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Bereaved parents' intentions and suggestions about research autopsies in children with lethal brain tumors

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Abstract

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 (DIPG). 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 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.

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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 badly needed 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 the above studies explored parental perceptions and feelings associated with consent to autopsy of their child, parents' reasons for and hopes (i.e., 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 are reported elsewhere.[5, 16] The current 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 seven questions/statements by telephone interview or by completing a mail-in form (Table I).

Qualitative Data Analysis

Qualitative semantic content analysis[17] 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 inter-rater reliability of team members was 92.1% for question 1, 96.6% for question 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 was also 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 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 (question 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 (question 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 family's needs and preferences when conducting these discussions.

We compared the responses to questions 1-3 that were given by parents of patients treated at St. Jude with those of parents whose children were treated at other institutions. For question 1, the theme of helping others was more frequent in the St. Jude cohort (73.7%) than in parents of patients treated at other institutions (42.9%). For question 3, the theme of finding meaning in the child's death was less frequent in the St. Jude cohort (10.5%) than at other institutions (48.9%). No other site-associated differences were noted.

A total of 10 of 33 (30.3%) parents responded that they had already been in contact with bereavement resources. However, 5 (21.7%) of the remaining 23 parents reported a need for bereavement follow-up or resources in their response to question 7.

Discussion

This is study assessed the purposes and hopes of bereaved parents who consent to a research-related autopsy of their child. As in other autopsy-related studies[8, 18], a large percentage of the parents in our study consented to autopsy because of a desire to help other children and families avoid the suffering and loss of a child to this disease and to help other parents know that they are not alone. These reasons, coupled with parents' strong sense of altruism, may partly explain the absence of regret about consenting to their child's autopsy. Furthermore, in our clinical experience, almost all parents retain an ongoing positive feeling about their experience in the autopsy study, even after a long period of follow-up.

Although parents' perceptions about their child's autopsy are not widely reported, most findings indicate little or no parental regret about the decision to participate in autopsy-related studies.[12, 18] Parents have reported that consenting to their child's autopsy helped them during the grieving process.[8, 11] However, Sullivan and Monagle recently found that 42% of bereaved parents reported that their child's autopsy added to their grief, although 90% valued autopsy as a means of finding out why their child died.[15] Their study sample differed profoundly from ours. Although our study included only parents of children who died of DIPG, the other included parents whose children had died of diverse reasons, including accidents, acute illness, chronic illness, and disability. All of the autopsies were performed for clinical rather than research reasons, providing parents no opportunity for altruism, and many were legally mandated with or without parental consent, possibly adding to parents' grief.

In contrast, none of the parents in our study reported decisional regret, and all reported that they would consent to autopsy again. Children with DIPG have a grim prognosis and a predictable disease progression, and their parents must inevitably face the reality of their child's death early in the disease trajectory. These parents have formed strong relationships with the medical team, and most have previously enrolled their child in a clinical trial. These families have come to understand the benefits of research and may be more likely to view the autopsy and related research in an altruistic framework.

Parents' purposes and hopes did not differ by primary treatment site, with the exception of the purposes of helping others (more prevalent at St. Jude) and of finding meaning (more prevalent at other sites). These differences may reflect the immersion of families at St. Jude in a research environment. In contrast, parents at other sites were self-selected. The consistency of the remaining themes across the three questions and across treatment sites suggests that these themes broadly reflect the perspectives of bereaved parents of children with DIPG. Although DIPG differs from some other diseases in that it has a dismal prognosis at the point of diagnosis, many of these themes are likely to apply to the parents of children who die of other pediatric diseases.

Approaching parents for consent to autopsy, either before or (more frequently) immediately after death, can be a challenging experience for both the physician and the family members. Parents report that they find the initial discussion of autopsy disturbing, brief, clinical, and lacking in detail.[8, 9, 15] These responses point to the need for longer discussions and more detailed explanations. Parents in our study, when asked how clinicians could better discuss autopsy, gave several thoughtful and specific suggestions (Table V) that can be implemented clinically to improve the way families are approached. They also suggested that although this discussion must be sensitively timed, it need not be postponed until after the child's death.

Parents' suggestions also reveal that the discussion was better tolerated when the physician was one they had a relationship with and who showed concern. Consistent and credible care by the medical staff were also significant factors in how parents perceived the autopsy discussion. One parent was approached about autopsy by a staff member who had consistently cared for her child. She described the discussion as genuine, thoughtful, and considerate, noting that she would not have changed a thing.

Parents also noted that there is no right time to bring up the topic of autopsy. They appeared to understand the difficulty experienced by medical staff in finding the most appropriate time, as exemplified by the comment, "I know the difficult part for all of the doctors is the trouble with finding the right timing to bring this up." Many parents stated that they would have preferred an earlier discussion, whereas others felt that this idea was unhelpful and offered less comfort. Parents agreed that the child's primary physician should initiate the autopsy discussion in a manner consistent with the needs of individual parents. The parents' theme of "Each family has individual needs" further illustrates the importance of taking an individualized approach when having these discussions.

