The Danish Youth Survey 2002: Asking young people about sensitive issues

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ABSTRACT

Objectives. To explore ethical, legal and practical issues related to conducting a youth survey in Denmark on sexual experiences before the age of 15 and thereby achieve reliable data on child sexual abuse. Study design and methods. The relevant authorities were consulted on possible legal and ethical objections. By a pilot study based on conventional self-administered questionnaires, information was obtained about the reactions of school boards, teachers and 9th grade students. Results. The necessary conditions were present for the implementation of a nationwide anonymous youth survey without obtaining parental consent. The Central Scientific Ethical Committee had no objections. In a number of fields, Danish legislation accords 15-to-18-year-olds the competence to make independent decisions regarding their personal circumstances, and the UN Convention of Children’s Rights states that a child’s viewpoints must be accorded appropriate significance in relation to that child’s age and maturity. In the pilot study, no negative reactions were observed among the students and school authorities. About 25% of the students had difficulties in filling the questionnaire. No student made use of the accompanying offer of counselling. Conclusion. An anonymous youth survey based on computer-assisted self-interview (CASI) would increase the validity of youth surveys on child sexual abuse to which no ethical or legal objections were found.

Keywords: youth survey; ethical issues; child sexual abuse; pilot study; Denmark

INTRODUCTION

The National Institute of Public Health, Denmark (NIPH) has recently highlighted the scope and nature of child sexual abuse (CSA) in Denmark, based on a number of data sources including available register data and a review of all police reported cases in 1998 (1). However, the study only included those instances of abuse which had been made public knowledge, not young people’s personal experiences of CSA. In the beginning of this century, only a limited amount of knowledge existed about the extent and nature of CSA in Denmark. In 2001, the National Council for Children recommended that a study be conducted amongst young people, in order to obtain information necessary for the planning of strengthened initiatives against abuse. A foregoing pilot study was a prerequisite to clarify ethical and legal issues related to conducting a youth survey, which was estimated to present the best data on CSA.

Youth surveys conducted in schools are rarely affected by a social selection bias, as the sample includes people from diverse social strata and the response rate is typically very high (2). 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 will limit both reporting and recall bias and thus increase the accuracy of responses (3).
Another serious bias would be if the survey only could be conducted on the basis of active parental consent. Active consent procedures are reported to produce deleterious effects on participation rates and under-representation of at-risk youth in the sample (4). Studies have pointed out that it is an ethical problem to establish indicators for health amongst young people based on data that primarily affects persons from higher social groupings, and which do not include families with concrete problems, who may be less willing to consent to the child’s participation (5). Parental refusal may pose a problem even for studies on “non-sensitive” issues, as shown in a recent Danish study (6). We have previously reviewed international experiences and the current national legislation concerning the implementation of youth surveys without obtaining active parental consent (7). However, research groups from different countries have conducted youth surveys without parental consent, with seemingly little criticism being raised on the part of authorities (8,9).

In the present study we aimed to illuminate the possible contradictions between legislation on parental custody and on children’s rights to contributory influence. A further objective was to discuss the ethical issues concerning detection of abuse. An additional significant aim of the pilot study was to develop a methodology suited for obtaining data on significant risk factors for ill health and poor welfare in childhood and youth.

**METHOD**

Information about current Danish legislation and the attitudes of relevant authorities and the national scientific ethical board were collected by review and personal interviews.

A pilot study based upon traditional self-administered questionnaires was conducted in five schools among 150 students in the 9th grade. Initially, interviews with teachers and members of the school boards informed us about their attitudes to the survey.

The questionnaire addressed six main themes: family, school, leisure and social networks, health and health behaviour, sexual experiences with peers and adults and violence in immediate surroundings. A series of questions with which to assess the students’ reactions to the sensitive themes of the study were included in the questionnaire. Students were given written information about the study, as well as an information card about the offer of counselling, should they have experienced the study as personally discomforting.

The students answered the questionnaire in a gym hall in an exam set-up in the presence of an interviewer, who informed about the practical aspects of the study, including the anonymity of the answers. Following the study, the children met with the researchers to present their comments.

