

Ethical Issues in Youth Surveys: Potentials for Conducting a National Questionnaire Study on Adolescent Schoolchildren's Sexual Experiences With Adults

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The difficulties in obtaining valid and reliable data on child sexual abuse (CSA) have been discussed by Martin,¹ among others. One avenue by which to obtain valid data could be youth surveys among minors. High response rate and low social selection bias are reported in surveys conducted among children in the mandatory school system.^{2,3} A further advantage of school-based surveys is that the results gathered reflect ongoing or recent abuse, thus increasing their relevance for national action plans. Although there are advantages to asking young people about their experiences of CSA, reporting bias may be expected due to fear of perpetrator retaliation. It may, however, be expected that anonymous self-administered questionnaires about recent events could limit both reporting and recall bias and thus increase the accuracy of responses.

A request for active parental consent may represent a threat to the validity of a youth survey. The consequences of a change from passive to active parental consent procedures were evaluated in a longitudinal youth survey.⁴ The results indicated that active consent procedures produce deleterious effects on participation rates and underrepresentation of at-risk youth in the sample. Therefore, to secure a high response rate with low selection bias, written permission from parents for young adolescents to participate in anonymous surveys should be avoided.

In planning a survey on child sexual and physical abuse in Denmark, we reviewed international experiences and the current Danish national legislation concerning the implementation of youth surveys without obtaining active parental consent. Our goal was to find guidance regarding the ethical and legal aspects of conducting youth surveys about sensitive topics.

Objectives. We evaluated ethical constraints concerning youth surveys on child sexual abuse (CSA).

Methods. We reviewed internationally published studies and Danish regulations concerning school-based surveys conducted without active parental consent.

Results. Ethical constraints concerning participants in youth community studies have been scantily assessed. Danish legislation accords minors the right to be heard on issues concerning themselves. The anticipated societal benefits of children's participation in community studies justify conducting anonymous surveys among schoolchildren based upon their own informed consent.

Conclusions. No ethical or legal objections were found to conducting an anonymous survey in Denmark on CSA among 9th-grade pupils without parental consent, provided that the survey was accompanied by an offer of counseling. (*Am J Public Health*. 2003; 93:1878-1882)

METHODS

A prerequisite for conducting a questionnaire-based study on CSA in Denmark without procuring active parental consent was a review of the limited number of studies from the international published literature that described ethical concerns and principles related to research among children, both CSA-related and more general. We also consulted a number of Danish organizations and bodies about potential ethical and legal problems.

RESULTS

Published Studies

Ethical considerations about research conducted on young people have primarily concerned biomedical research, including the circumstances under which children may be used in clinical research—for example, in the testing of various treatment methods.^{5,6} Discussions have focused on the dilemma of how to promote the best interests of children as a group through research while protecting the rights and welfare of individual research subjects.⁷ Ethical issues within epidemiological studies have received less attention, as recently pointed out by Canadian researchers

who emphasized the importance of establishing ethical standards for epidemiological research with children.⁸

There exist a number of problems concerning youth surveys, including who can give consent for children's participation in research, how "informed" informed consent must be, how to ensure that the information is understood by mentally impaired youth, how to conduct surveys among abused children who might be emotionally harmed by being questioned about their experiences, and how to provide information on study results when abuse is so often unacknowledged. These issues are generally not discussed in published reports of research results from youth surveys.

A study in the United States evaluated the practices of institutional review boards concerning consent of adolescent minors participating in anonymous surveys.⁹ With a review board response rate of 39%, the majority (72%) required parental consent for longitudinal surveys on sexual behavior and CSA. However, 93% supported minors being able to give informed consent for anonymous surveys. In a study examining parent and child perceptions of the need for parental consent in youth studies, a minority of parents (33%)

and adolescents (26%) reported believing that parental consent was needed for anonymous surveys.¹⁰

The ethical issues that arise when implementing a questionnaire-based study among schoolchildren naturally demand that the same considerations be taken as for corresponding studies among adults. These include providing sufficient information regarding the aims of the study, the methodologies used, the expected results, and potential risks and discomforts that participation in the study may entail. Additionally, each participant should be informed that the child is free to abstain from participation in any part of the study at any time. The integrity of the participant should be respected, and all measures should be taken to respect the individual's privacy, as well as to ensure that the study has a minimal impact on the child's physical, mental, and emotional integrity.

