Participation of Next of Kin in Research Following Sudden, Unexpected Death of a Child

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Objective: To assess parents' perceptions of their experience being interviewed after the sudden, unexpected death of their child.

Design: Case-control study in which cases were victims of unintentional drowning.

Setting: Households of recent drowning victims in 6 states in the United States.

Participants: Caregivers (primarily parents) of 87 cases and 491 matched controls were interviewed via telephone about their child.

Main Exposure: Recent death of a child by unintentional drowning.

Main Outcome Measures: Degree of stress related to interview, perception of interview length, and participants' views about their willingness to participate in this type of interview again, given their experience with the current interview.

Results: Although case participants were more likely than controls to perceive the interview as somewhat or very stressful (odds ratio, 3.64; 95% confidence interval, 1.67-7.96), most of the case participants (87.2%) and controls (96.1%) perceived the interview to be not at all or a little stressful. A greater percentage of controls (37.8%) found the interview to be too long, compared with case participants (20.9%). Among case participants, perceived stress during the interview and the perceived length of the interview were not associated with willingness to participate again. Both of these associations were significant (P<.001) for controls.

Conclusions: Caregivers who chose to participate in the study generally rated their experiences as not very stressful. Most of the caregivers indicated that they would be willing to participate again in a similar study.

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Research on pediatric injury prevention is often dependent on data collected from parents. Although there has been some concern regarding parents' feelings about being interviewed about how their child became injured, previous research on nonfatal injuries has shown that parents willingly participate in this research and view it as worthwhile.1 Less is known about collecting information from parents whose child has recently died as a result of an injury. This information is needed because institutional review boards are often faced with the difficult decision of whether participation in research will cause harm to the bereaved. Moreover, institutional review boards and investigators must judge whether grieving parents are able to make decisions about participation in research studies during this difficult time.

Two studies have assessed bereaved parents' feelings about participating in research; however, these studies were conducted several months or years after the death. A study2 in Sweden, which sought to question parents who had lost a child to cancer, was initially rejected by the ethics committee because of concerns over potential harm to the parents. Based on the results of pilot work, the ethics committee eventually approved the study, which collected data from parents 4 to 9 years after their child had died. Ninety-nine percent of those who participated found their participation valuable, and 68% believed that they were positively affected by their participation (28% reported being negatively affected). Another study,3 conducted in Norway, sought to describe parents' experiences while participating in research following the sudden, traumatic...
death of their child. Parents were interviewed in person, 9 to 27 months after their child had died. A subset was then interviewed about their experiences while participating in research. All of those interviewed perceived their experience to have been positive.

Interviewing parents soon after their child has died presents a unique set of ethical considerations. Parents who lose a child as a result of a chronic disease might have a grieving experience different from that of parents who lose their child as a result of an unexpected injury. Although studies have been conducted with parents very soon after their child’s unexpected death, those studies have not assessed how bereaved parents felt about participating in such research. In studies on sudden infant death syndrome, investigators interviewed caregivers a few weeks after the death of their child. In at least 1 other study, interviewers waited several months to a year to talk to the caregivers, based on the recommendation of the institutional review board. In a study on gun-related deaths, interviewers talked to caregivers a few weeks after the death of their child.

As stated by Dyregrov, “information from the bereaved is needed to shed light on the relations between the expression of emotions during interviews and the perceived stress experienced, and to explore which methodologies cause [the] least distress.” In the present study, caregivers of children who recently drowned were interviewed by telephone as part of a case-control study on the risks for drowning. At the end of the interview, participants were asked about their interview experience to assess the degree to which they found the interview stressful and to solicit their views on whether they would be willing to participate in this type of interview again, given their experience with the current interview. Matched control subjects underwent a nearly identical interview and were also asked about their interview experience.

**STUDY DESIGN**

This study used a case-control design in which cases were drowning victims who were prospectively identified through medical examiner’s/coroner’s offices in 21 jurisdictions across 6 states in the United States. Medical examiner investigators collected study data as part of their routine investigation of the death. Following this investigation, they presented 157 case families with the opportunity to participate in an interview about their child. Ultimately, 87 cases participated in this interview (selection procedures are described in the last paragraph of this subsection). The interviews were conducted via a computer-assisted telephone interview system.

