Feasibility of Recruiting Spouses With DSM-IV Diagnoses for Caregiver Interventions

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Background. Reviews and meta-analyses suggest that caregiver interventions have only been modestly effective in reducing caregiver distress. One possible reason is that many intervention studies have recruited heterogeneous caregivers with subclinical symptoms. This study examined the feasibility of recruiting a more homogenous group of caregivers with high clinical distress levels for an intensive therapy intervention.

Methods. During the 2-year study and under ideal circumstances, we recruited caregivers of community-dwelling older adults with dementia for group cognitive behavioral therapy at a University of Toronto affiliated and internationally recognized geriatric health sciences center. We used strict eligibility criteria to recruit primary spouse caregivers with a DSM-IV diagnosis, normal cognitive functioning, and clinically significant distress levels.

Results. Of the 97 caregivers screened, 61 were ineligible or uninterested. The 36 interested caregivers who met screening criteria completed a diagnostic intake assessment and only 28 were eligible to begin therapy.

Discussion. These results indicate that it would be extremely difficult for clinicians or researchers working in smaller cities or health care centers to run caregiver intervention groups using strict entrance criteria such as those employed in this study. The results of this study provide further support for the importance of diverse and tailored caregiver interventions.

Key Words: Caregiving—Dementia—Interventions—Psychotherapy—Recruitment—Services—Stress.

INDIVIDUALS with dementia experience progressive declines in physical functioning, worsening cognitive abilities, and challenging neuropsychiatric symptoms for an average of 8 years and as many as 20 years (Rhodes-Kropf, 2007). In most cases, family members undertake the burden and responsibility of providing care and, consequently, are faced with a myriad of physical, psychosocial, and financial demands. Given these chronic stressors, family care providers are more likely than noncaregivers to experience elevated rates of anxiety and clinical depression (Joling et al., 2010), poorer cognitive functioning (Mackenzie, Wiprzycka, Hasher, & Goldstein, 2009), and impaired health behaviors and stress hormone levels that increase their risk for health problems (Vitaliano, Zhang, & Scanlan, 2003) and premature mortality (Schulz & Beach, 1999). Reviews and meta-analyses suggest that interventions for caregivers of older adults with dementia have only been modestly effective in reducing caregiver distress and have had mostly domain-specific effects (Gallagher-Thompson & Coon, 2007; Pinquart & Sörensen, 2006; Schulz et al., 2002; Schulz, Martire, & Klinger, 2005). Critiques of caregiver outcome research highlight methodological flaws surrounding recruitment, intervention design, and implementation that limit the effectiveness of treatments (Mittelman, 2008; Zarit & Femia, 2008). Although a variety of criticisms have emerged from the literature, two key recommendations to enhance the clinical significance of interventions are to (a) recognize that caregivers have heterogeneous needs and risk profiles that require tailored treatments and (b) recruit caregivers who have a problem that particular interventions are designed to treat.

With respect to the first of these recommendations, to flexibly and individually adapt interventions to the heterogeneous needs of caregivers (Pinquart & Sörensen, 2006; Zarit & Femia, 2008; Zarit, Femia, Kim, & Whitlatch, 2010), outcomes have been mixed. On the one hand, impressive results have come from multidimensional interventions of Mittelman (2008) that consist of individual and family counseling adapted to caregivers’ specific and changing situations, followed by ongoing support groups and ad hoc telephone counseling as needed throughout the period of caregiving. On the other hand, results from the multicomponent Resources for Enhancing Alzheimer’s Caregiver Health II interventions that were explicitly tailored to caregivers’ risk factors determined during initial assessment were significant for some outcomes and racial/ethnic groups but disappointing overall (Belle et al., 2006). Nevertheless, despite the difficulty of tailoring treatments to caregiver risk factors, this goal remains an important one.

Less research has addressed the second recommendation of enhancing clinically meaningful outcomes of caregiver intervention studies by enrolling caregivers who have a problem that the intervention is designed to address (Schulz et al., 2002, 2005; Zarit & Femia, 2008). Intervention studies...
have tended to recruit heterogeneous groups of caregivers with varying levels of distress, including those who are coping relatively well or who are not necessarily highly distressed. Those caregivers who do not exhibit significant distress or subjective burden are unlikely to demonstrate improvement on outcome measures (Schulz et al., 2005; Zarit & Femia, 2008). Although recruiting a caregiver sample with both increased homogeneity and clinically significant distress might enhance the clinical effectiveness of an intensive caregiver intervention designed specifically for this population, evidence of the viability of doing so is lacking. The purpose of this study was to examine the feasibility of recruiting spouse caregivers with diagnosed mood, anxiety, or adjustment disorders for 13 weeks of group cognitive behavioral therapy (CBT).

