TCARE: TAILORED CAREGIVER ASSESSMENT AND REFERRAL

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CARE MANAGERS, including nurses and social workers, often lack information that would help them more effectively target services to caregivers' needs. Useful information includes the type of services that will be most helpful for caregivers and the best time to start using these services (Coon et al., 2003; Pillemer et al., 2003). Generally, caregivers are simply told what services they are eligible for among those that are available in their communities, such as respite care and caregiver support groups, rather than being referred to the services that are most pertinent to their needs. As a result, caregivers fail to use services or tap into them too late in the care process to be beneficial (Montgomery, 2002).

Evidence from studies assessing the effect of single-component interventions such as family counseling (Mittelman et al., 1996), behavioral therapy (Teri et al., 1997), and care management (Gitlin et al., 2006) indicate that such programs are most effective for reducing caregiver burden when the services are provided in sufficient quantity and targeted to specific needs. The most promising findings have emerged from studies that include multiple relatively comprehensive support services (Belle et al., 2006; Bourgeois et al., 1996; Burgio, et al., 2003). Such interventions are more likely to meet a caregiver's immediate needs because at least one of the support services probably will be appropriate at any point in time. Multicomponent interventions also have a higher probability of meeting caregivers' needs as they change over time. Changes in the caregiving experience require corresponding changes in caregiving behaviors and, therefore, changes in the services caregivers need (Aneshensel et al., 1995; Schulz & Martire, 2004; Zarit & Leitsch, 2001).

Without valid and reliable measures for assessing caregivers' needs and targeting services to meet them, care managers, nurses, and social workers aren't able to use resources efficiently, and caregivers are not well served. We are part of a team that developed the Tailored Caregiver Assessment and Referral (TCARE) process, an evidenced based approach that provides a systematic process for assessing caregiver needs and delivering services more efficiently.

***Journal of Social Work Education*, Vol. 44, No. 3 (Fall 2008); Supplement.**
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Caregiver Identity Theory

The caregiver identity theory articulated by Montgomery and colleagues (Montgomery & Rowe, 2007; Montgomery et al., 2007) is the theoretical underpinning for the TCARE process. This theory describes caregiving as a systematic process of identity change in which the initial familial relationship (such as mother–daughter) gives way to a relationship characterized by caregiving. This change in identity influences the type and level of stress or burden for the caregiver and serves as a guide for effectively targeting services.

The TCARE process reflects three important aspects of the caregiver identity theory. First, caregiver stress has been shown to be the most direct measure of the caregiving experience (Stull et al., 1994). Caregiver stress is multidimensional and influenced by a wide range of factors, such as a change in the relationship between the caregiver and care recipient or a change in the caregiver's physical health (Montgomery et al., 2000).

Second, the caregiver identity theory takes into account the great diversity among caregivers. They vary in the type and number of tasks they undertake, the length of time they serve as caregivers, the costs they incur, and the benefits they perceive in their caregiving role. The theory recognizes that the experience of caregiving is determined not only by the care recipient's disease process and level of disability, but also by factors that are grounded in family roles and culture (Caron & Bowers, 2003; Gaugler et al., 2005; Montgomery, 2002).

Third, the caregiver identity theory provides insights about the great variation in the services that caregivers use (Montgomery et al., 2002). Essentially, caregivers will not use services that they don't perceive having a need for. The perception of need is influenced by characteristics of the caregiver, the care recipient, and the provider (Kosloski et al., 1999, 2001; Montgomery et al., 2002). This theory helps explain why some caregiver interventions, such as respite services, are not uniformly beneficial (Montgomery, 2002; Montgomery & Datwyler, 1990).

Development of TCARE

Our team presented the caregiver identity theory as a model of the caregiving journey to 12 focus groups composed of caregivers and care managers. Both care managers and family caregivers agreed that the theory resonated with their own experiences.

Our team used the caregiver identity theory as a framework for developing TCARE, a caregiver assessment tool and referral process. The major goal of TCARE is to enhance practitioners' skills in effectively and efficiently targeting services to benefit family caregivers. This goal is achieved by training care managers to follow a set protocol and providing them with a detailed manual outlining it.

Development of Tools

We created several tools that are integral to the TCARE process. Two of them are described below. The tools are not yet ready for dissemination.

Assessment tool. Our goal was to create a tool that is clear, specific, reasonably short, easy to use, and helpful in creating effective care plans. In 2005 the project team began developing a registry of more than 900 caregivers. Each one completed a series of four questionnaires designed to identify caregiver burden. The questionnaire was refined at each stage of administration. From the responses, we developed an assessment tool consisting of 32 questions that gather information about the caregiver's activities, obligations, resources, and stress and the care recipient's physical and mental conditions.

Decision maps. A central feature of the TCARE protocol is a set of maps, or algorithms, that guide care managers through a decision process. The maps help them use the information gleaned from the assessment tool to identify for each caregiver the most appropriate intervention goals and strategies for reaching the goals. The decision maps are consistent with the caregiver identity theory and with current knowledge about caregiver stress and the effects of various types of support services.

