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What Do Parents Want To Know When Considering Autopsy For Their Child With Cancer?

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Abstract

Research has suggested that autopsy in pediatrics is a valued way for parents to better understand and process their child's death, yet physicians often express hesitancy in discussing this topic with parents. To better assist clinicians with initiating discussion about this often sensitive topic, the current study examined bereaved parents' preferences about the timing and content of the autopsy discussion as well as reasons for considering autopsy. This study explored the views of 30 parents who lost a child to a variety of malignancies between 6 months and 6 years ago. Results showed that 36.7% of parents recalled having a discussion about autopsy, and the vast majority of those who did not recall a discussion (89.5%) would have considered an autopsy if it had been discussed. The majority of participants in this study indicated their preference to have the first conversation about autopsy when it becomes clear that cure is no longer possible. Findings suggest that educating parents about the clinical, emotional and potential research benefits of autopsy and tissue procurement will ultimately help them make informed decisions and understand the importance of autopsy in medical progress. The future research and clinical implications of these findings are discussed.

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Keywords

pediatric oncology; autopsy; post-mortem examination; end-of-life

Background

Post-mortem examination, most often referred to as autopsy, has been an important foundation of medicine since ancient times.¹ In the neonatology literature, studies have examined issues related to approaching parents about the autopsy of a deceased child.² Despite literature suggesting that parents are both interested in autopsy information and altruistic about contributions to research, neonatologists still express discomfort and concern that approaching bereaved parents to discuss autopsy will cause further distress or infer pressure to consent. However, the degree of caution and selectivity exercised by neonatologists may not be entirely warranted; evidence indicates that parents are interested in information that can be obtained from an autopsy as well as a desire to make an altruistic contribution to research.² In a study of bereaved parents' perceptions of the autopsy examination of their child (death by any cause), 90% valued autopsy as a means of finding out why their child died and 77% appreciated its contribution to medical knowledge.³ Moreover, bereaved parents have expressed a need for comprehensive information regarding their child's illness and death, an appreciation of follow-up by their child's physicians, and an overall desire for emotional support.⁴⁻¹⁰ Professional organizations such as the American Academy of Pediatrics, the Royal College of Paediatrics and Child Health, and the Society of Critical Care Medicine suggest that physician-parent meetings to discuss the child's death and review autopsy results may help meet families' needs during bereavement.¹¹⁻¹³

To determine the proportions of pediatric autopsies yielding various types of new information that might be valued by families, between 2003-2004, a large urban children's hospital examined 100 consecutive autopsies. The study found that pediatric autopsies can yield different types of information that may be useful to physicians counseling families about autopsy.¹⁴ In the field of pediatric oncology, autopsy can be especially useful to better understand cancer genetics, tumor progression, and new and innovative treatments, and thus, it can potentially improve overall rates of survival in cancers among children.^{15, 16} Most of the work within pediatric oncology has been conducted with diffuse intrinsic pontine glioma and the data suggests autopsy for research purposes is feasible¹⁷ and satisfying for participating parents,¹⁸ with no parents regretting the choice made.¹⁹ Moreover, research has shown that adolescents and young adults living with a life-limiting disease would like to have the option of donating their body or cells for specific research on their disease after their death.²⁰ Yet, despite the probable scientific impact, autopsy is often not discussed with parents whose children are dying from cancer. A recent survey of bereaved parents, most of whom had a child who died from a brain tumor, found that the most significant barriers to autopsy were the physicians' reluctance to discuss autopsy with a grieving family and a lack of awareness about research opportunities.²¹

Only recently has research attention been given within pediatric oncology to bereaved parents' insights about autopsy, and to date, the literature has focused on parents of children with diffuse intrinsic pontine glioma.^{21,22} Research is lacking on the most appropriate time

and place for an autopsy discussion as well as the specific topics parents bereaved by other cancer types perceive as important to cover. Such information is critical to developing training programs for physicians and to encouraging sensitive communication. Thus, the purpose of the current study was to examine the preferences about the timing and content of the autopsy discussion as well as reasons for considering autopsy in a sample of parents bereaved by a variety of cancers.

Methods

As part of a larger IRB-approved clinical study sponsored by Memorial Sloan-Kettering Cancer Center (MSKCC), parents who lost a child to cancer between 6 months and 6 years ago and whose child was between the ages of 6 months and 25 years old at the time of death were recruited from the National Cancer Institute Pediatric Oncology Branch to participate in the study.

Procedure

Participants were mailed a letter that invited them to participate in the study. Along with this letter, they received a study fact sheet and an IRB-approved study consent form. The letter informed them that they would be contacted within 2 weeks by phone to see if they were interested in participating. Those sent a letter were provided with the option of sending an email or leaving a voice message if they were not interested in being contacted. The study and consent form were reviewed by phone, and once the signed consent was received by mail, fax, or email attachment, participants were provided a choice of completing the study instrument in person, over the phone, or on their own. Participants provided demographic information in addition to completing the study questionnaire.

