

Bereaved Parents' Intentions and Suggestions about Research Autopsies in Children with Lethal Brain Tumors

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Objective To determine bereaved parents' perceptions about participating in autopsy-related research and to elucidate their suggestions about how to improve the process.

Study design A prospective multicenter study was conducted to collect tumor tissue by autopsy of children with diffuse intrinsic pontine glioma. In the study, parents completed a questionnaire after their child's death to describe the purpose for, hopes (ie, desired outcomes of), and regrets about their participation in autopsy-related research. Parents also suggested ways to improve autopsy-related discussions. A semantic content analytic method was used to analyze responses and identify themes within and across parent responses.

Results Responses from 33 parents indicated that the main reasons for participating in this study were to advance medical knowledge or find a cure, a desire to help others, and choosing as their child would want. Parents hoped that participation would help others or help find a cure as well as provide closure. Providing education/anticipatory guidance and having a trusted professional sensitively broach the topic of autopsy were suggestions to improve autopsy discussions. All parents felt that study participation was the right decision, and none regretted it; 91% agreed that they would make the choice again.

Conclusion Because autopsy can help advance scientific understanding of the disease itself and because parents reported having no regret and even cited benefits, researchers should be encouraged to continue autopsy-related research. Parental perceptions about such studies should be evaluated in other types of pediatric diseases. (*J Pediatr* 2013;163:581-6).

Brain tumors are the second leading cause of death among children with cancer.¹ Despite significant advances in the field of pediatric neuro-oncology, there has been little improvement in the outcome of children with some of the most lethal brain tumors, including diffuse intrinsic pontine glioma (DIPG).

New treatment approaches are needed urgently for DIPG. Although targeted therapies have been successful in selected subsets of patients with other cancers whose tumors harbor specific genetic abnormalities,^{2,3} little is known about the mechanisms of tumorigenesis in DIPG because tumor samples are rarely available for analysis.⁴ Therefore, a sound scientific rationale is lacking for the development of targeted therapies for childhood DIPG.

We and others have shown that tumor tissue obtained at autopsy from children with DIPG is suitable for extensive molecular studies.^{5,6} However, many barriers limit pediatric autopsy for clinical and research purposes.⁷ Several studies have reported parents' experiences with pediatric autopsies performed for clinical evaluation.⁸⁻¹² Parents report that autopsies contribute to a better understanding of the factors contributing to their child's death, of potential health implications for their other children, and of family planning considerations.⁸⁻¹⁴ In another study, however, a fairly large percentage (42%) of parents reported that their child's autopsy added to their grief.¹⁵

Although in the aforementioned studies investigators explored parental perceptions and feelings associated with consent to autopsy of their child, parents' reasons for and hopes (ie, desired outcomes) of participating in research-related autopsy are unknown. Therefore, we conducted a study of parents' hopes and purposes for participating in our multicenter autopsy study.

Methods

A prospective, multicenter institutional review board–approved study headed by investigators at St. Jude Children's Research Hospital (St. Jude) was conducted to collect childhood DIPG tissue samples for detailed molecular analysis.^{5,16} The specifics of this study are reported elsewhere.^{5,16} The current

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DIPG Diffuse intrinsic pontine glioma

Table I. Questions/statements to parents about their purposes, hopes, regrets, and suggestions related to participation in the autopsy study

1. Please share with us your reasons for deciding to participate in this study.
2. Please share with us what you hope will happen for you, your family, or others because of your/your child's participation in this study.
3. Would you offer any suggestions for a better way for us to discuss autopsies with family caregivers of children who have suffered and died from a brain tumor?
4. What was good about participating in the autopsy study?
5. What was disappointing or bad about participating in the autopsy study?
6. Is there anything else you would like us to know?
7. Would you like us to try to find professional support options in your community to assist you with your grief?

report addresses the study's secondary objective of determining parents' hopes and purposes for enrollment in the autopsy study. Eligible participants were the parents of a child with DIPG who consented to autopsy at the time of death as part of this protocol. After the autopsy findings were shared with families, parents were asked to complete a decisional regret survey and answer 7 questions/statements by telephone interview or by completing a mail-in form (Table I).

Qualitative Data Analysis

Qualitative semantic content analysis¹⁷ was performed on responses to 1, 2, and 3. Questions 4-7 were excluded from content analysis because few parents answered them and the responses were generally brief and lacked significant content. The unit of analysis within each response was the phrase, and each phrase was analyzed for meaning. Two study team members jointly reviewed the responses and applied codes to each key phrase to capture its meaning. Three other team members then completed study-specific training in semantic content analysis and independently analyzed the interviews. The mean interrater reliability of team members was 92.1% for question 1, 96.6% for statement 2, and 96.3% for question 3.

The frequency of each code was tallied. To compensate for multiple occurrences of a code in a single interview, the percentage of parents for whom the code appeared also was tallied. For each question, multiple codes coincided frequently or overlapped in meaning. Such codes were grouped and identified as a theme that captured the shared meaning. As with the codes, the frequency of occurrence of each theme and the percentages of parents to whom each theme applied were tallied. The responses of St. Jude parents versus those of parents whose children were treated elsewhere were compared. Descriptive statistics were generated for responses to question 7.

Results

The parents of 38 consecutive children who underwent autopsy as part of the original research study were invited to complete this questionnaire. Thirty-three parents of 32

children consented (84.2% participation rate; 2 participants were parents of the same child). Eighteen of the children received treatment at St. Jude, and the remaining 14 received care at other institutions. The parents of these 14 children either contacted St. Jude directly or were referred to St. Jude for the autopsy study. The mean time from the child's death to the parents' completion of the questionnaire was 11 months (range, 2.9-35 months). Parents' demographic data are summarized in Table II.

All parents reported that participating in the study was the right decision and that they did not regret it. Specifically, 91% strongly agreed or agreed that they would make the choice again; 88% did not think participating did a lot of harm, and 97% felt it was a wise decision (Table III).

Parents' responses to questions statements 1, 2, and 3 generated 75, 51, and 74 unique codes, respectively. The grouping of codes with similar meanings generated 7, 5, and 13 themes, respectively (Tables IV and V). When asked about their reasons for consenting to autopsy (statement 1), parents most frequently mentioned their wish to advance knowledge or find a cure, a desire to help others, and choosing as their child would want. When asked about what they hoped would happen as a result of the study (statement 2), parents reported hoping that participation would help others, help find a cure, and help provide closure for their family (the term closure was introduced without definition by participants). When asked for suggestions to improve the autopsy discussion (question 3), parents most frequently suggested providing education/anticipatory guidance, having a trusted professional sensitively broach the topic, and understanding each

Table II. Demographics of parents participating in the autopsy questionnaire study (n = 33)

Demographics	N
Education level	
Graduated grade school	3
Graduated high school	12
Completed college	13
Completed graduate school	2
Left blank	3
Religion	
Protestant	9
Muslim	0
Jewish	0
Catholic	10
Other	6
None	7
Left blank	1
Marital status	
Married	22
Single	7
Divorced and separated	3
Other	0
Left blank	1
Child's treatment location	
St. Jude*	19
Other	14

Time from child's death to parent's interview: mean, 11 months; median, 8.5 months; range, 2.9-35 months.

*St. Jude Children's Hospital.

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