

## Ethical Implications of Asking Sensitive Questions

### Background

Research on abuse, self-harm, sexual and illegal behavior, frequently requires subjects to respond to sensitive questions about their behaviors or attitudes. In assessing the risk of such human subjects research, it is important to evaluate the extent of subjective levels of discomfort and distress and the probability of such occurrences.

### Method

One hundred and fifty-seven undergraduate students read an informed consent document and completed an 80-question anonymous survey containing sensitive questions on various aspects of behavior and personal attitudes to taboo topics. Questions were based on yes/no, Likert-type, or numeric responses, and included the following "If I could have sex with someone against their will, without any chance of getting caught, I would", "I believe that I was sexually abused between the ages of 6 and 12", "How many times have you deliberately hurt yourself without trying to kill yourself?", and "During the past 2 years, approximately how many times have you driven a car or motorcycle while intoxicated?". The final section of the survey included questions related to honesty of reporting, perceptions of anonymity/confidentiality, level of distress/discomfort experienced while completing the survey, desire to discontinue participation, and perceived ability to discontinue participation.

"Many of the questions on the survey deal with sensitive or taboo topics, such as cheating, sexual behavior, and racism."

"Given that the survey questions deal with some sensitive topics, you may be uncomfortable answering certain questions."

"If any questions cause you psychological distress, you should talk to the researcher who can provide you with some resources for further assistance."

"While the survey includes some questions about illegal and taboo behaviors (such as drug use), none of your responses can be traced back to you."

22. I have masturbated while another person was watching.  
A) True B) False
28. I have never tried to kill myself.  
A) True B) False
30. I believe that I was sexually abused before age 6.  
A) True B) False
45. I sometimes fantasize about being raped or about raping someone else.  
A) Strongly Disagree B) Disagree C) Slightly Disagree D) Slightly Agree E) Agree F) Strongly Agree
49. AIDS will help society by reducing the number of homosexuals.  
A) Strongly Disagree B) Disagree C) Slightly Disagree D) Slightly Agree E) Agree F) Strongly Agree
60. How many times have you deliberately hurt yourself without trying to kill yourself?  
A) 0 B) 1-2 C) 3-5 D) 6-9 E) 10-15 F) 16 or more

### Results

As researchers, we are interested in whether or not participants experience any discomfort or distress while answering sensitive questions. With this in mind, please answer the following questions.

75. How much psychological discomfort or distress did you experience while completing this survey?

- |   |        |
|---|--------|
| A) No discomfort or distress.                       | 50.6%  |
| B) Some minor discomfort/distress.                  | 44.9%  |
| C) I found a number of questions quite distressing. | 4.5% * |
| D) Most of the questions caused me distress.        | 0.0%   |

76. Do you think that the level of discomfort or distress that you experienced while taking this survey is more than you might experience in your regular life (outside of this research session)?

- |        |     |
|--------|-----|
| A) Yes | 6%  |
| B) No  | 94% |

77. If you had known what the questions on this survey were going to be like, would you have chosen NOT to participate?

- |        |     |
|--------|-----|
| A) Yes | 6%  |
| B) No  | 94% |

\* NONE of the subjects that reported finding a number of questions quite distressing felt that the level of discomfort/distress was more than they might experience in their regular life.

† Fifteen percent of subjects felt that it would have been "difficult" or "very difficult" to have stopped their participation if they had wanted to.

23% of subjects indicated that they had lied or "were not completely honest" on one or more of the questions.

54% of subjects said that they would have not have answered the questions as honestly if we had collected surveys marked with their name and promised confidentiality.

4% were "not very confident" or "not at all confident" that their answers were being collected completely anonymously

78. At any time, did you want to discontinue your participation?

- |        |     |
|--------|-----|
| A) Yes | 6%  |
| B) No  | 94% |

79. How easy do you feel it would have been to stop your participation if you had wanted to?

- |                   |       |
|-------------------|-------|
| A) Very Easy      | 61%   |
| B) Easy           | 24%   |
| C) Difficult      | 12% † |
| D) Very Difficult | 3%    |

80. Did you feel at any point that you had been coerced (pressured) into participating in this study? point

- |        |     |
|--------|-----|
| A) Yes | 3%  |
| B) No  | 97% |

### Discussion

In assessing whether such studies should be considered minimal risk, one must evaluate the probability and magnitude of harm or discomfort. Although 45% of the individuals completing our survey of sensitive questions experienced some minor discomfort or distress (high probability, low magnitude) and 4.5% found a number of questions quite distressing (low probability, high magnitude), none of subjects who found the experience quite distressing considered that the level of discomfort or distress was more than experienced in their regular life. This study demonstrates how easily data can be generated to empirically evaluate risk, thus allowing researchers and IRBs to base their decisions about acceptable levels of risk on subjects' actual experiences rather than personal best-guesses of how subjects might respond. Our results also suggest that while a consent process may emphasize the notion of voluntary consent and freedom to withdraw participation, some subjects still feel that halting their participation would be difficult. Additional data is needed to determine the factors influencing the likelihood and extent of experienced distress. It is also critical that we examine methods to improve subjects' sense of agency in withdrawing participation.