating higher level of intention to place ( $\alpha = .74$ ).

### Statistical Analysis

We conducted repeated measures random effects regression analysis, which allowed the estimation of longitudinal trajectories for individual participants at one level with the intercepts and slopes of these person-specific longitudinal trajectories analyzed as the effects of between-subjects predictors at a higher order second level (Singer & Willett, 2003). To determine whether it was necessary to account for clustering at this higher level, we examined the size of the design effect for each outcome in the study. In accord with the recommendations of Muthen and Satorra (1995), the design effects were comfortably below 2.0 for every outcome, indicating that there would be no significant bias introduced by ignoring clustering at this higher level.

Predictor variables included in the analysis were *group* (intervention vs. control), *time* (measured in months from baseline interview), and a *group by time* interaction term indicating whether the groups differed from one another with respect to their trajectory of change. There was no evidence of skewness or kurtosis on any of the measured variables. Restricted maximum likelihood estimation as provided by the SAS Proc Mixed procedure was used to address missing data (Littell, Milliken, Stroup, & Wolfinger, 1996).

### RESULTS

Demographic characteristics and measures of outcome variables at baseline are shown in Table 1. Almost half of the caregivers were adult children (49.6%) and half (42.5%)

Table 1. Caregiver Characteristics at Baseline (*n* = 266)<sup>a</sup>

	All ( <i>n</i> = 266)	TCARE <sup>®</sup> ( <i>n</i> = 143)	Control ( <i>n</i> = 123)
Gender		Percentage	
Female	79.70	76.92	82.93
Male	20.30	23.08	17.07
Race			
White	75.67	73.76	77.87
Black or African American	19.39	23.40	14.75
Other <sup>b</sup>	4.94	2.84	7.38
Relationship to the care recipient			
Spouse/partner	42.48	43.36	41.46
Parent	49.62	47.55	52.03
Other <sup>c</sup>	7.90	9.09	5.51
Self-reported health			
Very poor/poor/fair	42.42	41.84	43.09
Good/very good	57.58	58.16	56.91
Care receiver memory problems			
No memory problem	9.51	9.22	9.84
Cognitive or memory problems suspected	16.35	19.15	13.11
Alzheimer's or other dementia suspected	15.97	15.60	16.39
Alzheimer's or other dementia diagnosed	58.17	56.03	60.66
Care receiver needs help with two or more ADLs	78.95	81.12	76.42
Care receiver needs help with two or more IADLs	100	100	100
		<i>M (SD)</i>	
Age in years	62.43 (13.02)	62.59 (14.04)	62.25 (11.80)
Identity discrepancy	20.77 (7.02)	20.53 (7.15)	21.04 (6.89)
Objective burden	21.52 (6.35)	21.50 (6.30)	21.54 (6.43)
Relationship burden	10.59 (4.82)	10.37 (5.25)	10.86 (4.25)
Stress burden	13.99 (5.27)	14.39 (5.56)	13.52 (4.89)
Depressive symptoms	12.10 (6.33)	12.23 (6.81)	11.95 (5.73)
Intention to place	4.50 (1.71)	4.43 (1.63)	4.58 (1.80)

*Notes:* No statistically significant difference between the two groups was found for any of the characteristics shown in the table. ADLs = activities of daily living; IADLs = instrumental activities of daily living.

<sup>a</sup>Thirty-four caregivers whose care recipients were institutionalized at some point during the study were included in the analysis because caregivers were still involved in caregiving for their care receivers.

<sup>b</sup>Other race refers to caregivers who did not identify as Caucasian or African American or who identified with two or more races or ethnicities.

<sup>c</sup>Other relationships to the care receiver include friends and other relatives.

were spouses. Seventy-six percent of caregivers were White and 19% were Black or African American. Most (79%) of the care receivers needed help with at least two activities of daily living and all needed assistance with two or more instrumental activities of daily living. The majority of care receivers also had memory or cognitive problems (90.5%). Independent samples *t* tests and chi-square tests indicated that there were no differences between the intervention and control groups in demographic characteristics or outcome variables at baseline.

Results of the repeated measures random effects regression analyses are shown in Table 2. We found statistically significant group by time interactions for identity discrepancy, relationship burden, stress burden, depressive symptoms, and intention to place. Over time, caregivers in the intervention group experienced a significant decrease in scores for these outcome measures, whereas the scores for caregivers in the control group increased. Of particular note is that caregivers in the intervention group experienced substantially lower levels of depressive symptoms compared with those in the control group over the nine-month period (see Figure 2).

## DISCUSSION

The study findings provide strong support for our main hypothesis that the use of the TCARE<sup>®</sup> protocol, which is designed to identify the unique needs of an individual caregiver and strategically recommend a set of services, will promote the well-being and mental health of caregivers. With the exception of objective burden, significant differences were found between the intervention and control groups for all of the key outcome measures, indicating that the protocol promoted the well-being of family caregivers. It is hypothesized that these differences can be attributed to more effective assessment of the caregivers' current circumstances and needs and the creation of a care plan that identifies goals, strategies, and resources specifically selected to alleviate or diminish identity discrepancy, depression, and any of three types of burden that a caregiver is experiencing. As described previously, an essential element of the TCARE<sup>®</sup> protocol is the selection of one of the three intervention goals aimed at minimizing identity discrepancy. Caregivers become distressed when their care activities and responsibilities are inconsistent with their own identity standards. Simply put, it is not what a caregiver is



Three aspects of this study should be noted when interpreting the results. First, the sample includes a small percentage of caregivers from racially/ethnically diverse backgrounds. Second, the attrition rate was relatively high, although this is not uncommon for a longitudinal study of caregivers. Third, we were only able to look at the intention to place rather than the actual placement due to the short observation window and small number of actual placements.

A more complete understanding of the pathways by which the TCARE® protocol affects caregiver outcomes will emerge when the final data from the study become available. Nevertheless, the present results provide initial support for the TCARE® protocol as an effective means to reduce multiple dimensions of caregiver burden and depression, which may also reduce the desire for institutionalization of care receivers.

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R. J. V. Montgomery, K. Kosloski, and J. Kwak participated in the planning of the study. J. Kwak conducted the analyses, interpreted the results, and wrote the article. R. J. V. Montgomery and K. Kosloski interpreted the results and wrote the article. K. O'Connell Valuch participated in collecting the data, interpreting the analysis, and revising the manuscript. All authors approved the final version of the manuscript.

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