



Translation of the Care of Persons with Dementia in their Environments (COPE) intervention in a publicly-funded home care context: Rationale and research design☆☆☆

Richard H. Fortinsky^{a,*}, Laura N. Gitlin^b, Laura T. Pizzi^c, Catherine Verrier Piersol^d, James Grady^e, Julie T. Robison^a, Sheila Molony^f

^a Center on Aging, School of Medicine, University of Connecticut, United States

^b School of Nursing, Johns Hopkins University, United States

^c College of Pharmacy, Thomas Jefferson University, United States

^d College of Health Professions, Thomas Jefferson University, United States

^e Department of Community Medicine and Health Care, School of Medicine, University of Connecticut, United States

^f School of Nursing, Quinnipiac University, United States

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ABSTRACT

Background: Dementia is the leading cause of loss of independence in older adults worldwide. In the U.S., approximately 15 million family members provide care to relatives with dementia. This paper presents the rationale and design for a translational study in which an evidence-based, non-pharmacologic intervention for older adults with dementia and family caregivers (CGs) is incorporated into a publicly-funded home care program for older adults at risk for nursing home admission.

Methods: The 4-month Care of Persons with Dementia in their Environments (COPE) intervention is designed to optimize older adults' functional independence, and to improve CG dementia management skills and health-related outcomes. COPE features 10 in-home occupational therapy visits, and 1 in-home visit and 1 telephone contact by an advanced practice nurse. COPE was deemed efficacious in a published randomized clinical trial. In the present study, older adults with dementia enrolled in the Connecticut Home Care Program for Elders (CHCPE) and their CGs are randomly assigned to receive COPE plus their ongoing CHCPE services, or to continue receiving CHCPE services only.

Outcomes: The primary outcome for older adults with dementia is functional independence; secondary outcomes are activity engagement, quality of life, and prevention or alleviation of neuropsychiatric symptoms. CG outcomes include perceived well-being and confidence in using activities to manage dementia symptoms. Translational outcomes include net financial benefit of COPE, and feasibility and acceptability of COPE implementation into the CHCPE. COPE has the potential to improve health-related outcomes while saving Medicaid waiver and state revenue-funded home care program costs nationwide.

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1. Introduction

Dementia, an umbrella term encompassing multiple causes of brain neurodegeneration and multiple patterns of associated cognitive decline and neuropsychiatric symptoms, affects >46 million people worldwide; by 2050, this number will reach >130 million people [1]. Considered a global public health priority, dementia is the principal

cause of morbidity burden; in 2015, the estimated cost of dementia worldwide was \$818 billion [1]. >5 million Americans have dementia and >15 million unpaid caregivers, mostly family members, provide care to these individuals. Persons with dementia plus other health problems generate greater Medicare and Medicaid expenditures than those with similar health problems without dementia [2].

In the absence of widely effective pharmacotherapy to combat dementia and its health-related consequences, translation and implementation of evidence-based, non-pharmacologic interventions into existing service programs are sorely needed to improve outcomes for persons with dementia and their family and other informal caregivers (CGs), thereby potentially avoiding or delaying costly hospitalizations and nursing home admissions [3]. The Connecticut Home Care Program for Elders (CHCPE), a combined Medicaid and state-funded program for older adults at high risk for nursing home admission, provides in-home

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* Corresponding author: UConn Center on Aging, UConn Health, 263 Farmington Ave., Farmington, CT 06030-5215, United States.

E-mail address: Fortinsky@uchc.edu (R.H. Fortinsky).

and community-based services coordinated by care managers [4]. However, CHCPE clients with dementia (25–30% of all clients) do not routinely receive evidence-based services directed at their cognitive impairment that could potentially improve their health-related outcomes and sustain living at home. Moreover, no CHCPE services currently engage CGs to help improve their dementia-related symptom management skills and health-related outcomes. Thus, the CHCPE is an ideal setting for translating an evidence-based, non-pharmacologic intervention designed to reduce functional disability in older adults with dementia and improve CG dementia management skills.

In this paper, we describe a translational study in which an evidence-based intervention, Care of Persons with Dementia in their Environments (COPE), is incorporated into the CHCPE. COPE is a 4-month, in-home, non-pharmacologic intervention using occupational therapists and advanced practice nurses to optimize functional independence in older adults with dementia, and to improve CG dementia management skills. In the original COPE randomized trial with community volunteers, persons with dementia receiving COPE experienced less functional decline and more activity engagement designed to keep them independent, compared to an attention control group. CGs receiving COPE, compared to controls, reported improved well-being, increased confidence in using behavioral strategies to address dementia symptoms, and greater ability to keep their family member at home [5].