**METHODS**

**Recruitment Procedures**

Over a 2-year period, research assistants recruited family care providers for a study investigating the efficacy of group CBT for caregivers (Gallagher-Thompson et al., 2002) that involved weekly 2-hr meetings at Baycrest Health Centre for 13 weeks. We recruited caregivers via referrals from health professionals from Baycrest, other Toronto hospitals, and community agencies; by direct mailings or calls to previous research participants; by print media via newspaper advertisements and flyers; and by word of mouth from recruited group members and Baycrest employees. Research assistants screened interested caregivers by telephone and then in person to determine eligibility prior to the start of the intervention, and tracked reasons for participation and nonparticipation.

**Eligibility Criteria**

A telephone screening interview determined whether caregivers met preliminary entrance criteria for the study, which included (a) being a primary spouse caregiver (60+ years of age) for and residing with a community-dwelling adult with a dementia diagnosis, (b) being fluent in written and spoken English, and (c) having no visual impairment.

For those caregivers who passed the screening interview and expressed an interest in group CBT, a comprehensive in-person preintervention assessment determined whether they were eligible. To be eligible for this study, participants had to (a) have a Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) diagnosis of a mood, anxiety, or adjustment disorder; (b) have no diagnosis of substance abuse or psychosis or active suicidal ideation; (c) have stable psychotropic medication use for the duration of the study; (d) have normal cognitive functioning; and (e) experience clinically significant levels of distress, as indicated by meeting clinical cut scores on at least one of our depression, anxiety, or caregiver burden measures. We offered a family caregiver support group to caregivers who did not meet eligibility criteria for this study.

**Preintervention Assessment Battery**

Research assistants administered the Structured Clinical Interview for DSM-IV (First, Spitzer, Gibbon, & Williams, 1998) to assess DSM-IV Axis I psychiatric diagnoses, the Kaplan Baycrest Neurocognitive Assessment (Leach, Kaplan, Rewilak, Richards, & Proulx, 2000) and the Mini-Mental Status Examination (Folstein, Folstein, & McHugh, 1975) to measure cognitive and neuropsychological functioning. Caregivers also completed the Beck Depression Inventory (BDI-II; Beck, Steer, & Brown, 1996) to measure the intensity of self-reported depressive symptoms, the Hamilton Depression Rating Scale (HAM-D; Hamilton, 1960) to measure the severity of depressive symptoms via a semi-structured clinical interview, the Beck Anxiety Inventory (BAI; Beck & Steer, 1990) to measure the intensity of self-reported anxiety symptoms, and the short form of the Zarit Burden Interview (ZBI; Bedard et al., 2001) to measure perceived caregiver burden.

**RESULTS**

**Recruitment**

During a two-year period, we contacted 97 caregivers; 50.52% were referred from within Baycrest, 20.62% participated in previous research conducted by the study authors, 10.31% were referred from other Toronto hospitals and community agencies, and 18.56% self-referred after learning about the study from community flyers or newspaper advertisements (13.40%) or word of mouth (5.16%).

**Participation**

As illustrated in Figure 1, a total of 61 caregivers (62.89%) were either ineligible for (n = 28) or not interested in (n = 33) the study following the telephone screen. Of the 36 interested caregivers (37.11%) who met preliminary entrance criteria and completed the comprehensive preintervention assessment, only 28 were eligible to begin group CBT. Overall, 36 caregivers were ineligible for the study following the telephone screen (n = 28) or in-person assessment (n = 8). Caregivers were most likely to meet our clinically significant distress eligibility criteria based on their scores on the BDI-II (70.37%) and ZBI (92.59%). A minority of caregivers scored at or above the clinical cut scores on the HAM-D (40.74%) or BAI (34.85%) (BDI-II scores ≥ 14, ZBI scores ≥ 17, HAM-D scores ≥ 16, and BAI scores ≥ 16 indicated clinically significant levels of distress. We chose these cut scores based on Seggar, Lambert, & Hansen (2002) for the BDI-II, based on Bedard et al. (2001) for the
WIPrzycka et al. based on Mottram, Wilson, & Copeland (2000) for the HAM-D, and based on the test manual for the BAI).

Despite comprehensive recruitment methods, 33 spouse caregivers (34.02%) who met our inclusion criteria following the telephone screen refused to participate in group CBT. The most significant and sometimes overlapping reasons cited for nonparticipation included unwillingness or inability to commit to commuting to or attending the 13-week group (n = 19, 57.58%), a lack of perceived need for help (n = 8, 24.24%), lack of interest for other reasons including skepticism about the potential benefits of the program or preferences for alternate ways of reducing stress such as individual therapy or social outings (n = 4, 12.12%), and personal health limitations (n = 2, 6.06%).

