The Nurse Researcher

Author(s)

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Year

2000

Description

A scenario meant to stimulate discussion regarding ethical issues in conducting research with children as a nurse researcher working with Trisomy 21 (Down's Syndrome).

Body

Dr. P. D. Ahtric is a nurse researcher interested in working with families who have children with Trisomy 21 (Down's Syndrome). Dr. Ahtric's interest is in developing a predictive model that will help identify families at risk for less-than-effective coping. She is primarily focused on demographic and social-psychological factors, such as family composition and dynamics, coping strategies, and self-efficacy, and other measures of stress and family functioning.

Her methodology involves use of several questionnaires and open-ended interviews twice a year for two years. Her subjects will include both parents and any children in the family between the ages of 6 and 12. She expects recruitment to be difficult and wants to offer an incentive for participation. She proposes offering the family $400 ($100 per interview).

Discussion Questions:

- If the parents consent, what, if any agreement does Dr. Ahtric need from the children? How, if at all will this vary with the children's age?
- One of Dr. Ahtric's subjects is Mary, a 10 year old sibling of Helen, a 5 year old child with Trisomy 21. Mary completed the first interview, but when it came time for the second, said she did not want to talk about her sister because it made her sad. Dr. Ahtric stopped the interview, but Mary's parents told her that it was "OK", to just keep going and finish the questionnaire. What should Dr. Ahtric do?
- Who gets the $400 incentive? Should a different form of payment be used?

As Dr. Ahtric's research progresses, she decides to add a supplement, investigating both physiologic indicators of stress and genetic factors that might play a role in family response to stress. This will involve obtaining a blood sample from all children, affected and unaffected, and from both parents. Dr. Ahtric plans to offer another incentive for this part of the study.

Discussion Questions:

- Since Helen, the child with Trisomy 21, is unlikely to benefit directly from this aspect of the research, what pain or risk to her is justified in carrying out the research?
- How could assent be obtained in a meaningful way from Mary, Helen's sister?
- Is it proper to offer an extra incentive for this blood draw, and if so, what sort of incentive and to whom?

Notes

Caroline Whitbeck introduced methods and modules for discussing numerous issues in responsible conduct of research at a Sigma Xi Forum in 2000. Partial funding for the development of this material came from an NIH grant.

You can find the entire sequence on the OEC at Scenarios for Ethics Modules in the Responsible Conduct of Research. Some information in these historical modules may be out-of-date; for instance, there may be a new edition of the professional society's code that is referred to in an item. If you have suggestions for updates, please contact the OEC.

Contributor(s)

Caroline Whitbeck

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Resource Type

Open-ended scenario

Parent Collection

Scenarios for Ethics Modules in the Responsible Conduct of Research

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