# Informing Subjects of Epidemiologic Study Results

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**ABSTRACT.** *Objective.* **To assess the feasibility and process of providing feedback to parents regarding the results of epidemiologic research, in particular to look at the importance and clarity of the information provided, parental reactions to the results, and utilization of the data provided.**

*Methodology.* **Parents who participated in an epidemiologic study of pediatric brain tumors (patient and control mothers) were sent a letter summarizing the results of the study and the Parent Study Results Survey to complete and return. The final sample used for analyses was 109 (patient) and 90 (control) mothers. Analyses were conducted to determine differences between patient and control mothers and differences among subsets defined by educational level and vital status of the patient.**

*Results.* **Mothers rated the importance and clarity of the information very highly, although patient mothers were more likely than control mothers to want more information and a telephone contact. Patient and control mothers were similar in reported sadness, anxiety, and being overwhelmed, but patient mothers felt less satisfied and relieved. Patient mothers expressed feeling more guilt and anger than control mothers, although even the levels among the patient mothers were only moderate. Close to half of all mothers commented on the inconclusiveness of the study results. Nearly all mothers indicated they would suggest that other parents participate in epidemiologic research.**

*Conclusions.* **It is valuable to many parents that they receive information about results of research in which they have participated. We found little evidence of strong negative effects to a detailed feedback letter. We recommend that evaluative data be used to guide the process of informing research participants about study results and that investigators consider making feedback letters a standard part of research protocols.** ***Pediatrics* 1996;97: 486–491; *pediatric oncology, parents, communication, epidemiology.***

ABBREVIATIONS. NIOSH, National Institute of Occupational Safety and Health; CCG, Children's Cancer Group; PSRS, Parent Study Results Survey.

In the past decade, epidemiologists have increasingly studied childhood malignancies and congenital anomalies and contributed knowledge about the development of these conditions. The subjects (usually parents) comprise a large and generally cooperative group, hopeful that their participation will benefit them either directly, or others indirectly. The focus of this article is to provide parents of pediatric patients with the results of epidemiologic studies in which they have participated. Our premise is that parents are interested and will benefit from learning the results, that researchers must develop ways of providing feedback, and that further exploration is needed with regard to how, when, and with whom information should be shared.

### Traditions of Providing Feedback

Although epidemiologic researchers disseminate their findings widely in scientific publications, they usually do not directly inform parents of the results. Most hospitals and the epidemiologic community do not have a policy that provides recommendations for dissemination. However, the National Institute of Occupational Safety and Health (NIOSH) practices "worker notification," a policy of informing "workers who were subjects of epidemiologic studies of the overall results of those studies."[1] Some companies and unions follow similar policies. The issue of whether and under what circumstances a researcher has an obligation to inform participants of results in other types of epidemiologic studies has had only limited discussion.[2] The issues of the appropriateness of providing information that will often be inconclusive and difficult to interpret requires discussion. In addition, researchers have raised the concern that participants may experience negative psychological reactions to learning that they may be at increased risk. Pediatric research differs from other research in that the parents' exposures may have increased the risk of disease in their children, rather than in themselves. Whether this circumstance puts parents at greater risk of adverse psychological reactions because of the potential for exacerbating guilt, anger, and anxiety is not known. Little or no data exist on participants' reactions to receiving information about possible causes of either their own conditions or those of their children.

In contrast to the lack of guidance on this issue in the epidemiology community, the psychology profession's ethical standards includes an "enforceable rule" about the need for a "prompt opportunity for participants to obtain appropriate information about the nature, results, and conclusions of the research" in which they have participated.[3] However, there are no data available on the extent to which this is practiced.

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### Knowledge and Reactions of Parents

Parents may find the questions asked in epidemiologic studies psychologically difficult as they may raise questions about what caused their child's cancer (eg, something a parent did may be found to be associated with risk of disease). In addition, the psychological sequelae of their child's cancer and its treatment appears to persist over time for parents,[4] suggesting that there is no established "cutoff" for when these questions would diminish in their significance. However, obtaining information represents a powerful coping mechanism with the act of participating in, and learning about, research potentially helping parents and families understand what happened to them, and their reactions to it. Parents express intense interest in information about possible causes of their child's cancer.