**RESULTS OF THE ASSESSMENT OF THE ETHICAL ISSUES**

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, for example legislation concerning patient rights, which maintains that informed consent to treatment must be obtained from children aged 15 years and above. The Danish Parental Custody and Care Act provides from the age of 12 onwards the right to co/joint-determination, regarding whom a child wishes to live with in the case of parental divorce. Additionally, the child must be heard by the social services should the case involve a placement outside the home, while children older than 15 years have independent party status in placement cases.

The UN Convention on the Rights of the Child

Article 12 of the convention 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 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 tasks of the Council are to ensure children’s interests and rights on the basis of the UN Convention of the Rights of the Child. The function of the chairman of the Council parallels the “ombudsman” function for adults. Recently, the Council reviewed the ethical issues related to using children as informants, and referred to the principles of respecting children’s right to contributory influence, ratified in the UN Convention of Children’s Rights (10). Hence, the Council recommended the implementation of a representative survey about CSA among 15-16-year-olds, and found that validity 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 Denmark, questionnaires and information relating to epidemiological studies conducted by physicians are conventionally forwarded for assessment to an ethical committee. This evaluation often occurs in the form of a ‘self-declaration’, whereby the ethical committee is oriented about 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 scientific epidemiological studies. The fact that sensitive issues may in some cases lead to distress or other adverse reactions in the respondents (11) may not be acknowledged.

The Danish Primary Education Act
Every school must have a board consisting of parents, teachers and of students’ representatives. The board decides on principal matters concerning the school, whereas the head master is entitled to make decisions in concrete matters. In this way, both the school board and the head master may feel entitled 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.

RESULTS OF THE PILOT STUDY
The response rate
All students present in the classroom participated and completed the questionnaire, although a number of questions were left unanswered in some of the questionnaires. There was no correlation between the students’ family backgrounds and the number of unanswered questions, or between negative reactions to the questionnaire’s themes and the number of unanswered questions. About 10% of the students were absent from school, which is within the normal average for absence due to illness.

The students’ evaluations of the themes covered
The students were asked how they felt about being questioned about the various topics in the questionnaire. Table I shows that the majority of students considered the different questions to be "OK". The most accepted questions were those concerning school attendance and health. More than half the students considered the questions on sexual experiences to be "OK", almost one-eighth found them "uncomfortable", and a minority found these questions to be "unpleasant". Neither gender nor ethnic differences appeared to exist in the students’ acceptance of sensitive questions. The students who found the questions to be uncomfortable or embarrassing did not refrain from answering the questions altogether.
The students’ understanding of the questions
The comprehensibility of the questions asked was investigated in two ways. Firstly, by including direct questions asking to what degree respondents had understood the questions and secondly, by observing a number of students in special education classes while they completed the questionnaire. Almost 76% of students answered that they had no comprehension problems, while nearly 23% had experienced difficulties in answering some of the questions. Two students experienced problems in answering most of the questions.

Many of the special education students read at such a slow rate that they lost grasp of what had been asked in the immediately preceding text and were unsure of whether to answer questions or whether to jump ahead to the next section. They were unused to participating in questionnaire-based studies, perhaps because they gave up reading and understanding the questions from the outset.

A number of questions were formulated in such a way that the pupils pointed out that they were incomprehensible, despite the fact that the questionnaire was based upon currently used Danish school surveys.

The credibility of responses given
The students were asked whether they thought their fellow classmates had answered the questions honestly. Only one fifth of children were sure that their fellow classmates had answered honestly, whilst one quarter were sure that their classmates had not answered honestly and one fifth didn’t think the questions were answered honestly (Table II). A control for the preciseness of the answers was incorporated into the questionnaire. A minority of answers (2%) were inconsistent.

The students’ assessments of the respect of anonymity
Out of 127 answers, almost 6% of students did not think their answers would remain anonymous, while more than one-quarter were a little doubtful. This doubt may be partly explained by the pupils’ misunderstanding of the concept of anonymity.

The reactions of the participants
The students considered it important to gain knowledge about the potential problems young persons might experience by actually asking them personally. Additionally, they suggested further themes that could be included in a nationwide study. No students criticised the study’s practical set-up, or openly expressed distress on being asked to participate or because parental permission was not obtained. They thought it fair that they themselves decided whether or not to participate in a study.

The schools informed the researchers that none of the students, parents or school boards had since criticised the pilot study. No student made use of the offered psychological counselling.

