



A telephone intervention for dementia caregivers: Background, design, and baseline characteristics

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ARTICLE INFO

Article history:

Received 1 May 2013

Revised 25 July 2013

Accepted 28 July 2013

Available online 3 August 2013

Keywords:

Dementia

Caregivers

Telephone

Psychosocial intervention

ABSTRACT

Family caregivers of individuals with dementia are at heightened risk for emotional and mental health problems. Many caregivers do not seek assistance or become isolated in their caregiving role. Multi-component interventions have demonstrated efficacy for reducing emotional distress and burden, although these approaches are potentially costly and are not widely accessible. In response to these issues, we developed the Family Intervention: Telephone Tracking – Caregiver (FITT-C), which is an entirely telephone-based psychosocial intervention. The purpose of this paper is to describe the study design, methodology, and baseline data for the trial. This study uses a randomized controlled trial design to examine the efficacy of the FITT-C to reduce depressive symptoms and burden in distressed dementia caregivers. All participants ($n = 250$) received a packet of educational materials and were randomly assigned to receive 6 months of the FITT-C intervention or non-directive telephone support. The FITT-C intervention was designed to reduce distress in caregivers and is based on the McMaster Model of Family Functioning, transition theory, and Lazarus and Folkman's Stress and Coping Models. The primary dependent variables were depressive symptoms (Centers for Epidemiological Studies – Depression) and burden (Zarit Burden Interview, Revised Memory and Behavior Problems Checklist – Reaction). Secondary outcome measures included family functioning, self-efficacy, and health-related quality of life. Results of the study will provide important data about the efficacy of a telephone-based approach to reduce distress in dementia caregivers.

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1. Introduction

More than 15 million Americans provide 17.5 billion hours of unpaid care each year for persons with dementia [1]. Providing

care for an individual with dementia has been shown to be more stressful than caring for a physically-impaired older adult [2]. Family caregivers of individuals with dementia are at heightened risk for a variety of negative health consequences and even their own dementia and death [3–5]. Dementia caregivers report high levels of depression and anxiety and exhibit elevated rates of mood disorders, with about 1/3 of individuals meeting diagnostic criteria for depression [6]. Caregivers often sacrifice their own needs and well-being to provide care for their loved one. In addition,

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it is common for caregivers to experience feelings of social isolation [7].

A variety of educational, psychosocial, and psychotherapeutic interventions have demonstrated modest success in improving the quality of life and negative consequences associated with dementia caregiving. Many of these studies have methodological problems, such as small sample sizes, lack of appropriate control conditions, or inclusion of non-distressed caregivers. Recently, comprehensive, multicomponent interventions have been developed and tested with dementia caregivers. There is evidence that these interventions can reduce burden and depressive symptoms as well as delay institutionalization of the care recipient [8,9]. Although there is evidence that these interventions are effective, practical implementation on a wide scale and accessibility to family members with extensive caregiving responsibilities restricting their travel are significant challenges.

In response to the need for cost-effective and highly accessible dementia caregiver interventions, we developed a telephone-based, psychosocial intervention for dementia caregivers (Family Intervention: Telephone Tracking – Caregiver; FITT-C). Theoretical underpinnings of the intervention are based on psychosocial transition [10], transactional stress and coping [11], and a systems view of family functioning (i.e., McMaster Model of Family Functioning) [12]. Taken together, the three underlying theories of the FITT-C are geared toward enhancing coping within the caregiver through active problem-solving and facilitating positive changes within the family system. According to these models, dementia caregiving is comprised of potentially stress-inducing transitions that prompt an appraisal process by the caregiver to identify whether resources (particularly those within a family) can be mobilized to cope with the changes. Within these overlapping models, caregiver burden is viewed as a situation in which demands (both perceived and objective) exceed the coping and resources (both perceived and objective). As burden persists, it becomes a stressor in its own right, leading to feelings of helplessness, hopelessness, and depression. Overall, the FITT-C directly targets caregiver appraisal and coping processes to reduce stress, improve caregiver mood and quality of life, and positively impact the family system. In a preliminary study of an earlier version of this intervention, we found that caregivers who received the FITT showed greater reductions in perceived burden and less-severe reactions to memory and behavior problems than individuals in a standard care condition [13].

The purpose of the FITT-C trial was to establish whether an entirely telephone delivered intervention could reduce depressive symptoms and burden in distressed dementia caregivers. Aims of the current paper are to describe the study design, methodology, and baseline data for a randomized controlled study of the FITT-C intervention compared to non-directive telephone support.

2. Methods

2.1. Participants

Participants included 250 family caregivers and their care recipients who were required to be formally diagnosed with dementia. A diagnosis of dementia was made by a neurologist, geriatrician, or psychiatrist. In cases in which the

diagnosis was made by a general practitioner, the study neurologist (BRO) confirmed the diagnosis. We chose to include any dementia subtype (e.g., Alzheimer's disease [AD], vascular, frontotemporal) because of considerable overlap in symptoms among different dementias. FITT-C was designed to be flexible enough to assist caregivers whose care recipient has a predominance of neuropsychiatric, cognitive, or behavioral symptoms. Caregivers were required to endorse experiencing at least two of the following in a screening interview: 1) feeling overwhelmed and stressed; 2) sad mood/depression; 3) anger or frustration; 4) loss of contact with family and friends; 5) conflict in family or family stress; 6) neglecting their own health; 7) demands or pressures of caregiving are too much; 8) exhaustion and fatigue; and 9) not taking care of their own needs or other significant responsibilities.

Caregivers were excluded based on the following criteria: 1) major acute medical illness; 2) English was not their primary language; 3) cognitive impairment as defined by Mini Mental State Examination score falling 1.5 or greater standard deviations below age- and education-corrected normative data; or 4) no access to a telephone. Care recipient inclusion criteria included: 1) formal DSM-IV diagnosis of dementia by a neurologist, psychiatrist, or geriatrician; 2) family member or other adult in caregiver role for at least 6 months, and who provided at least 4 h of supervision or direct assistance per day for the person with dementia; 3) care recipient lived in the community, including senior/retirement centers, but excluding nursing homes and assisted living centers; and 4) there was no plan for the care recipient to be placed in long term care or the caregiver to end their role within 6 months of study enrollment. Those care recipients with other major medical conditions affecting independent functioning were excluded.

2.2. Procedure

2.2.1. Telephone and in-person screening interviews

Participants were enrolled on a rolling basis over 53 months (March 2008 to August 2012). In addition to physician referrals and referrals from two local hospital memory clinics, we recruited from the community in the following ways: 1) distribution of recruitment flyers to other memory clinics, neurologist and geriatric psychiatrist practices, geriatrician offices, and large primary care physician practices; 2) distribution of flyers and other advertising materials through town and regional senior centers and Councils on Aging, and similar agencies; 3) attendance/presentations at support groups and similar groups at the local Alzheimer's Association chapter; 4) newspaper advertisements targeting communities and publications with large numbers of elderly readers; 5) television advertising on local cable systems; and 6) lectures to both lay and professional groups on the topic of caregiving given by members of the research team on at least a monthly basis.

Potential participants either contacted our research staff by telephone or email or were contacted by research staff after agreeing to contact with their physician or other referral source. Potential participants completed a telephone screening interview to establish that the caregiver and their care recipient met inclusion/exclusion criteria. Prior to the screening, individuals were read a script (approved by the IRB) describing the duration of the screening (approximately 5 min) and that questionnaires would be kept confidential.

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