Even when not officially told the results of studies, patients and parents may learn the results of studies from other sources. A member of the child's treatment team may informally give the family information. Books, pamphlets, and newsletters for parents of children with specific diseases may report on the study. Increasingly accessible computer databases provide relevant data. In addition, the media frequently reports on high-profile studies. There are no data available to suggest how often families of pediatric patients obtain information through these channels. Perhaps more importantly, there are no data reporting on the extent to which information received is understood accurately, and translated into strategies for coping with the unknown etiology of their child's condition.

## METHODS

### Background Epidemiologic Study

During 1987 through 1990 the Childrens Cancer Group (CCG) conducted an epidemiologic study of risk factors for childhood brain tumors (CCG E-12). Children with brain tumors were identified from the approximately 100 CCG hospitals in the United States and Canada. Control children were identified by random-digit dialing. Mothers and fathers completed 30- to 60-minute structured telephone interviews about pregnancy history, family medical history, and occupational history. Exposure to kerosene during pregnancy, birth by cesarean section, and seizures in a close relative were associated with one type of brain tumor, astrocytic glioma. For another tumor, medulloblastoma or primitive neuroectodermal tumor, residence on a farm, low maternal intake of fruits or vegetables, lack of multivitamin use in the first 6 weeks of pregnancy, and childhood cancer in a close relative were associated with increased risk. Use of tobacco, alcohol, and medications during pregnancy were not associated with increased risk.

### Sample and Procedure

In the epidemiologic study, 354 mothers and 330 fathers of children with brain tumors and 345 mothers and 336 fathers of control children were interviewed. There had been no contact between the researchers and families in the interim. All parents who had completed the epidemiologic study were sent a letter summarizing the results of the study and a questionnaire to return in a self-addressed stamped envelope on August 6, 1993. The letter was resent if returned with a forwarding address. Two subsequent letters were sent to nonrespondents. To ensure that the health professionals who had treated the brain tumor patients in the study were knowledgeable about this effort, a copy of the letter was also sent to each hospital that had enrolled patients. On August 19, 1993 the results of the study were reported in the medical literature[5] and received some media attention over the next several months. Fathers are not included in this report because few responded.

The four-page letter summarized the purpose of the study, the way in which it was conducted, the results, and the implications. Also enclosed was a two-page question and answer sheet for commonly asked questions about the study (eg, does the study prove that not taking vitamins in the first few weeks of pregnancy causes brain tumors?) Both the letter and the question and answer sheet were written in lay language.

The Parent Study Results Survey (PSRS) was developed for the current study and is a 16-item self-report questionnaire with precoded answers, five-point Likert type scales, and open-ended questions. In Likert-type scales, the respondent chooses a level of a response between one and five. For example, for the importance of learning the results of the study, one indicated not at all important and five indicated extremely important. The survey covers the following areas:

1. **Importance and clarity of the written information provided** consists of questions about the importance of the material in the accompanying letter, perceptions of the best ways of providing information to parents (eg, letter, phone, in person, media), ease of understanding the information, and amount of detail provided.
2. **Reactions to the findings** is comprised of questions that assess the extent to which the information provided was surprising, applicability of the results to the respondent, unanswered questions, and a list of seven possible psychological reactions to learning the results of the study (satisfied, relieved, sad, anxious, guilty, angry or overwhelmed).
3. **Utilization of the information** determined whether participants felt that they could talk with others about the study results, who they would call if they had questions, how they would use the information, and whether they would recommend that others participate in similar research projects.

Content analysis was performed on the open-ended questions by creating categories based on subjects' responses. We (A.E.K. and G.R.B.) created categories separately, discussed differences, and reached agreement. Two of us (G.R.B. and O.M.) coded responses and discussed and resolved discrepancies.

### Analysis

The responses of parents of children with brain tumors and of control children were compared using $t$ tests for Likert variables and $\chi^2$ tests for categorical variables. Responses were compared between subgroups of patient and control mothers based on educational level (12 years or fewer vs more than 12 years) and whether or not their child died. Responses did not vary by education or patient vital status, except where noted.

Patient mothers whose children had one of the exposures or characteristics observed to be associated with increased risk (ie, a risk factor) in the epidemiologic study might react differently than other patient mothers. Therefore, responses of patient mothers were compared by the presence or absence of any risk factor. The presence or absence of a risk factor was determined from the telephone questionnaire data from the original epidemiologic study; 62% of the brain tumor patients whose mothers completed the survey had one or more risk factors. The presence of a risk factor did not affect patient mothers' survey responses, except where noted. Only seven patient and six control mothers had seen a media report of the findings of the epidemiologic study before returning the survey. Therefore, the effect of the media on parents' reactions could not be assessed.