Previously, knowledge about young people's health, their use of the health care system, their health-related behaviors, and risk factors for ill health was rather sparse. However, in the past 5 to 10 years, a number of surveys have collected general information on young people's health and lifestyles, with a focus on the well-known risk factors in young boys and girls: tobacco smoking, low physical activity, and high alcohol consumption.¹¹⁻¹³ These youth surveys have been based on parental consent on behalf of the young respondents. In general, they have not included any discussion of the ethical and methodological issues in the data collection: namely, what impact required parental consent might have on the study.

An exception is a questionnaire-based study conducted in Switzerland among 15- to 20-year-olds in 1992.¹⁴ This study discussed the potential ethical problems involved in establishing health indicators for young people based on data that primarily concern persons from higher socioeconomic status groups and that do not include youths from specific risk groups. One of the reasons for this omission is that families with current psychosocial problems may be less willing to give their consent for the child's participation in such a study.

Other research teams, including Lépine and Smolla,⁸ have pointed out society's obligation to conduct research with particular

groups to avoid cutting them off from scientific advancement. The discussions, however, concerned mainly ethical principles related to biomedical research on children and, to a lesser extent, children's participation in community surveys. Lépine and Smolla referred to child and adolescent psychiatric community surveys, which serve to establish the prevalence of psychopathology, the need for care, and the utilization of health services. They argued that such nontherapeutic studies are justified by their anticipated social benefits. In child psychiatry community surveys, it has been shown that the information children provide about themselves may diverge from that provided by their parents.¹⁵

The issue of parents refusing to give their consent to children's participation in community surveys may pose problems even in studies on nonsensitive issues. For example, in a recent study on backache in young people, a total of 153 students aged 16 to 18 years reported experiencing chronic low back pain.¹⁶ These students were requested to complete a self-administered questionnaire, as well as to participate in a face-to-face interview, on the condition that informed consent was obtained from their parents. Only 57 of the 153 students (37.3%) participated in the study from that point on.

In Denmark, there is no established set of rules governing the extent to which it is necessary to obtain parental consent for persons younger than 18 to participate in anonymous questionnaire- and interview-based studies. The practice of obtaining parental consent has been upheld in earlier studies conducted by a number of Danish epidemiological research institutes. It was found that a substantial number of parents did not consent to their children's participation in the studies, apparently regardless of the nature or the themes of the studies. In a recently completed general health survey among 9th-grade pupils, 11% of parents refused to grant their children permission to participate, despite the absence of sensitive topics in the questionnaire.¹⁷ The study did not analyze whether the parental reluctance was due to lack of confidentiality, as there was a request for possible participation in a follow-up study.

In Finland, a questionnaire-based nationally representative study was conducted in

the late 1980s among 9th-grade schoolchildren aged 15 to 16 years.¹⁸ The questionnaire itself included neutral information on family circumstances, and also whether or not physical violence or threats of violence were used as punishment, as well as a number of questions about sexual experiences with adults. The study was described to school authorities and the public as "a study of 9th-grade pupils' childhoods, upbringings, and sexual experiences with adults, aimed at improving the welfare of children and young people in Finland."¹⁹ With the permission of the Finnish Ethics of Science Committee and local Finnish educational authorities, the study was conducted as an anonymous self-administered questionnaire without prerequisite parental consent. The study achieved a high response rate, with 90.5% of the randomly selected school classes participating.²⁰

In a questionnaire-based study on the sexual experiences of high school and college students in Sweden in 1990, the view was upheld that 17-year-olds are sufficiently mature to decide for themselves whether to participate or not.²¹ Accordingly, parental consent was not considered a prerequisite for subject participation.

An English study has assessed different methodologies employed for questionnaire-based studies about young people's sexual experiences.²² The main conclusion drawn was that whereas young people themselves found questions on sexual experiences to be relevant in youth surveys, the participants acknowledged that such a survey would be difficult to implement should parental consent be required.

Opinions of Relevant Organizations and Bodies

In the preparation of a nationally representative survey on CSA, we lacked a critical overview of the ethical issues of self-interviewing youth in Denmark or other European countries about sensitive topics. We therefore aimed to illuminate the possible contradictions between the legislation on parental custody and legislation concerning children's rights to contributory influence. A further objective was to discuss the ethical issues concerning detection of abuse and the influence of anonymity on the type of follow-up that can be offered in

connection with a self-administered questionnaire on CSA.

The United Nations (UN) Convention on the Rights of the Child. Article 12 of the UN Convention on the Rights of the Child states that a child's viewpoints must be accorded appropriate significance in relation to that child's age and maturity. Children have knowledge and a right to be heard, as they are the best informed about important aspects of their lives. Children should also be given joint determination, such as the right to refuse participation in a given study.