The purpose of the interview was to collect detailed information on the drowning victim’s exposure to water, swimming ability, participation in formal swimming lessons, medical conditions, and household characteristics. Depending on the age of the child, the interview also contained questions on child development and psychosocial attributes such as temperament, risk-taking behaviors, and sensation-seeking tendencies. At the end of the interview, respondents were asked 3 questions about their interview experience: (1) Did you think the interview was (a) too short, (b) too long, or (c) just about right? (2) Do you think the interview was (a) not at all stressful, (b) a little stressful, (c) somewhat stressful, or (d) very stressful? (3) If you were asked, would you participate in an interview like this again? (a) Yes or (b) no.

Controls were selected through random-digit dialing and matched by age, sex, and county of residence. We sought a minimum of 2 controls per case. All of the 491 controls were interviewed using an almost identical interview script (differing on only 1 question relating to the drowning incident). All case participants and controls were offered $25 to compensate them for their time. Most accepted the payment. 9 case participants and 21 controls refused payment, and 5 case participants and 8 controls asked that the money be sent to a charity. (We honored their wishes.)

**INTERVIEW/CONSENT PROCEDURES**

After completing their routine investigation of case drowning deaths, medical examiner investigators were asked to inform the next of kin that their office was collaborating with the National Institute of Child Health and Human Development on a study about childhood drowning and that someone would be contacting them for an interview. If the next of kin asked not to be contacted, we did not contact them; however, if they did not decline contact, the investigator sent study staff their contact information. Study staff then mailed a study brochure and a letter to the family alerting them that they would be contacted to schedule an interview. This letter included a telephone number they could call if they did not wish to be contacted. Within 2 weeks after the letter was sent, the next of kin were contacted by telephone to schedule an interview. At that point, they were given another opportunity to decline participation. When the next of kin were contacted for the actual interview, they participated in a verbal consent process in which they were told that their participation in the study was voluntary. They were told that there was a risk they might feel emotional discomfort answering questions about their child and that they could skip over any questions they did not want to answer. Furthermore, they were told that they could stop the interview at any time.

Interviewers were experienced in conducting computer-assisted telephone interviews and received additional training from a grief counselor who specialized in working with parents following the death of a child. Interviewers received 16 hours of classroom training, and their first actual interviews were supervised closely by senior interviewers. The classroom training included a lecture, role playing, and skills practice. Interviewers were taught specific strategies to help them talk with emotional respondents, and they were given opportunities to use these skills on practice (fictional) cases.

Interviewers were trained to give respondents the opportunity to stop or shorten the interview if the respondents appeared distressed or fatigued. Respondents could elect to end the interview at any time or to switch to a short interview in which only key questions were asked. The 577 caregivers who completed the entire interview were asked the 3 questions about their interview experiences. Those who completed the short form of the interview were not asked those questions. All study data, including the interviews, were collected by Westat, a research firm based in Rockville, Md. The study was approved by the institutional review boards at Westat and the National Institute of Child Health and Human Development.

**DATA ANALYSIS**

We used χ² tests to detect differences between case participants and controls with regard to interview length and percep-

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The study was introduced to 157 case families. Of these, 52 (33.1%) declined participation when the study was initially introduced; thus, they were never called. Of the 105 case families whom study staff attempted to contact, 9 (8.6%) were never reached, and 8 (7.6%) opted out of the interview once contacted. One case participant (1.0%) and 4 controls (0.7%) did not complete the interview and are also excluded from the analysis. Finally, 1 case participant (1.0%) and 74 (13.0%) of 569 controls ultimately chose to switch to the short form of the questionnaire and were also excluded from the analysis. We included 577 interviews in this analysis, which consisted of interviews with the caregivers for 86 drowning cases and 491 controls. Most of the 577 respondents were mothers (56 [65.1%] case respondents and 369 [75.2%] control respondents), followed by fathers (24 [27.9%] and 81 [16.5%], respectively) and grandparents (3 [3.5%] and 23 [4.7%], respectively). The small numbers of remaining respondents included aunts and other relatives.