## RESULTS

Of the 354 patient mothers and 345 control mothers to whom we mailed letters, 31% and 26% returned a completed survey, respectively. Nineteen percent of the letters were undeliverable. The final sample consisted of 109 patient mothers and 90 control mothers.

Rates of response to the survey were analyzed for patient and control mothers separately to determine the possible effects of demographic variables (Table

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1). For both patient and control mothers, response rates were higher among those who were white and had higher incomes. In addition, patient mothers, but not control mothers, with more education were more likely to respond. Patient mothers whose children had survived were also more likely to respond. The differences in response rates were generally statistically significant or nearly so, but not dramatic. For example, 25% of lower income mothers of patients responded compared with 37% of those with higher incomes. The one dramatic difference in response rates was categorized by race; for both patients and controls, the response rates among whites was two to three times higher than among nonwhites (28% to 32% for whites vs 9% to 14% for nonwhites). The response rate among patient mothers did not differ by the presence or absence of a possible risk factor mentioned in the letter. We did not study the effect of the presence of a risk factor among control mothers because the definition of a risk factor depended on the type of brain tumor and the controls did not have brain tumors.

The 109 patient mothers and the 90 control mothers who returned questionnaires were similar in demographic characteristics. Ninety-six percent of both groups was white. Thirty-eight percent of patient mothers had 12 or fewer years of education, as did 42% of the control mothers.

### Importance and Clarity of Information Provided

In general, mothers found the results important and clear (Table 2). It was extremely important to patient mothers that they learn the results of the study in which they participated [mean (M) = 4.5]. To control mothers, it was also important but significantly less so (M = 3.7, $P < .001$). About 40% of the patient mothers compared with 20% of the control mothers ($P = .002$) would have liked a phone number to call for questions about the study. Patient mothers with less education were significantly more likely than more educated patient mothers to want a phone number (33% vs 58%, $P = .03$). The majority of mothers responding to the survey found the amount of detail in the letter appropriate. More patient than control mothers (29% vs 10%, $P = .003$) would have liked more detail about the study. The proportion of patient mothers who wanted more detail did not change significantly with educational level or vital status of the child.

A five-point scale assessed difficulty in understanding the letter, with one being completely understandable and five being very difficult to understand. The respondents generally found the letter to be understandable (M = 1.7) with no difference between patient and control mothers. For both groups, those with more than a high school education found the letter significantly easier to comprehend ($P = .01$ and $P = .03$, for patient and control mothers, respectively). For those with 12 or fewer years of school, the Likert scores were 2.0 and 2.1, for patient and control mothers, respectively. For mothers with more education, the mean scores were 1.5 and 1.6, respectively.

**TABLE 1.** Parents' Survey: Participation Rates

| | Percent Participating | |
|---|---|---|
| | Patient Mothers | Control Mothers |
| Annual Income | | |
| <$25,000 | 25* | 20* |
| >$25,000 | 37 | 31 |
| Race | | |
| White | 32* | 28* |
| Nonwhite | 14 | 9 |
| Educational level | | |
| High school or less | 26* | 25 |
| More than high school | 35 | 26 |
| Vital status of child | | |
| Alive | 36* | N/A |
| Deceased | 22 | |
| Risk factor | | |
| Present | 29 | N/A |
| Absent | 34 | |

* $P \leq .05$ for difference of marked percent and percent below.
Abbreviation: N/A, not applicable.

