Information Sheet for Participation in a Research Study

UCONN
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Principal Investigator: Sandra M. Chafouleas
Study Title: Understanding Stress and Personal Well-Being During COVID-19 Pandemic Among Primary Caregivers of Children Aged 6 to 18

Introduction

You are invited to participate in a research study that is exploring the experience of primary caregivers of children aged 6 to 18 during the COVID-19 pandemic. We are particularly interested in understanding the impact the pandemic is having on your personal well-being and levels of stress.

Why is this study being done?

Information from this exploratory study will be used to inform the development of guidance on how to support caregivers of school-age children in the wake of a global pandemic.

What are the study procedures? What will I be asked to do?

The study first involves completing a series of questions about you, your family, and the impact COVID-19 is having on both you and your family. Questions provide background information, such as age, gender, employment, income, etc… Questions also ask specifically about the impact of COVID-19 on you and your family with regard to physical and mental/emotional functioning. Your answers will be used to determine eligibility to proceed to the interview portion of the study and to participate in a follow-up survey. We will review the information to make sure that you meet the criteria to be included, and to make sure that our total sample includes a diverse range of caregivers of a children with and without developmental disabilities. You will be notified if you are invited to proceed to the next stage of the research study, which involves an individual semi-structured phone interview, facilitated by a member of the research team.

If you proceed to the interview portion of the research study, we will review the study procedures with you and ask that you provide written consent to continue. During the interview, you will be asked to describe aspects of your experience as a caregiver for a child, self-care behaviors you engage in to support your health and well-being, and your network of support. The interview will take between 30 and 60 minutes and will be scheduled at your convenience to take place over the phone. The interview will be audio-recorded and transcribed using otter.ai, a secure audio-recording and transcription software. Following completion of the interview, you will be contacted again within 3 months to participate in a follow-up interview. You may also be contacted again within a 3-year period regarding opportunities to participate in a follow-up study.

UConn IRB Protocol L20-0017 Approved March 31, 2020

What are the risks or inconveniences of the study?

We believe there are no known risks associated with this research study; however, a possible inconvenience may be the time it takes to complete the questions, which should take no longer than 30 minutes.

What are the benefits of the study?

By participating in this study, you will contribute to the knowledge about the experiences of caregivers of children aged 6 to 18 during a global pandemic. It is expected that your responses will help guide researchers in developing supports for caregivers during and after a pandemic.

Will I receive payment for participation? Are there costs to participate?

There are no costs and you will not be paid to participate in this survey. If you proceed through completion of the interview portion of the study, you will receive a $15 gift card in appreciation. If you proceed through the follow-up survey, you will also receive a $15 gift card in appreciation.

How will my personal information be protected?

The following procedures will be used to protect the confidentiality of your screening data. All electronic files (e.g., database, spreadsheet, etc.) containing identifiable information will be password protected. Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords. If you have not been selected to continue to the interview or follow-up survey phase, all records to your information will be destroyed after 3 years. If you continue to the interview or follow-up survey phase, your research records will be labeled with a code. The code will be derived from a number that reflects how many people have enrolled in the study. A master key that links names and codes will be maintained in a separate and secure location. The master key and audio recordings will be destroyed after 3 years.

Data that will be shared with others will be coded as described above to help protect your identity. At the conclusion of this study, the researchers may publish their findings. Information will be presented in summary format and you will not be identified in any publications or presentations

We will do our best to protect the confidentiality of the information we gather from you, but we cannot guarantee 100% confidentiality. Your confidentiality will be maintained to the degree permitted by the technology used. Specifically, no guarantees can be made regarding the interception of data sent via the Internet by any third parties.

You should also know that the UConn Institutional Review Board (IRB) and Research Compliance Services may inspect study records as part of its auditing program, but these reviews will only focus on the researchers and not on your responses or involvement. The IRB is a group of people who review research studies to protect the rights and welfare of research participants.

Can I stop being in the study and what are my rights?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate. In addition, you do not have to answer any question that you do not want to.

Whom do I contact if I have questions about the study?

Take as long as you like before you make a decision. We will be happy to answer any questions you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the principal investigator, Dr. Sandra Chafouleas, at 860-486-6868, or the co-investigator, Emily Iovino, at emily.iovino@uconn.edu. If you have any questions concerning your rights as a research subject, you may contact the University of Connecticut Institutional Review Board (IRB) at 860-486-8802.