Alzheimers Medical Advisor: A Symptom and Sign Management Toolkit for Caregivers

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Country

USA

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Alzheimers Medical Advisor: A Symptom and Sign Management Toolkit for Caregivers

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NIH (NIA)

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27/09/2012

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2

The project/programme is most relevant to:

Alzheimer's disease & other dementias

Keywords

Signs and Symptoms, informal caregiver, Caregivers, Alzheimer's Disease, Medical

Research Abstract
DESCRIPTION (provided by applicant): Most persons with Alzheimer's disease (AD) live at home with informal (usually family) caregivers who must evaluate, manage, and communicate

with health care providers about medical symptoms (e.g., pain and shortness of breath) and signs (e.g., fever and agitation). As dementia progresses, susceptibility to comorbid illness increases, communication and decision-making capacity are reduced, and transport to medical facilities becomes increasingly difficult. As a result, informal caregivers need tools that will hep them evaluate, make decisions about, and manage symptoms and signs that could represent new or evolving medical illness. The proposed project will develop, field test, refine, evaluate, finalize, and disseminate the Alzheimer's Medical Advisor (AlzMA), a multi-component toolkit that will assist informal caregivers of persons with AD to identify, evaluate, and manage new or increasing symptoms and signs of illness and then, if necessary, clearly and effectively communicate the information to health care providers. AlzMA will provide tools to evaluate a wide range of possible illnesses, include review and consultation by an on-call nurse, and be available in online and printed formats. Our long-term goal is for the AlzMA to undergo clinical trial testing and be adopted widely by medical practices and health systems serving persons with AD. During the first 2 years of the project we will develop, test, and refine the toolkit through a series of steps involving our research team, consultant clinicians, and informal caregivers (Aim 1). We will also develop and refine a measure of caregiver confidence in the ability to assess and manage symptoms and signs (Aim 2). During years 3 and 4 of the project (Aim 3) we will conduct an implementation trial of the AlzMA toolkit among 200 diverse caregivers of persons with AD who are managed by two diverse medical practices. The trial will (a) evaluate the toolkit in terms of caregiver use, knowledge gained, satisfaction of caregivers and medical practice staff, and effectiveness; (b) evaluate the following caregiver outcomes at baseline, 6 and 12 months: self-efficacy in managing dementia, anxiety, confidence in symptom and sign management, burden, and depression; and (c) on a preliminary basis, evaluate emergency department visit and hospitalization rates before and during toolkit use. Analyses will evaluate the impact of caregiver factors and toolkit format on the above outcomes. During year 5 we will disseminate components of the toolkit nationally through a web application and DVD, and make the system available to medical practices and health systems (Aim 4); in addition, we will complete the analysis and dissemination of our research results. This project represents a unique collaboration of teams from the University of North Carolina at Chapel Hill; the Duke Family Support Program; and Keona Health, a company devoted to online protocol and nurse-assisted triage and decision support on symptom evaluation and management.

Lay Summary
Approximately five million persons in the U.S.A. currently suffer from Alzheimer's Disease and Related Disorders (AD), and that number is anticipated to grow to between 12 and 14 million by 2050. The majority of persons with AD are live at home with family members, who serve as informal caregivers and often need to evaluate new symptoms and signs and communicate with health professionals about them. Few resources exist to assist family caregivers of persons with AD in interpreting symptoms and signs. The project will develop, test, and disseminate materials that educate caregivers and assist them in making decisions around new and increasing symptoms and signs that may reflect a serious medical condition. The goal is for informal caregivers to perform better assessments and communicate more effectively with health professionals around symptoms and signs, thereby resulting in improved caregiver self-confidence and more appropriate health services utilization.

Further information available at:

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Investments > €500k

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United States of America

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