**TABLE 2.** Parents' Survey: Results for Patient and Control Mothers

| | Patient Mothers N = 98–109 | Control Mothers N = 77–89 |
|---|---|---|
| | Mean* or % | Mean or % |
| Importance and Clarity | | |
| Importance§ | 4.5 (mean) | 3.7 (mean) |
| Difficulty understanding | 1.6 (mean) | 1.8 (mean) |
| Would like phone number‡ | 42% | 20% |
| Too little detail‡ | 29% | 10% |
| Reactions to Findings | | |
| Question/surprise | | |
| re: exposure mentioned | 23% | 17% |
| re: exposure not mentioned | 11% | 7% |
| Inconclusiveness | 49% | 42% |
| Applicable§ | 48% | 13% |
| Satisfied§ | 2.5 (mean) | 3.4 (mean) |
| Relieved§ | 2.4 (mean) | 2.9 (mean) |
| Sad | 2.4 (mean) | 2.5 (mean) |
| Anxious | 2.3 (mean) | 2.0 (mean) |
| Guilty† | 1.8 (mean) | 1.4 (mean) |
| Angry† | 1.9 (mean) | 1.6 (mean) |
| Overwhelmed | 1.8 (mean) | 1.8 (mean) |
| Utilization of information | | |
| Had someone to ask questions | 59% | 56% |
| Health professional | 86% | 98% |
| Had someone to talk to | 74% | 61% |
| Health professional | 65% | 81% |
| Can use information | 37% | 40% |
| Recommend participation | 97% | 90% |
| Comfort in sharing with: | | |
| Spouse | 4.0 (mean) | 4.2 (mean) |
| Parents | 4.0 (mean) | 4.1 (mean) |
| Children | 3.7 (mean) | 3.9 (mean) |

* Mean Likert score (scores of 1 to 5); standard errors of the mean were 0.1, except for the last three pairs of mean (comfort in sharing) for which the standard errors were 0.2.
† $P < .05$ for case-control difference.
‡ $P < .01$ for case-control difference.
§ $P < .001$ for case-control difference.

### Reactions to the Findings

The mothers were asked what questions and comments they had about study findings (Table 2). Thirty-two percent of patient mothers and 29% of control mothers mentioned exposures discussed in the letter. Smaller proportions, 15% and 16% of patient mothers and control mothers, respectively,

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mentioned exposures not mentioned in the letter, such as electromagnetic fields. Many mothers (patient: 49%; control: 42%) mentioned the inconclusiveness of the findings in answer to these questions or elsewhere in the questionnaire. The tone of the comments included resignation or sadness that the cause of the brain tumor was still unknown and surprise, frustration, or anger that the study was not conclusive. The proportion of mothers commenting on inconclusiveness did not vary by education or by whether their child survived. More patient mothers than control mothers felt that the results applied to them (patient: 48%, control: 13%; $P < .001$).

Patient mothers felt significantly less satisfaction and relief than control mothers (2.5 vs 3.4 for satisfaction, $p < .001$; 2.4 vs 2.9 for relief, $p = .002$). Indeed, half of the patient mothers and about 25% of the control mothers felt little satisfaction or relief (Likert scores 1 and 2). Interestingly, there were no differences between patient and control mothers for self-reported feelings of sadness, anxiety, or being overwhelmed. Patient mothers reported significantly higher levels than control mothers of guilt ($P = .01$) and anger ($P = .04$), although the average levels for patient mothers were still only moderate (1.8 to 1.9 for guilt and anger). Substantial feelings of guilt and anger (Likert scores of 1 or 2) were reported by 13% to 16% of patient mothers and 3% to 9% of control mothers, but these differences were not statistically significant. Patient mothers whose children had died reported more sadness (3.3 vs 2.4, $p = .02$) compared with patient mothers whose children had survived. The emotional reactions of patient mothers did not differ by educational level.

### Utilization of the Information

Most mothers (56% to 59%) reported that they had someone who they could ask questions about the study (Table 2). The vast majority, 86% to 98%, would ask questions of a health professional. Most mothers also had someone to talk to about any feelings or worries that the letter had evoked. Patient mothers were more likely than control mothers to have someone to talk to (74% vs 61%, $P = .09$). That person was somewhat less likely to be a health professional for patient mothers compared with control mothers (65% vs 81%, $P = .07$).

Mothers were very comfortable sharing the information about the study with spouses (4.0 to 4.2 for both groups) and with their parents (4.0 to 4.1). They were slightly less comfortable talking about it with their children (3.7 to 4.0). Nearly all would recommend participation in a study like this one to others. The proportion of control mothers who recommended participation was slightly lower than that of patient mothers (90% vs 97%, $P = .09$).

### Effect of Risk Factors on Responses

We investigated patient mothers' responses by whether or not their child had an exposure that was mentioned in the letter as a possible risk factor for developing a brain tumor. The presence of a risk factor did not affect any of the mothers' responses, including whether she felt that the results of the study applied to her child; 46% of patient mothers whose children did not have a risk factor and 49% of patient mothers whose children had a risk factor felt that the study's results applied to them. Compared with other patient mothers, those patient mothers who felt that the study's results applied to them were significantly less likely to mention the inconclusiveness of the study (33% vs 64%, $P = .003$) and significantly more likely to say that they would be able to use the information (59% vs 16%, $P < .001$) (Table 3). There were also trends that these mothers were more likely to have someone who they could ask questions (73% vs 51%, $P = 0.06$), and they were more likely to feel comfortable discussing the information with spouses (4.4 vs 3.8, $P = 0.07$) and with parents (4.4 vs 3.8, $P = 0.05$). In addition, these patient mothers reported more satisfaction (3.1 vs 2.3, $P = 0.002$), more relief (3.0 vs 2.2, $P = 0.002$), and similar degrees of the other emotions.