Short-form interviews ranged from 7 to 35 minutes, with a mean length of 17 minutes. Regular interviews ranged from 17 to 118 minutes, with a mean length of 44 minutes. Case interviews (mean length, 54 minutes) were longer than control interviews (mean length, 42 minutes) \(P < .001\). For case participants, the median length of time between the child’s death and the interview was 6 weeks (range, 1.5–51 weeks). In all, 398 caregivers (69.0%) were interviewed within 3 months of the child’s death.

Case participants were more likely than controls to perceive the interview as somewhat or very stressful, although most of the case participants (87.2%) and controls (96.1%) perceived the interview to be at all or only a little stressful (odds ratio [OR], 3.64; 95% confidence interval [CI], 1.67–7.96) (Table 1). A lower percentage of case participants (20.9%) found the interview to be too long compared with controls (37.8%) (OR, 0.45; 95% CI, 0.24–0.79), although the majority of case participants and controls found the interview length to be just right (76.7% and 62.0%, respectively) (Table 1). The perception of interview length was unrelated to willingness to participate again for case participants, but it was related for controls. Tests for trend showed that controls who perceived their interview to be too long were less likely to be willing to participate again (OR, 0.06; 95% CI, 0.01–0.20) (Table 2). When asked whether they would participate in this type of interview again, 91.9% of the case caregivers and 94.1% of the controls answered yes. Actual interview length was unrelated to willingness to participate in a study like this again for both case caregivers and controls (data not shown).

Among case participants, perceived stress during the interview was not associated with willingness to participate again (OR, 0.32; 95% CI, 0.05–1.91). Among controls, those who found the interview to be somewhat or very stressful were less likely to want to participate in such an interview again (OR, 0.17; 95% CI, 0.05–0.55). The number of days between the child’s death and the interview was not significantly associated with partici-
parents’ reports of stress. Furthermore, the age of the victim and whether the victim was the only child in the household was also not significantly associated with perceived stress (data not shown).

The results of this study suggest that parents who have recently and unexpectedly lost a child are often willing to participate in research. After completing the interview, most of the participants in this study indicated that, if asked again, they would be willing to participate in this type of interview.

Not surprisingly, case participants found the interview more stressful than did controls; however, case participants were just as likely as controls to indicate that they would be willing to participate in a similar interview again, regardless of their stress levels during the interview. On the other hand, control participants who felt stressed during the interview were less likely than controls who were not stressed to be willing to participate again. The fact that case participants and controls differed is notable. At the very least, it seems that cases did not regret their choice to participate. A previous study on participation in public health prevention campaigns showed that parents whose child died as a result of an injury appreciated being given the opportunity to participate in such campaigns. In the present study, it is possible that case respondents found their participation to be a worthwhile experience that might prevent other children from drowning.

Although the case interviews were longer, the respondents did not perceive the interviews to be too long compared with controls. The fact that the case interviews were longer suggests that case participants talked more than did the controls, perhaps because they believed they had more at stake in the interview or perhaps because they wanted to talk about their child. In an editorial commenting on research that uses bereaved parents as informants, the importance of giving bereaved individuals multiple opportunities to refuse or cease participation was emphasized. In the present study, participants were given multiple opportunities to decline participation in the study interview. Given this, along with the fact that the interviews were conducted by professionals trained in talking with bereaved parents, we believe that case participants were comfortable talking about their child.

The conclusions we are able to draw from this analysis are limited by the fact that we asked only 3 questions about participants’ interview experiences. To assess whether participation in such research is beneficial or perhaps even therapeutic to bereaved parents, one would have to talk with the participants in greater depth. In addition, these results only reflect the experiences of those who chose to participate. Those who chose not to participate might have had different experiences; however, there is no way to assess this. Randomized assignment of bereaved parents into groups that participate in research and groups that do not is obviously not possible. Most individuals who chose to participate rated their experiences as not very stressful.

To our knowledge, this study was the first to assess parents’ feelings about participating in research soon after the sudden, unexpected death of their child. More evidence-based research about study participants’ experiences is needed to inform institutional review and ethics boards about research following other types of traumatic events (eg, natural disasters).

Although talking with the bereaved is not always easy, the results of this study suggest that the discomfort of researchers and institutional review boards should not get in the way of giving bereaved individuals the opportunity to speak to researchers if they wish. The information collected from these individuals might prevent future tragedies.

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REFERENCES


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