The Danish National Council for Children. The Danish National Council for Children is a public institution established in 1994 at the behest of the Danish parliament. The council is both professionally and politically independent of the government. The task of the council is to ensure children's interests and rights as described in the UN Convention on the Rights of the Child. The council chairman functions as an ombudsman for the rights of children.

The council draws on the views and opinions of children in its work toward the improvement of children's living conditions. Its efforts occur in conjunction with those of a Children's Panel made up of 60 randomly selected 5th-grade classes comprising approximately 1225 students. The Children's Panel has been available for questioning in 1998–1999 and 1999–2000 on topics such as friendship, teasing, and bullying.²³ Recently, the council published an anthology that illuminates issues related to using children as informants.²⁴ It referred to the principles of respecting children's views as ratified in Article 12 of the UN Convention on the Rights of the Child in upholding the child's right to contributory influence by according her/him joint determination. Hence, the council has recommended the implementation of a representative survey about CSA among 15- to 16-year-olds. Representativity would best be achieved by requesting informed consent for participation from the youth, but not from their parents.

The Danish Central Scientific Ethical Committee. In the World Medical Association's Declaration of Helsinki, basic principles have been outlined for biomedical research, including the concept that informed consent

must be obtained from a guardian if the subject of biomedical research is a minor.²⁵ Although these principles relate primarily to biomedical research, it has been widely accepted that epidemiological research should be assessed according to the same principles. A case in point is the principle regarding the protection of the research subject's integrity—that all measures should be taken to respect the subject's privacy and that the study's impact on the subject's physical, mental, and emotional integrity should be minimized. The research subject should be sufficiently informed of the objectives of the study, as well as the methodologies to be employed, the expected results, and the discomforts and potential risks that participation might entail. Similarly, subjects should be informed that they are free to disengage themselves from the study at any time.

In Denmark, questionnaires and information relating to epidemiological studies conducted by physicians are conventionally forwarded to an ethical committee for assessment. This evaluation often occurs in the form of a "self-declaration," whereby the ethical committee is apprised of the research project, and the project leader confirms that no ethical problems requiring consideration by the committee occur in the project at hand. Conversely, such declarations are rarely used in social science epidemiological studies. The fact that sensitive issues may in some cases lead to distress or other adverse reactions in the respondents²⁶ may not be acknowledged.

Civil rights authority of the Ministry of Justice. The Danish national legislation on parental custody and care rules that children under the age of 18 are wards of their parents. However, other laws also regulate a child's right to self-determination. Legislation concerning patient rights maintains that informed consent to treatment must be obtained from children aged 15 years and older. According to the Danish Parental Custody and Care Act, from the age of 12 onward, a child has the right to codetermination or joint determination regarding whom she/he wishes to live with in the case of parental divorce. Additionally, she/he must be heard by the social services should the case involve a placement outside the home, whereas children older

than 15 years have independent party status in placement cases.

Thus, in Denmark children under the age of 18 have, to varying degrees, the right to self-determination and joint determination within health, social, and educational contexts. Furthermore, it should be emphasized that consensual sexual relations between children older than 15 and adults (or older children) are legal, unless there is a kin or dependency relationship between the parties. The minimum age for criminal responsibility is 15 years.

The Danish Primary Education Act. This act states that every school must have a board consisting of parents, teachers, and pupil representatives. The pupil representatives are included as full members of school boards. The board decides on matters of general principle concerning the school, whereas the headmaster is entitled to decide in specific issues such as the school's participation in surveys. In this way, both the school board and the headmaster may feel they have a right to decide whether they will allow a survey to take place in their school.

The Social Security Law. According to the Danish Social Security Law, every citizen is obligated to inform municipal authorities in cases of suspected abuse of children younger than 18. A situation could potentially arise, during a youth survey on CSA, in which concrete knowledge of abuse of an identified minor was obtained, thus creating an obligation to inform authorities. However, no conflict regarding notification duty will arise when a youth survey is structured so as to ensure absolute anonymity of the respondents when answering the self-administered questionnaire.

DISCUSSION

There is a clear public interest in obtaining knowledge about the extent and nature of CSA, with a view to effective prevention. We aimed at illuminating the ethical and legal issues involved in obtaining this knowledge through a youth survey conducted among schoolchildren, which likely would not be biased by social selection and would achieve a very high response rate.¹⁹ Requiring parental consent could result in a significantly lower

participation rate, and pupils whose parents withheld consent could disproportionately represent those from relatively disadvantaged backgrounds with a high rate of problems.