## DISCUSSION

In pediatrics, parents are active partners with researchers, providing a large portion of the epidemiologic and psychologic data used regularly in practice. The premise of this paper was that this partnership can be enhanced by providing these participants in research with useful and appropriate feedback, in return for the valuable data they provide. As there were few prior data to guide this study, its purpose was to encourage further explora-

**TABLE 3.** Results for Patient Mothers by Whether Results Were Applicable

| | Results Applied N = 39–49* | Results Did Not Apply N = 42–53 |
|---|---|---|
| | Mean† or % | Mean or % |
| Had a risk factor | 64 | 60 |
| Importance and clarity | | |
| Importance | 4.6 (mean) | 4.5 (mean) |
| Difficulty understanding | 1.5 (mean) | 1.8 (mean) |
| Reactions to findings | | |
| Inconclusiveness§ | 33% | 64% |
| Satisfied§ | 3.1 (mean) | 2.3 (mean) |
| Relieved§ | 3.0 (mean) | 2.2 (mean) |
| Sad | 2.8 (mean) | 2.8 (mean) |
| Anxious | 2.4 (mean) | 2.4 (mean) |
| Guilty | 2.2 (mean) | 2.0 (mean) |
| Angry | 2.0 (mean) | 2.1 (mean) |
| Overwhelmed | 2.1 (mean) | 1.9 (mean) |
| Utilization of information | | |
| Had someone to ask questions‡ | 73% | 51% |
| Had someone to talk to | 74% | 76% |
| Can use information‖ | 59% | 16% |
| Comfort in sharing with: | | |
| Spouse‡ | 4.4 (mean) | 3.8 (mean) |
| Parents‡ | 4.4 (mean) | 3.8 (mean) |
| Children | 3.9 (mean) | 3.7 (mean) |

* Results are given for 102 of the 109 patient mothers. Risk factor information was not available for seven mothers.
† Mean Likert score (scores of 1 to 5). Standard errors for the variables "Importance" and "Difficulty understanding" are 0.1; all other standard errors are 0.2.
‡ $p < .10$.
§ $p < .01$.
‖ $p < .001$.

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tion of the issues and suggest directions for enhancing the provision of feedback to parents.

The response rate for this survey was typical for a mailed questionnaire, although lower than optimal. Other structured approaches, such as sending a copy of the survey by certified mail or telephoning the nonrespondents, should be considered in future studies to improve the response rate.[6] The response rate was low enough to warrant consideration of its generalizability. We were able to evaluate this issue using data from the larger epidemiologic study on all subjects, those who later responded to the PSRS and those who did not. The largest difference in response rates occurred by race with few blacks responding. Therefore, the results provide little information on this group.

Although the respondents represented a select group in terms of education, income, and vital status of the patient, these differences were relatively small. More importantly, few of the responses to survey questions differed by these characteristics. The fact that demographic factors other than race did not greatly affect response rate or mothers' responses suggests it is unlikely that the results are biased. Further research on these issues is needed to demonstrate the validity of this pilot study. Although this study was conducted only on pediatric brain tumors, it is likely that the data would be generalizable to other conditions. Brain tumors have relatively high rates of mortality and morbidity and would therefore be analogous to other serious pediatric conditions in terms of the potential impact of study results.

With regard to whether parents should be informed of the results of studies in which they participated, the data indicated that the mothers felt that the information was very important. They also generally felt able to comprehend the information and identify resources if they had questions or reactions. Although patient mothers reported significantly higher levels of anger and guilt than control mothers, they did not differ with regard to self-reported sadness, anxiety, and feeling overwhelmed. And, in general, ratings on all these variables were moderate in magnitude, suggesting that receiving the study results in this type of letter is not particularly difficult emotionally, at least not so for the subset participating in this study.