**DISCUSSION**

The primary outcome of this study is that recruiting spouse caregivers with DSM-IV diagnoses to improve caregiver therapy effectiveness is not a highly feasible endeavor for most clinicians and researchers. Our study was located in one of the busiest geriatric health care centers in North America, we had at least one research assistant whose primary responsibility was recruitment, and our recruitment strategy was comprehensive. Nevertheless, over a two-year period, we admitted only 28 spouse caregivers (28.87%) with mood, anxiety, or adjustment disorders into our group CBT intervention. Although many caregivers were interested in participating, they were not admitted into the study unless they had a DSM-IV diagnosis, clinically significant distress, normal cognition, and were providing care to spouses with dementia within their homes. These results clearly indicate that it would be extremely difficult, or even impossible, for clinicians or researchers working in smaller cities or health care centers to run therapy groups using strict entrance criteria such as those employed in our study that restrict recruitment efforts. Our results also provide support for the notion that it may be too early to begin widely disseminating empirically supported interventions that have proven efficacious in randomized controlled trials, but that have not had sufficient tests of their effectiveness in clinical settings (Mittelman, 2008; Zarit & Femia, 2008).

There are at least two possible explanations for why we encountered such difficulty recruiting caregivers. The first and most obvious reason is that caregivers are notoriously overburdened by their many care and noncare responsibilities (Dura & Kiecolt-Glaser, 1990; Robinson, Buckwalter, & Reed, 2005), which is likely especially true for older spouse caregivers with DSM-IV disorders. As a result, spouse caregivers may perceive commitment to a time-intensive structured program as an additional burden that does not outweigh its potential benefits and/or cannot be undertaken for practical reasons. Indeed, nearly 60% of screened caregivers in this study were unwilling or unable to commit to the time demands of commuting to and attending the weekly 2-hr group sessions. The length and/or sensitive nature of our extensive assessment battery may have additionally contributed to the disinclination of prospective participants to enter treatment. This finding highlights the importance of enhancing the attractiveness and accessibility of caregiver interventions, and considering alternative treatments that are shorter, delivered via nontraditional means.

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**Figure 1. Flow of participants through the study.** LTC = long-term care facility.
A second more provocative reason for our recruitment difficulties is that it may be relatively rare for primary caregivers to experience full-blown mood or anxiety disorders while they are caregiving. In support of this notion, a recent prospective naturalistic cohort study of nearly 340,000 general medical practice patients over a six-year period found low rates of incident mood and anxiety disorders in caregivers (i.e., approximately 15/1000 person-years), and that the majority of spouse caregivers experienced incident depression or anxiety, not while caregiving, but following the death of their partner (Joling et al., 2010). One quarter of the caregivers in our study refused to participate because they were reportedly coping well. Although numerous barriers to service use have been identified, a lack of perceived need for help has been identified as a key barrier to service use for caregivers (Brodaty, Thomson, Thompson, & Fine, 2005) and for older adults with mental health concerns more generally (Mackenzie, Pagura, & Sareen, 2010). Additionally, several of our caregiver participants indicated, anecdotally, that they could not afford to become clinically depressed or anxious for fear of what would happen to their spouse. Whereas others responded to our recruitment efforts for reasons other than their experience of clinically significant caregiver distress and burden (e.g., grieving loss of spouse), further suggesting the importance of examining individualized treatment goals.

The findings of this study address the challenges involved not only in using strict inclusion criteria in order to enhance the likelihood of clinically significant outcomes in empirically validated interventions (Schulz et al., 2005; Zarit & Femia, 2008) but also in disseminating intensive caregiver treatments. One way to overcome these challenges may be to implement a flexible, stepped-care model of treatment delivery (Bower & Gilbody, 2005). This model would present caregivers with less intensive and intrusive interventions (e.g., Mittelman, 2008) prior to proceeding, if necessary, to more intensive interventions such as the one we used. Family members may also require treatment when their role as a caregiver ends, at which time intensive interventions may become more accessible. This graduated approach would allow a larger number of caregivers at various phases of the caregiving process to obtain help, particularly those who face access barriers to traditional treatment.

In conclusion, caregivers play a fundamentally important role in providing quality care for large and growing numbers of older adults with dementia. Although this role can be rewarding, it also comes with a variety of health risks that can negatively impact both caregivers and care recipients. Flexible interventions tailored to caregivers’ diverse needs are particularly important for supporting them during challenging times. Additional research is needed to understand the need for and methods of optimizing mental health during various phases of the caregiving journey.

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