

We Are Seeking Participants for the Following Studies

Title: Medical Treatment Preferences

Funding Source: National Institutes of Health

Principal Investigator: Susan M. Parks, MD

Target population: Family members 70 or older who serve as proxy decision makers

The purpose of the study is to find ways to improve advance directives, medical counseling for family members, and training of clinicians who care for patients with life-limiting illnesses.

Telephone interviews will be conducted separately with people 70 or older and their relatives who they designate as likely proxies (whether or not they have power of attorney or other legal arrangements). Participants are asked their opinions about several types of treatment, both life-prolonging treatments, as well as questions about health, mood, and physical functioning. ■

Title: The Morality of Giving Care to a Demented Mother

Funding Source: National Institute on Aging

Principal Investigator: Helen K. Black, PhD

The purpose of this study is to examine the experience and meaning of caregiving to daughters who have been the primary

caregiver to their demented mother for at least 6 months. The research interview is conversational and includes questions about how the daughter came to be the primary caregiver for her mother, and the accomplishments, difficulties, joys and stresses that occur with caregiving. ■

Title: Project COPE

Funding Source: PA Department of Health

Principal Investigator: Laura N. Gitlin, PhD

The purpose of this study is to evaluate a program of in-home services to address family caregiver upset and boredom, depression, and troublesome behaviors in persons with dementia. Participants are assigned by chance to one of two groups. One group receives services from an occupational therapist (OT) and a visiting nurse. The nurse examines the client to identify possible medical problems. The OT works with family caregivers to identify the potential behavioral triggers of their

relative's problem behaviors and designs a tailored program of activities to address these behaviors. ■

Title: Health-related Quality of Life in Persons with Dementia Living at Home

Funding Source: Alzheimer's Association

Principal Investigator: Laura N. Gitlin, PhD

This 3 year study will examine the quality of life of individuals with dementia who are living at home. Family caregivers will be interviewed about their perceptions of their quality of life and that of their family member. Individuals with dementia will be asked to participate in brief assessments of their functional and cognitive abilities, activity interests and other health-related factors. The study seeks to identify the factors that support or serve as a barrier to quality of life that can be modified. Families that participate will receive a written report of health and functioning of the person with dementia. ■

All participants in our research projects receive compensation for participating in study interviews.

For further information about these and other studies, please visit our website at www.jefferson.edu/jchp/carah or call **215-503-2897** to speak to a member of our staff.

If I Decide to Participate, What Will I Be Asked to Do?

You will first be asked some questions over the phone to make sure that the study you are interested in is right for your situation. For some studies a trained interviewer will then come to your home at a time that is convenient for you. The interviewer will first explain the study, review the benefits and any minimal risks of participation, and ask you to sign an Informed Consent form that describes the study procedures and acknowledges your willingness to participate. You also will have an opportunity to ask any questions and decide whether you want to participate. If so, the interviewer will conduct the first interview, and will then review with you the next steps of your

participation, depending on what study you are participating in.

Am I protected as a study participant?

All research studies must be approved and continuously monitored by an Institutional Review Board (IRB), a legal entity of a sponsoring institution. The IRB ensures that you are protected from risks that may be too great, that your privacy is protected and that you are completely informed about the study and have chosen freely to participate.

In addition, if you participate in research projects at CARAH, your confidentiality will be protected. All information we

receive is stored in locked cabinets that is only accessible by members of the project team. Your name will never be identifiable on any of the information you provide. ■

Did You Know?

Caring for someone with dementia is associated with a higher level of stress than caring for someone with functional impairment from another type of chronic illness.