The question of informing subjects in epidemiologic studies of the results has generally been discussed little outside of occupational cohorts. Although workers are now generally notified of the results of studies, negative psychological effects have been cited as reasons for withholding information.[7] These reasons also arise in the discussion of informing parents of the results of epidemiologic studies of diseases in their children. In a few instances, the psychological effects of worker notification have been studied. There has been no association found between notification and psychological disturbances.[8] In one study,[9] workers who had been notified of their asbestos exposure and the associated risks did not differ from unexposed workers on various measures of psychological stress several years after the notification. In another study,[10] the workers notified of their asbestos exposure reported initial distress but it consisted of realistic concern about future health rather than "generalized anxieties or fear."

The argument can be made that the circumstances of worker notification differ intrinsically from those of parental notification in that their exposures may have contributed to their child's disease. The latter situation includes the potential for guilt that is not present in worker notification of risk resulting from involuntary exposures. Mothers of brain tumor patients did feel more guilty than control mothers. However, because mothers of brain tumor patients may have felt guilty before receiving our letter, the more relevant comparison would be patient mothers who were informed about the study results and those who were not. Despite some negative emotions, it appears from our study that the mothers had a strong desire to be informed. A study of worker, notification also found that 90% of workers wanted to be informed.[10] There is now some discussion of informing study participants of the results as a possible obligation of researchers.[2,11] In this context, it is interesting to note the concept of worker notification has progressed to the point that discussion centers on how best to do it, not whether it should be done.

This study also addressed the issue of how to inform parents. Most mothers were satisfied with the letter they received. However, substantial proportions of both patient and control mothers would have liked a telephone number to call to have questions answered. A phone number contact would also provide a means of evaluating the communication effort, as it would allow participants to give immediate feedback.[7] The experience of NIOSH suggests that the response will not overwhelm the system. In a mailed notification to 1663 workers, NIOSH received 40 calls to a toll-free telephone number.[7]

The mothers in our study generally found the information they received understandable. Mothers with less education found the letter more difficult to understand than those with more education. This finding may explain the lower response rate among those with less education and also suggests the need to modify similar letters in the future to improve readability. In a study in which the educational level of the mother is known, different versions of the letter could be tailored for different educational levels.

Nearly half of both patient and control mothers commented on the inconclusiveness of the results. The tone of the comments included resignation, sadness, surprise, frustration, and anger that the study did not have conclusive results. We feel that these comments reflect general unfamiliarity about research and what any one study can accomplish. Researchers may wish to consider providing parents with more information about the likely magnitude of results from one study. The many small steps needed to accomplish a major goal could be introduced without diminishing the importance of participation in a given study. With more realistic expectations, participants may learn more about the process of research and avert later disappointment. It may be helpful to suggest that although the results may seem disap-

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pointing, they are important and will be helpful to patients and researchers.

We observed that whether a patient mother thought that the results applied to her was unrelated to the presence or absence of an exposure identified in the letter as a possible risk factor. Mothers who felt that the results applied to them were more likely to have a positive reaction to the letter, ie, they were more satisfied, more relieved, less likely to comment on the study's inconclusiveness, and more likely to be able to use the information. This correlation may reflect the interpretation of the question about applicability to mean whether the mothers found the information helpful. For example, a mother who found that she had none of the mentioned exposures may have reported that the results applied to her because they provided relief from guilt that something she had done had caused her child's brain tumor. Another possibility is that the lack of correlation between the question about applicability and risk factor status reflects the difference in definition of the risk factors between participants and researchers. For example, we defined a family history of childhood cancer as a cancer before age 15 in a sibling, parent, aunt, uncle, or grandparent. A mother with a more distant relative with a cancer before age 15 or one of the mentioned relatives with a cancer at age 18 might consider her child to have this risk factor.

## CONCLUSIONS

The data presented highlight the value of providing parents with feedback about the results of epidemiologic studies. We found little evidence of negative effects associated with providing a detailed letter to families, although the depth of our survey was limited and our response rate was lower than optimal. Participants reported a high level of appreciation for the material. The data support the recommendation that feedback to participants be made a standard part of the epidemiologic research protocol. Based on the data in this study, researchers may wish to alert participants of the inconclusive nature of results from one study, assure an appropriate level of readability of written materials, and consider providing phone contacts for participants who seek further information or clarification. The issue of providing feedback to the parents of pediatric patients is a relatively new one. As such, there is also a need for further investigation of ways in which researchers and participants can communicate about the information that is learned in the process of conducting research.

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