We will randomly assign 290 CHCPE clients with dementia and their CGs to receive the COPE intervention plus customary CHCPE services or customary CHCPE services alone. Primary and secondary client-specific and CG-specific outcomes will be similar to those in the original COPE trial, to determine whether similar outcomes are obtained in a real-world setting. To maximize translational effort, we will: conduct a cost-benefit analysis to determine potential economic benefits of adding COPE to customary CHCPE services; gather interview-based and focus group data from CHCPE care managers and other stakeholders to evaluate feasibility and acceptability of COPE as a new CHCPE service; and convene a Translational Advisory Committee of experts in publicly-funded home care programs for older adults to help guide COPE dissemination and implementation activities.

2. Translational study and intervention rationale

Several health-related and scientific issues helped frame the rationale for this translational study. First, as already noted, dementia is a rapidly growing national and global public health problem, with dementia prevalence projected to nearly triple worldwide and in the U.S. by mid-century [1,2]. The National Alzheimer's Project Act in the U.S. (NAPA), legislated in 2011, includes objectives aimed at supporting families caring for relatives with dementia from pre-diagnosis to end of life stages of the journey, and numerous countries have developed national dementia plans that include similar objectives [6]. A recent Institute of Medicine (IOM) report emphasized the need for studies testing models of care linking existing community and healthcare systems to develop and understand payment considerations associated with comprehensive care for persons with dementia [7]. Other reports similarly have identified the need for and challenges of translating evidence-based programs in service delivery settings [8–10]. This translational study directly addresses this national public health imperative, legislative goal, and IOM directive.

Second, dementia leads to poor health-related outcomes. In addition to behavioral symptoms and cognitive decline, functional disability is a hallmark of dementia but is less studied as an outcome in its own right [11]. Also, there are no known pharmacological treatments that address daily functional concerns such that there is an urgent need to advance nonpharmacological approaches to help families manage increasing dependencies among individuals with dementia. Due in part to these poor outcomes, dementia is an independent risk factor for nursing home admission in numerous studies of community-dwelling older adults, even when controlling for numerous comorbidities [12]. Among community-

dwelling older adults with dementia, functional disability and family caregiver physical and emotional strain, are the most important predictors of nursing home admission, pointing to the need to keep older adults with dementia at the highest levels of functioning as possible to remain living at home [13,14]. Physical and emotional burdens of providing help with activities of daily living, as well as the challenges of managing disruptive behaviors such as wandering and resistance to care, place CGs at risk for depression, physical health problems, and admitting their relative to a nursing home [1,15–21]

Third, while dementia adds considerably to Medicare and Medicaid costs due primarily to excess hospitalization and nursing home use [2, 22] evidence-based interventions that might help reduce costs for the community-dwelling population with dementia are severely lacking. An appropriate test bed for such interventions is Medicaid and state revenue-funded home care programs that are designed to avoid or delay nursing home admission. Most states are aggressively rebalancing their Medicaid long-term care budgets, growing such home care program options while reducing nursing home use [23–27]. Yet no known evidence-based interventions designed to slow functional decline in older adults with dementia have been introduced into these publicly-funded home care programs in an effort to achieve cost savings while improving health-related outcomes and those of their CGs.

Fourth, COPE is an evidence-based intervention well-suited for older adults with dementia and their CGs already participating in publicly-funded home care programs. In an efficacy trial, COPE helped sustain greater functional independence in older adults with dementia by providing a non-pharmacologic intervention that included CG education to build their dementia management skills, in-home environmental modifications, and clinical and laboratory tests designed to detect undiagnosed medical conditions in the older adults with dementia [5]. The in-home nature of the COPE intervention and its focus on functional independence is highly consistent with the programmatic goals of Medicaid waiver and state revenue-funded home care programs for older adults nationwide.

Finally, publicly-funded home care programs are fertile yet understudied service settings for translational studies: Feasibility, sustainability, and cost-benefit can be simultaneously investigated along with health-related outcomes of interventions being translated. Embedding and testing evidence-based interventions for persons with dementia in existing publicly-funded home care programs and their CGs can help inform state and federal governments concerned with delaying or avoiding Medicaid-covered nursing home admissions and Medicare-covered hospitalizations. Translation of interventions with proven economic benefit would help address the rapidly growing problem of Medicaid and Medicare expenditures for America's costly dually-eligible population, more than half of whom have cognitive impairment [28].

3. Study design

3.1. Translational design overview

Many non-pharmacologic interventions for older adults living at home with dementia and their CGs delivered by health and social service professionals have been found to produce positive health-related outcomes [5,29–46]. This translational study, which targets the same population, is designed conceptually as an *effectiveness-implementation hybrid design* [47].

The effectiveness-implementation hybrid design blends components of clinical effectiveness and implementation research. Of the three types of such hybrid designs explained by Curran and colleagues, in this study we are dually testing clinical and implementation interventions and strategies [47]. This approach allows conclusions to be drawn simultaneously about the effectiveness of an evidence-based non-pharmacologic intervention on meaningful health-related outcomes at the individual level in a real-world service setting, and about the degree of

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