During the past 20 years, research groups from different countries have conducted youth surveys without parental consent, with seemingly little criticism being raised from authorities. However, it is not clear whether this acceptance was due to lack of awareness of or indifference toward ethical issues in research with children, and whether there has been a significant change in societal views and governmental policy.

The UN Convention on the Rights of the Child views older children as persons with the right to joint determination. A number of Danish regulations within the health and social systems accord young people this joint determination and express a regard for children's and young people's right to be heard on issues concerning them. Consequently, the Danish authorities had no objection to the conduct of a national survey among 15- to 16-year-olds, provided that data could not be linked to any respondent. Whether the current Danish interpretation of the national and international conventions and legislation can be generalized to other countries should be examined empirically.

The design of an anonymous survey will exclude the possibility of a longitudinal approach, such as the conduct of a follow-up study among the respondents to analyze the validity and reliability of the data on CSA. Among young adults aged 18 and 21 years, a face-to-face interview found substantial unreliability in the reporting of CSA, which resulted in a possible underestimate of the true prevalence of abuse.²⁶ The reliability of anonymous surveys cannot be evaluated by any follow-up study due to the provision of anonymity.

The possible harmful effects of participating in surveys that include questions about CSA have been investigated in a series of longitudinal studies that focused on the incidence of CSA among women in New Zealand.²⁷ The studies enabled the researchers to assess the participants' reactions to being questioned about the given topics. Findings revealed that 10 times more women recalled participation in the study as being a

positive experience than remembered it negatively. Furthermore, significantly more women who had been subjected to CSA recalled the study positively, in comparison with women who had not been abused. Another New Zealand research team has pointed out that for the majority of participants, CSA interviewing does not evoke observable distress reactions or difficulties.¹ Less than 2% of participants showed distress at the questioning, and among about 1000 respondents, only 1 showed a severe reaction that led to termination of the interview.

Additionally, Kinard has found that, despite the discomfort that some young people may experience in answering the questionnaire, many children may be comforted by the opportunity to pass on information concerning abuse.²⁸ Kinard pointed out that the offer of counseling and follow-up when needed should be an ethical prerequisite. However, other points of view have been expressed regarding the ethical issues concerning detection of abuse and follow-up. Kinard has emphasized that in research that is not clinically oriented, the investigator cannot offer or deliver intervention or treatment services for problems uncovered in the course of data collection that did not primarily aim at medical and psychological treatment. Although treatment of emotional problems may be in the best interest of the child, parents may resent any intrusion of the researchers beyond simply conducting the research. Fisher et al. evaluated adolescents' perspectives on referring and reporting at-risk participants.²⁹ Judgments of reporting options were related to risk severity; hence, confidentiality was viewed to be unfavorable in cases of child maltreatment and threats of suicide. The results confirm that it is mandatory to include an open offer of counseling and follow-up in youth surveys.

On the basis of our results, we feel that young people aged 15 years or older should be accorded the right to make an independent decision as to whether or not they want to participate in a study dealing with issues that are relevant to them. Assuming that the relevant educational authorities and school boards approve the study, a youth survey on CSA that respects the rights of the young person to decide whether to participate cannot be found to contravene any legislation. It

should be a condition that the minor's own consent is obtained explicitly, preferably before, during, and after participation, and that the minor is assured of the confidentiality of the results.

In our opinion, research on sensitive topics with young people should be assessed by an ethical committee and should be accompanied by an offer of counseling for all those who should need it. The cost of such counseling should be included in the research budget. An offer of counseling may violate the anonymity of the respondent. The offer could therefore be offered primarily by telephone, and future appointments could be agreed upon according to the respondent's wishes.

The use of computer-based self-administered questionnaires has been found to overcome both comprehension and ethical problems related to sensitive questions. Such questionnaires enhance the feeling of privacy and guarantee the anonymity of the answers.³⁰ This method may therefore increase the possibility of obtaining reliable data on CSA by limiting reporting bias related to fear of perpetrator retaliation. Accordingly, we are preparing to conduct a computer-based self-administered questionnaire on CSA among a representative sample of 9th-grade pupils in Denmark, which will include a voice-over component. Using this computer-based questionnaire will increase the possibility that youths will be able to understand and give informed consent to participate in the study. ■

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Human Participant Protection

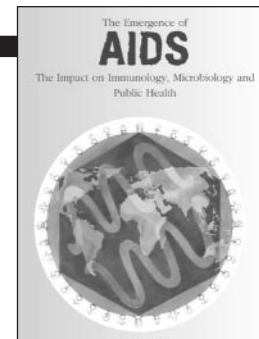
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