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Advance Directive Study Parent Information Sheet on Study Procedures

NAME OF INVESTIGATOR: Gretchen Chapman, Ph.D.

PURPOSE: An advance directive is a document in which a patient expresses his or her preferences for medical care. If the patient is ever incapacitated and cannot make decisions for him or herself, the surrogate (the person designated to make medical decisions on behalf of the patient) can use the advance directive as a guide to what treatment the patient would want. The purpose of this research study is to find out how patients can effectively express their preferences in advance directives and how family member surrogates can effectively use the information in the advance directive. In this study, you (the parent) will play the role of the patient and your child (the student) will play the role of the surrogate.

DURATION:

You will complete a questionnaire packet that takes about 1 hour to finish.

PROCEDURES:

You play the part of the patient. You will complete an advance directive describing your preferences for medical care if you were to have a serious illness and could not decide for yourself. You will also complete a questionnaire consisting of nine different scenarios describing possible medical situations. For each one, you will indicate which medical treatments you would want in that situation and which treatments you would not want.

Your child will play the part of the surrogate. S/he might receive a copy of the advance directive you completed for this study. (Some students will and other will not receive the advance directive, so that we can compare these two conditions.) The surrogate will also complete the questionnaire that contains nine different scenarios describing possible medical situations. For each one, the surrogate will indicate which medical treatments s/he thinks you would want in that situation and which treatments you would not want. The surrogate will also complete some other related questionnaires.

It is important that you and your child not discuss your responses until after both of you have returned your completed questionnaire packets. **Your responses are just for our research – nothing you write will actually be used to guide your medical care.**

SUBJECTS:

About 200 student-parent pairs will participate in this study.

EXCLUSIONS:

You should not participate if you are not able to complete a written English-language questionnaire.

RISKS/DISCOMFORTS:

There are no risks to participating in this study.

BENEFITS:

Unless you specify otherwise, both you and your child will receive a summary of your questionnaire responses, showing where you agreed and disagreed on preferences for medical treatment. We hope that this feedback will benefit you by facilitating family discussions of planning for end-of-life care. Researchers will benefit because your responses may aid in the design of better types of advance directives that help surrogates to represent patient preferences more accurately.

CONFIDENTIALITY:

Your questionnaire contains a secret code number that has been randomly assigned to you. Your child's questionnaire will have this same code number. This code number allows the responses from the two of you to be matched up. Only the secret code number will be linked to your responses on the questionnaire and in the computer data file of all participants' responses. If the findings from the study are published, you will not be identified by name. Your identity will remain confidential unless disclosure is required by law.

PAYMENT FOR PARTICIPATION:

For every 5 student-parent pairs who participate in the study, one pair will be randomly selected to win a prize. If you are part of a winning pair, you and your child will each receive a \$50 gift certificate to Barnes and Nobles book store (good at local stores and on line). You will receive the full amount if you complete the entire study and a prorated amount if you complete only part of the study.

RIGHT TO REFUSE OR WITHDRAW:

Your participation is voluntary, and you may refuse to participate or may discontinue your participation at any time. If you do not wish to participate, simply do not complete the questionnaire.

INDIVIDUALS TO CONTACT:

If you have any questions about your participation in this study, you can contact Prof. Gretchen Chapman, Rutgers University Psychology Department, 152 Frelinghuysen Road, Piscataway, NJ 08854, (732) 445-2640, gbc@rci.rutgers.edu. If you have any questions about your rights as a research subject, you can contact Laszlo Szabo, Sponsored Programs Administrator, Office of Research and Sponsored Programs, Rutgers, The State University of New Jersey, ASB III, 3 Rutgers Plaza, New Brunswick, NJ 08901, szabo@orsp.rutgers.edu, 732/932-0150 x2104.