Parents also expressed the need to receive clear, concrete information about the autopsy procedure. Not knowing the specific details of the process can lead to marked anxiety.[9] The physician who asks for consent can reduce this anxiety by spending the necessary time to describe the concrete steps of the autopsy process in detail. Parents stated that knowing what to expect significantly alleviated their concerns about providing consent. For example, they reported that knowing details about what specifically will be removed during autopsy and whether the child's body will remain presentable for funeral planning were helpful.

Although parents did not specifically suggest grief and bereavement services, several parents in the study reported contact with bereavement resources of some kind, and some of the remaining parents reported a need for additional bereavement follow-up or resources. Therefore, these parents have an ongoing need for assessment of grief and bereavement-related issues, and a coordinated institutional effort should be made to allocate resources to include bereavement care planning in end-of-life care plans.

Our study was limited by the fact that some potential participants could not be contacted and the primary team recommended that someothers not be approached; these potential participants had undergone the same experience but may have had perspectives that differed from those reported. Furthermore, because this was a cross-sectional study conducted at a single point in time, it is unclear whether parents' perspectives change over time. Our study included only the parents of children who died of DIPG; this factor limits the generalizability of our findings because most families face the reality of their child's impending death later in the disease trajectory than do parents of children with DIPG and, therefore, may have different perspectives. Still, the parental experiences reported here should help to inform future autopsy-related research in pediatrics. Because autopsy can advance scientific understanding of the disease itself and because parents reported having no regret and even cited benefits, researchers should be encouraged to promote autopsy-related research. Parental perceptions about such studies should be evaluated in other pediatric diseases.

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Table I

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?

Table II

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

Time from child's death to parent's interview	**Mean**	**Median**	**Range**				
Months	11.0	8.5	2.9-35				
Education level	Graduated grade school	Graduated high school	Completed College Completed	Graduaet School	Left blank		
No.	3	12	13	2	3		
Religion	Protestant	Muslim	Jewish	Catholic	Other	None	Left blank
No.	9	0	0	10	6	7	1
Marital status	Married	Single	Divorced or separated	Other	Left blank		
No.	22	7	3	0	1		
Child's treatment location	St. Jude[#]	Other					
No.	19	14					

[#] St. Jude Children's Research Hospital

Table III

Decisional regret about participation in an autopsy-related research study among bereaved parents of children with diffuse intrinsic pontine glioma

	It was the right decision	I regret the choice that was made	I would go for the same choice if I had to do it over again	The choice did a lot of harm	The decision was a wise one
Strongly agree	**31 (94%)**	0	**27 (82%)**	0	**27 (82%)**
Agree	**2 (6%)**	0	**3 (9%)**	1 (3%)[a]	**5 (15%)**
Neutral	0	1 (3%)	1 (3%)	3 (9%)	1 (3%)
Disagree	0	**5 (15%)**	0	**6 (18%)**	0
Strongly disagree	0	**27 (82%)**	0	**23 (70%)**	0
Left blank	0	0	2 (6%)	0	0
Comments	“It was the right thing to do. If you can help find a cure for cancer you must give everything you can to that cause.”	“I believe we made the best choice possible during such a traumatic time in our lives. I would only encourage other families to also donate the tumor that has affected their lives!”	“I feel that I would do it again for the reason that if you can help the next person then why not.”	“The choice did no harm. … my daughter looked beautiful at her funeral.”	“It was the only choice that made sense after watching our son die. I hope our son’s gift helps to find a cure.”

[a] Parent quote revealed that this response referred to the child’s therapeutic trial, not the autopsy trial.

Table IV

Question 1: “Please share with us your reasons for deciding to participate in this study.”

Theme	Theme definition	# codes (%)	# parents (%)	Example quotations
Wanting to help others	Parent was asked or desired to “give back” so that other families might be spared the loss of their child or other children might not suffer and die.	24 (32.9)	24 (72.7)	“Another family won’t have to go through what we did.”
Wanting to advance knowledge or find a cure	Parent recognized participation as a rare opportunity to assist in advancing understanding of this tumor and improving disease outcomes.	35 (47.9)	22 (66.7)	“We want to help in the battle against pediatric brain cancer every way we can.”
Choosing as our child would want	Parent believed that the deceased child would have wanted the parent to donate the tumor sample.	6 (8.2)	6 (18.2)	“It’s what our son would have wanted.”
Frustrated at inability to help child	Parent recalled feeling helpless at being unable to provide a cure for their child and/or viewed this study as the only action they could take.	4 (5.5)	3 (9.1)	“It’s frustrating to feel so helpless when your young child is counting on you!”
Finding meaning in tumor donation	Parent believed that including the child’s tissue in the study allowed them to help make a difference that may be part of a greater plan.	2 (2.7)	2 (6.1)	“If her tissue donation was God’s reason for taking her to Heaven so soon, then far be it from me to prevent that from happening.”
Our child does not need that tissue	Parents reported that their child was not hurt by the autopsy and/or their faith indicated to them that their child was not contained within the body.	1 (1.4)	1 (3)	“And he doesn’t need that tissue now.”
Learning results of autopsy study	Parent had a personal desire to participate in the study to gain information about the child’s tissue analysis and the overall study findings.	1 (1.4)	1 (3)	“We offered this … to learn the results of such a study.”