Table I. The students’ reactions to answering the sensitive topics in the study. What did you think of being asked about:

| Topic                        | OK | Uncomfortable | Unpleasant | Don’t know |
|------------------------------|----|---------------|------------|------------|
| Family                       | 106| 78.5          | 10         | 7.4        |
| School                       | 118| 87.4          | 4          | 3          |
| Someone to talk to           | 103| 76.3          | 11         | 8.1        |
| Health                       | 108| 80            | 9          | 6.7        |
| Sexual experiences           | 75 | 55.6          | 21         | 15.6       |
| Conflicts at home            | 96 | 71.1          | 16         | 11.9       |

Table II. Do you think you fellow students have answered all the questions honestly?

|                      | N | % |
|----------------------|---|---|
| Yes                  | 28| 21% |
| No, I am sure they haven’t | 38 | 28% |
| No, I don’t think they have | 26 | 19% |
| Don’t know           | 38| 28% |
DISCUSSION
In the planning of a youth survey on CSA, we took advantages of the experiences of prior studies, mainly those conducted in New Zealand (12-14). However, it was felt necessary also to carry through a pilot study as the foundation of a nationwide youth survey. The pilot study had four main objectives. Firstly, the evaluation of ethical issues related to conducting a self-administered questionnaire-based study about sexual experiences on young people, without active parental consent. Secondly, to gauge the education authorities’ reactions to such a study and thirdly, to assess the young people’s understanding of, and reaction to the questions posed. Finally, to find the best method for addressing this topic.

The Danish authorities had no ethical or legal objections against the conducting of an anonymous survey on sexual experiences among minors, aged 15-16 years, given that the survey was anonymous and based on their own informed consent. A number of Danish regulations within the health and social systems accord young people joint-determination and express a regard for children and young people’s right to be heard on issues concerning them. Consequently, the school boards supported the pilot study on these premises.

The students had no objections to participating and reported no need for counselling. No parental criticism was raised. A significant portion of the students were not able to answer a conventional, written questionnaire.

There is a clear public interest in obtaining knowledge about the extent and nature of CSA with a view to effective prevention, and the knowledge may be best achieved by a survey conducted among schoolchildren (15). The possible harmful effects of participating in surveys which include questions about sexual abuse have previously been investigated (16). The study revealed that ten times as many women recalled participation in the study as being a positive experience than those who remembered it negatively. Furthermore, there were significantly more women who had been subjected to CSA who recalled the study positively, in comparison with women who had not been abused. Another research team has pointed out that for the majority of subjects, child sexual abuse interviewing does not evoke observable distress reactions or difficulties. A minority of subjects showed some distress to the questioning, but among about one thousand respondents only one case showed severe reactions that led to termination of the interview. It is reported that despite the discomfort, which some young people may experience in being questioned on abuse, many children may be contended by the opportunity to pass on information concerning abuse (16). It is therefore a prerequisite that counselling and follow-up are offered if needed.

Recently a nation-wide youth survey among 12-to-18-year-olds in New Zealand was conducted using computer-based voice-over self-administered questionnaires (17). This method has been found to overcome both comprehension and ethical problems related to sensitive questions (18) (19). It enhances the feeling of privacy of the self-administered form, guarantees the anonymity of the answers, and may ensure the participation of reading-disabled students.

Accordingly, based on the experiences from the present pilot study, in 2002 we conducted a computer-based self-administered questionnaire on CSA among a representative sample of 9th grade students in Denmark, and included a voice-based component (20).

CONCLUSION
A questionnaire was developed for measuring young people’s sexual experiences with adults before the age of 15 and thereby defining the prevalence and character of CSA.

Assessment of the related ethical issues showed that anonymous surveys on CSA among minors might be conducted without active parental consent, provided that sufficient information is given about the aims of the study and the potential risks and discomforts that participation in the study may entail. The integrity of the participant should be respected and all measures should be taken to respect the individual’s priva-
cacy, as well as to ensure that the study has a minimal impact on her/his physical, mental and personal integrity.

Importantly, the present pilot study found that students in special education classes and a number of “mainstream” students would find answering a conventional questionnaire difficult. Therefore, we recommend youth surveys to be based on computer response with audiovisual equipment: Audio-CASI; computer assisted self-interviewing.

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