Five of the six decision maps are designed to address the specific needs of caregivers who have different combinations of scores on the three measures of caregiver burden and who intend to place the care recipient in an alternative care setting in the near future. The three measures of caregiver burden are

- relationship burden, or stress in the relationship between the caregiver and care recipient.
- objective burden, or the perception that caregiving responsibilities infringe upon other aspects of the caregiver's life, such as privacy, other relationships, work obligations, and opportunities for leisure activities.
- stress burden, or generalized anxiety or strain stemming from the caregiving experience.

The sixth map is a supplemental algorithm referenced in some of the other maps to guide care managers in making appropriate care plan goals based on all the assessment data collected.

Six-Step Process for Care Managers

The TCARE protocol is a six-step caregiver assessment and referral process. Along with a set of tools and resources, care managers use the protocol to create a care plan tailored to the needs of the specific caregiver. Descriptions of the six steps follow.

1. Assess the caregiver's needs using the 32-question TCARE Caregiver Assessment.
2. Complete an Assessment Summary Sheet. This tool helps interpret the TCARE Caregiver Assessment scores on key measures such as caregiver burden and depression. It includes information about norms and distributions of scores from the sample of 900 caregivers who completed the questionnaires during the development phase.
3. Select one of the six decision maps to identify goals and what support strategies and services are most appropriate for the particular caregiver.
4. Develop a Care Plan Consultation Worksheet, which includes a list of the available service options that are consistent with the identified goals and support strategies. Another tool, Guides for Selecting Support Services, helps to efficiently identify 15 general categories of community resource guides or databases that can be used to develop this worksheet.
5. Discuss with the caregiver the outcomes of the assessment process and the options

for obtaining the support services that are most likely to benefit the family.

6. Write a care plan that incorporates decisions made with the caregiver during the consultation. Provide detailed information about the specific services to be used and the dates for initiating them. Also indicate the actions to be taken by the care manager and the caregiver, the circumstances that should prompt the caregiver to contact the care manager, and the dates for follow-up assessment.

TRAINING

Before using the TCARE protocol, care managers and other practitioners participate in training. This includes a two-day intensive training program, a one-day follow-up workshop, and ongoing technical assistance provided via the Web.

At the two-day training session, practitioners are introduced to the caregiver identity theory and the six-step process for implementing the protocol. Small group sessions use case studies to allow participants to practice using the TCARE protocol.

Care managers are required to test the process with one or two clients before the one-day follow-up workshop, which is held one month after the initial training session. In the follow-up workshop, practitioners share their experiences with using the protocol. Administrators from participating organizations also attend this session so they can better understand the process and its implications for their organizations (for example, the initial up-front investment in staff time results in more efficient use of time with individual caregivers and allows more caregivers to be served). The administrators work with the care managers to explore ways to efficiently use community resource guides or databases.

After the second training session, care managers use the TCARE protocol to serve clients. They also participate in small group working sessions conducted over the Web. In addition, TCARE staff members provide ongoing assistance using Web-based seminars and one-on-one support as needed.

EVALUATION

As of May 9, 2008, more than 150 nurses, social workers, and other care managers and family specialists employed by various organizations in six states have been trained in using the TCARE process. The usefulness of this protocol in diverse settings is clearly evident. Evaluations are conducted at the end of every training session. Feedback from care managers and administrators of Area Agencies on Aging, Aging and Disability Resource Centers, Alzheimer's Association chapters, and home health agencies has generally been positive.

Participants in the training program have reported that the caregiver tool is easy to use, makes their work more efficient, and enhances their sense of professionalism. They say that the TCARE process has increased their knowledge about caregivers' needs and options for services. They have also reported that caregivers are satisfied with the process and are more compliant with care plans.

The initial users of the program have made suggestions for improving the supporting tools, identified barriers to implementation, and recommended ways to increase its use. Whenever possible, their suggestions have been incorporated into the program.

The major concerns expressed about the TCARE process are the initial up-front investment required to learn it and the complexity of the decision maps. The latter problem is being addressed with the development of a computerized version that will calculate scores, point users to appropriate decision maps, and link them to appropriate goals, strategies, and services.

A two-year, multisite, randomized control trial of the TCARE protocol is in progress. The trial is being conducted in collaboration with more than 15 partner organizations and state agencies in Georgia, Michigan, Minnesota, and Washington. Its purposes are to evaluate how effectively the TCARE process enhances practitioner skills and improves caregiver outcomes as well as how feasible its widespread use is.

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Montgomery and Kwak received grants for their research from the Helen Bader Foundation, the Hartford Foundation, and contracts with Georgia and Florida. UVM is in the process of registering a trademark for TCARE in the name of the Board of Regents. Montgomery holds the copyright for the training manual and supporting documents for the TCARE protocol.

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