Question 2: “Please share with us what you hoped would happen for you, your family or others because of your/your child’s participation in the study.”

Theme	Theme definition	# codes (%)	# parents (%)	Example quotations
Hope for a cure	Parent was motivated by a desire to improve the understanding of gliomas and perhaps ultimately to prevent or cure the disease.	33 (64.7)	26 (78.8)	“I hope they can come up with a cure.”
Hope to help others	Parent hoped their participation might help other parents, patients, and families avoid the suffering and loss of a child to this disease or hoped to contribute in some way.	11 (21.6)	11 (33.4)	“I feel good knowing that it could help to prevent this from happening to another child and their family.”
Hope for closure	Parent was motivated by a desire to promote the emotional recovery of self and family.	5 (9.8)	5 (15.2)	“That would bring closure to me and my family.”
Benefit from earlier research participation	Parent had had a positive experience when participating in earlier studies.	1 (2)	1 (3)	“We got to participate in a wonderful study that helped our daughter live a much better quality of life. “
Hope to know of study findings	Parents hoped to learn about the research outcomes and the impact of their child’s contribution on these outcomes.	1 (2)	1 (3)	“I also hope (expect) to be kept updated as to the findings of this study. Regardless of whether the findings are positive or negative, I want to be informed of the results.”

Table V

Question 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?”

Theme	Theme definition	No. of codes (%) n = 74	No. of parents (%) n = 33	Example quotation
Finding meaning in child’s death by helping others	Parents indicated that an explanation of our purpose for research was helpful and gave them a rare opportunity to help others and to find meaning in their child’s death and autopsy.	9 (12.2)	8 (24.2)	“While we understand the need, we have a desire to know that our daughter’s loss was one that may offer hope to others. I’d like to think that her death meant something.”
Autopsy discussion and process was fine	Parents were satisfied with the entire autopsy experience.	8 (10.8)	8 (24.2)	“We think that you did a great job explaining what you could to us.”
Inform others	Some parents had known about the study and suggested proactively informing other health care providers about the study and using novel outside resources, such as other parents, to get the word out.	10 (13.5)	8 (24.2)	“I found out about the study and brought it to the doctor’s attention.”
Be mindful of timing	Parents understood that autopsy must be discussed but felt that the health care provider should be sensitive about when to bring up the topic with families.	10 (13.5)	7 (21.2)	“I know the difficult part for all of the doctors is the trouble with finding the right timing to bring this up.”
This is hard	Parents expressed awareness that it is difficult to know what to do and that there is no good way to approach the autopsy discussion.	7 (9.5)	6 (18.2)	“I don’t think there will ever be a better way to discuss the death of their child.”
Caring request	Parents suggested that staff should be kind, considerate, and sympathetic when approaching families about autopsy research and should choose words and phrases that provide maximal comfort to the family when discussing death.	6 (8.1)	5 (15.2)	“We were comforted by his kindness.”
Let us know what to expect	Parents suggested that providing information about the autopsy process/procedure would help with the decision.	6 (8.1)	5 (15.2)	“We were a little uncertain on what was actually being removed, but when we asked more questions we got a better description.”
Having a consistent relationship with the health care provider	Parents felt that it was important to have an ongoing connection throughout the disease course with the physician who will discuss autopsy with them.	4 (5.4)	4 (12.1)	“If the choice had not been made before death, the discussion should be with the attending physician leading.”
Facilitate the process	All aspects of the autopsy should be coordinated.	4 (5.4)	4 (12.1)	“We did not have the necessary paperwork completed prior to my daughter’s death. She died late on a Saturday night and it was very difficult and time-consuming to get all the papers in order and the appropriate hospital contacted so that the biopsy could be performed. It would have been easier if we had this arranged while at St. Jude.”
Child will be presentable	Parents need to be reassured that their child will not be disfigured by the autopsy and can have an opencasket funeral.	3 (4.1)	3 (9.1)	“It was a comfort to us and I think it will be to parents to learn that you can still have an open casket and no one can tell that your child had an autopsy.”

Theme	Theme definition	No. of codes (%) n = 74	No. of parents (%) n = 33	Example quotation
Wanting to know findings	Parents suggested that it would be helpful to provide autopsy results, which may validate their decision to enroll in the study.	4 (5.4)	2 (6.1)	“In particular, I would like to learn the findings of such studies and when the tumors were analyzed. “
Each family has individual needs	Health care providers should understand and consider each family’s cultural and spiritual beliefs, as families are unique in the way they handle circumstances.	2 (2.7)	2 (6.1)	“It depends on the family because each family takes it all differently. ”
Telephone request is acceptable	Parents felt that it would be appropriate to telephone the parents of a child to discuss participation in autopsy-related research.	1 (1.4)	1(3)	“And if they don’t respond to the mailing, it is OK to call them. Parents would agree to discuss it.”