Disease Markers in Alzheimer’s Disease

Category: Clinical Research

Roles:
- Researcher
- Potential Participant
- Potential Participant’s Spouse

Background Information:

This research looks for disease markers in the cerebrospinal fluid of persons with Alzheimer’s disease. The fluid is removed by a process called a lumbar puncture. In a lumbar puncture, a doctor inserts a long needle through the lower back into the spinal canal. The patient is given numbing medicine in the lower back to minimize pain. Participants may experience minor pain. They may also feel cramped from being in the same position for 10 or more minutes. About 5% of patients get headaches, which is usually treated with bed rest and pain drugs like Tylenol. In about 1% the headache may be prolonged and the patient may have a procedure called a “blood patch” done, which involves inserting a needle into the lower back again. The study will not directly benefit these patients. But it may lead to better diagnostic tools and treatments that will help future patients with Alzheimer’s. The research and couple met once and discussed the study and the researcher now returns to answer questions and get a decision.

Researcher:

My job is to make clear that the research is not to benefit the Participant; it is to help others with Alzheimer’s disease in the future. I am now sitting with an elderly couple. I
have already told them about the study. They said they wanted to think about it for awhile so I gave them an hour and grabbed lunch.

**Potential Participant**

I am an 80 year-old woman with moderate (but can still cooperate) Alzheimer’s disease. Although I live at home with my husband, I need a lot of help with my daily tasks and cannot be left alone for extended periods. My short term memory is extremely poor; I forget things that were told to me a few minutes ago. I am too impaired to give my own informed consent. I am with my husband of 52 years, whom I still recognize and rely on; I trust him to make decisions for me. This nice young man/woman coming to talk to use seems familiar. Where have I seen him/her before?

**Potential Participant’s Spouse:**

I am 81 and with the help of my daughter close by, I am able to manage taking care of my spouse. I want to find out whether this study will benefit my spouse. Even if it doesn’t, I would still consider giving permission because I know Alzheimer’s is a terrible disease that needs to be studied. But I don’t want my spouse to be exposed to too much burden. It sounds like the research doesn’t involve much more than a poke with a needle. Although I want to do things that are at least consistent with my spouse’s values, I know that I will have to exercise my judgment the best I can since we never really talked about research participation in any detail.
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Participants may experience minor pain. They may also feel cramped from being in the same position for 10 or more minutes. About 5% of patients get headaches, which is usually treated with bed rest and pain drugs like Tylenol. In about 1% the headache does not go away and the patient may have a procedure called a “blood patch” done, which involves inserting a needle into the lower back again. The study will not directly benefit these patients. But it may lead to better diagnostic tools and treatments that will help future patients with Alzheimer’s.

My job is to make clear that the research is not to benefit the Participant; it is to help others with Alzheimer’s disease in the future. I am sitting with an elderly couple in the hospital. I have already told them about the study. They said they wanted to think about it for awhile so I gave them an hour and grabbed lunch.
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*Imagine you are the potential participant and that you will need, at the conclusion of your exchange with the researcher, to decide whether or not to participate. Which decision you make is up to you.*
Disease Markers in Alzheimer’s Disease: Roles

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