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Informed Consent for Research

Study Title: Caring for Dementia Caregivers in Ethnic Immigrant Communities

Principal Investigator: Yuri Jang, PhD

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Introduction

We invite you to take part in a research study. Please take as much time as you need to read the consent form. You may want to discuss it with your family, friends, or your personal doctor. If you find any of the language difficult to understand, please ask questions.

~~Key Information~~

~~The following is a short summary of this study to help you decide whether you should participate. More detailed information is listed later in this form.~~

1. ~~Being in this research study is voluntary–it is your choice.~~

2. ~~You are being asked to take part in this study because you are Korean American age 18 or older who provides care for a family member with Alzheimer's Disease and Related Dementias (ADRD). The purpose of this study is to test the efficacy of the culturally adapted Savvy Caregiver Program. If you volunteer to participate in this study, you will receive online education on healthy aging and/or dementia caregiving. The program includes six weekly sessions, each lasting 90 minutes. There will be periodic assessments—five using a short questionnaire and one involving a 60-minute individual interview. Program delivery and evaluation will be conducted in Korean, and the sessions will be recorded.~~

3. ~~There are risks from participating in this study. The most common risks are possible emotional discomfort as some of the questions may make you feel uneasy or embarrassed. More detailed information about the risks of this study can be found under the "Risk and Discomfort" section.~~

4. ~~You may not receive any direct benefit from taking part in this study. However, your participation in this study may help us learn about the benefits of a culturally adapt an evidence-based intervention in meeting the needs of ethnic minority caregivers.~~

~~5. If you decide not to participate in this research, your other choices may include not participating.~~

Purpose

The purpose of this study is to examine the efficacy of the culturally adapted Savvy Caregiver Program (SCP). We hope to learn how caregivers who are culturally and linguistically isolated would benefit from a culturally adapted evidence-based intervention. You are invited as a possible participant because you are Korean American age 18 or older who provides care for a family member with Alzheimer's Disease and Related Dementias (ADRD). About 150 participants will take part in the study. Funding for this research is pending at the National Institute on Aging.

Procedures

If you decide to take part, this is what will happen. You will be randomly assigned into one of the three conditions; (1) immediate enrollment in the SCP, (2) immediate enrollment in the Healthy Aging Program, and (3) usual care. The latter two groups will begin the SCP in 6 months. Both SCP and Healthy Aging are delivered online with six weekly sessions, each lasting 90 minutes. Randomization is like a flipping a coin. The programs will be virtually delivered by certified trainers in Korean. Upon completion of the program, you will be asked to complete a series of survey measures and interviewed for your feedback on the program. The survey measures will include questions about demographics, depressive symptoms, caregiver experiences and feelings, and about your satisfaction with the program. Interviews will be conducted in Korean. With your permission, the sessions will be recorded.

Risk and Discomforts

Some of the questions in the surveys and interviews may make you feel uneasy or embarrassed. You can choose to skip or stop answering any questions you don't want to.

There is a small risk that people who are not connected with this study will learn a participant's identity or their personal information.

Benefits

There are no direct benefits to you from taking part in this study. However, your participation in this study may help us learn how to modify an evidence-based intervention to meet the needs of ethnic minority ADRD caregivers.

Privacy/Confidentiality

We will keep your records for this study confidential as far as permitted by law. However, if we are required to do so by law, we will disclose confidential information about you. Efforts will be made to limit the use and disclosure of your personal information, including research study ~~and medical~~ records, to people who are required

to review this information. We may publish the information from this study in journals or present it at meetings. If we do, we will not use your name.

The University of Southern California's Institutional Review Board (IRB) and Human Research Protection Program (HRPP) may review your records. Organizations that may also inspect and copy your information include the National Institute on Aging.

Future use of data

This study is collecting data from you. We will make your data available for other research studies that may be done in the future. The research may be about similar diseases or conditions to this study. However, research could also be about unrelated diseases, conditions, or other types of research. These studies may be done by researchers at this institution or other institutions, including commercial entities. Our goal is to make more research possible. We plan to keep your data indefinitely. All data will be transferred securely. If you are not comfortable with this, you should not participate in this study.

Alternatives

An alternative would be to not participate in this study.

Payments/Compensation

You will receive a $20 e-gift certificate upon completion of each questionnaire-based assessment and a $50 e-gift certificate for the individual interview.

Distribution of the gift cards will be made at the completion of the session. In case of an incomplete session, a make-up opportunity will be offered, or a partial (prorated) payment will be made.

Voluntary Participation

It is your choice whether to participate. If you choose to participate, you may change your mind and leave the study at any time. If you decide not to participate, or choose to end your participation in this study, you will not be penalized or lose any benefits that you are otherwise entitled to.

Contact Information

If you have any questions or concerns about the research, please feel free to contact Yuri Jang, PhD at 213-821-6441 or yurij@usc.edu.

This research has been reviewed by the USC Institutional Review Board (IRB). The IRB is a research review board that reviews and monitors research studies to protect the rights and welfare of research participants. Contact the IRB if you have questions about your rights as a research participant or you have complaints about the research. You may contact the IRB at (323) 442-0114 or by email at hrpp@usc.edu.

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Statement of Consent

I have read (or someone has read to me) the information provided above. I have been given a chance to ask questions. By indicating below, I am agreeing to take part in this study.

_____YES, I agree to participate in the study.