

Consent to Participate in a Research Study
CAREGIVING: STRESSES AND SUPPORT FOCUS GROUP

Invitation to participate in a research study

Sarah Smith, M.A., a student at the University of Michigan in the Department of Psychology, invites you to be part of a research project that she will conduct in order to complete requirements for an advanced degree. She is supervised by Dr. John Jones, Ph.D. The project looks at the stresses that people experience when they are providing care to a seriously ill family member. The purpose of the study is to design better support programs for caregivers. The study is funded internally by UM's Rackham School of Graduate Studies. We are asking you to participate because you recently attended a meeting of a UM Caregivers Support Group.

Description of your involvement

If you agree to be part of the research study, you will be asked to participate in one focus group session at our research center at 123 East Hall on the University of Michigan campus. We will invite 12 to 15 people to meet together to discuss their experiences as caregivers. The discussion topics will include the aspects of caregiving that you found to be rewarding and the things that you found to be difficult. We will also talk about the kinds of support, if any, that you received and what types of help you needed. A member of the research team will help guide the discussion. To protect the privacy of your family member, we will not ask questions about the person for whom you provided care. The focus group will last about two hours and we will videotape the discussion to make sure that it is recorded accurately. You must agree to be videotaped to participate in the focus group.

Benefits

While you may not receive a direct benefit from participating in this research, some people find sharing their stories to be a valuable experience. We hope that this study will contribute to the improvement of social support systems for those who provide care to others.

Risks and discomforts

Answering questions or talking with others about the illness of a family member can be difficult. You may choose not to answer any discussion question and you can stop your participation in the focus group at any time. The interviewer will have a list of local agencies that can provide you with additional information or support if you are interested.

While unlikely, there is a chance that another member of the focus group could reveal something about you or your family that they learned in the discussion. All focus group members are asked to respect the privacy of other group members. You may tell others that you were in a focus group and the general topic of the discussion, but actual names and stories of other participants should not be repeated.

Compensation

You will be paid \$30 for participating in the entire focus group session. If you leave before the focus group ends, you will receive \$15. You will need to pay for your own travel and parking expenses.

Confidentiality

We plan to publish the results of this study, but will not include any information that would identify you or your family member. To keep your information safe, the videotape of the focus group will be placed in a locked file cabinet until a written word-for-word copy of the discussion has been created. The researchers will enter study data on a computer that is password-protected and uses special coding to protect the information. To protect confidentiality, your real name and your family member's name will not be used in the written copy of the discussion. The researchers intend to keep this study data, and the videotapes for future research about caregivers.

There are some reasons why people other than the researchers may need to see information you provided as part of the study. This includes organizations responsible for making sure the research is done safely and properly, including the University of Michigan, government research offices or the study sponsor, the National Institutes of Health. Because this study explores sensitive family relationships, if you tell us something that makes us believe that you or others have been or may be physically harmed, we may report that information to the appropriate agencies.

Voluntary nature of the study

Participating in this study is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time. You may choose not to answer a focus group question for any reason.

Contact information

If you have questions about this research, including questions about the scheduling of the focus group or your payment for participating, you can contact Sarah Smith, M.A., University of Michigan, Department of Psychology, 123 East Hall, Ann Arbor, MI 48104, (734) 123-4567, ssmith@umich.edu. You can also contact her faculty advisor, John Jones, Ph.D., University of Michigan, Department of Psychology, 121 East Hall, Ann Arbor, MI 48104, (734) 123-4678, jjones@umich.edu.

If you have any questions about your rights as a research participant, please contact the University of Michigan Institutional Review Board Health Sciences and Behavioral Sciences, (734) 936-0933, 540 E. Liberty St., Suite 202 Ann Arbor, MI 48104-2210, irbhsbs@umich.edu.

Consent

By signing this document, you are agreeing to be in the study. You will be given a copy of this document for your records and one copy will be kept with the study records. Be sure that questions you have about the study have been answered and that you

understand what you are being asked to do. You may contact the researcher if you think of a question later.

I agree to participate in the study. As part of my consent, I agree to be videotaped.

Signature

Date