Measures

Autopsy Questionnaire

The Autopsy Questionnaire (Table 1) is an 8-item self-report measure, developed by the study group for this study, which assesses parents' experiences with autopsy, preferences for autopsy conversation timing and content, and perceptions of autopsy helpfulness. Both open and closed-ended items were included. The survey was piloted with 5 parents whose child was receiving care for multiply relapsed disease. The first author (LW) used think-aloud and probing cognitive interviewing techniques described by the National Center for Health Statistics²³ to evaluate comfort with the interview and to assure that each question was understood, and that the response categories, including the time frames for autopsy discussion, were adequate and appropriate. Each of the text responses in the current paper were derived verbatim from answers provided to specific questions.

Data Analysis

Statistical analyses were performed using SPSS Version 21.0 (IBM, Chicago, IL). Descriptive statistics were used to characterize the sample. Frequencies and percentages were calculated to describe parents' experiences with and preferences about autopsy, and chi-square tests were used to examine group differences. Thematic content analysis was

used to analyze responses to open-ended questionnaire items.²⁴ After a codebook of themes was developed, two independent coders with qualitative research experience (KR, GC) independently coded the responses. Cohen's kappa statistic was 0.77, indicating substantial agreement between coders. Themes were modified and finalized based on team consensus.

Results

We did not receive any emails or phone calls asking not to be contacted. Of the 40 invitations sent, we were able to reach 31 households. Of those, 27 households (33 individual parents) agreed to participate in the study (87.1%). Ten parents were part of couples where both parents of the same child participated, for a total of five participating couples.

Of the 33 participants consented, 2 did not complete the questionnaire because of travel or time limitations, and 1 was lost to follow-up. Out of the 30 parents completing questionnaires (90.9% of those consented), 15 conducted the interviews by phone. Participants were primarily mothers of a deceased child, Caucasian, and an average of 49 years of age. The mean age of the parents' deceased children was 15 years old. (Demographic data presented in Table 2.)

Discussion of Autopsy

Approximately two-thirds of the sample (63.3%, $n = 19$ of 30) *did not* recall a discussion regarding autopsy, the majority of whom (89.5%, $n = 17$ of 19) indicated that they would have considered an autopsy if it had been discussed. Among these parents, the most common reason for considering an autopsy was the knowledge that it could provide tissue samples for research to better understand their child's disease (88.2%, $n = 15$ of 17).

Eight out of the eleven parents (72.7%) who *did recall* having an autopsy discussion with their healthcare provider elected to have an autopsy performed. One of the parents who did not agree to autopsy indicated the child's mother declined, without providing further explanation. The two others were parents of the same child and from the same household, and they reported that the father declined autopsy because his daughter wanted to be taken home and that an impending snowstorm prevented staying at the hospital any longer. The majority (80.0%, $n = 8$ of 10, response missing for one parent) of those who recalled a discussion about autopsy stated the discussion was respectful and culturally sensitive, with the remaining two parents indicating they were unsure. Only one parent reported feeling pressured to consent, but she noted this was by non-hospital personnel and that she *did not* recall having an autopsy discussion with their child's healthcare provider. Autopsy was completed for all but one child whose parents agreed to the procedure; in that case, the parent reported, "*It couldn't be arranged.*" In order to assess decisional regret, those who had agreed to have an autopsy performed were asked whether or not they found this decision helpful. All parents who had the autopsy completed reported that it was helpful to them.

Timing of Discussion

To assess parental preferences for timing of post-mortem conversations, participants were asked to specifically identify the best time for parents to be approached about autopsy, if

ever. More than one response was allowed. Overall, nearly all (86.7%, n = 26 of 30) of the parents believed it was appropriate to discuss autopsy prior to their child's death. Specifically, 30% of parents (n = 9 of 30) felt it was appropriate during their child's treatment, and 76.7% (n = 23 of 30) felt it was appropriate when death seemed near. Fewer parents (16.7%, n = 5 of 30) believed that it was appropriate for the discussion to occur after their child died. One parent responded "other" and reported, "*The provider should feel the parent out*" and decide then. No parent endorsed the statement, "Parents who lose a child to cancer should never be approached about this." The most common reasons provided for endorsing or preferring pre-death discussions were to avoid the overwhelming emotions following death that could hinder clear decision-making (60%), to help make meaning of their child's illness (20%), to have time to prepare (13%), and to have time to talk to their child about autopsy (7%).

Parents' qualitative responses, presented below, provided insight into their reasoning and the importance of this conversation. As one father eloquently stated, "*Every discussion at this time is acutely remembered.*"

Reasons for discussing during treatment—Of the parents who provided reasons for preferring the discussion of autopsy be held during the child's treatment, the majority (10) indicated they would be less likely to be overwhelmed by emotion prior to the death and thus, better able to plan.

- "No matter how hard it is it needs to be brought up, but definitely before- when logic has a chance."
- "Death can come quickly and unexpectedly – it's best to have a plan in place for the arrangements. Also, it is easier to decide before your emotions become clouded in grief."
- "I think it can be approached in a hypothetical scenario before death, but after death, the emotional stress is so high, and the window of time for that discussion is so limited."

However, most parents also provided responses that expressed a desire for physicians to wait until it is clear that cure is no longer possible in order to maintain a sense of hope or find meaning:

- "Parents hope for a miracle almost to the end. Being approached too soon would be extremely painful if the parents have not accepted that the end is near."
- "If there is hope, it shouldn't be raised. Once death seems near and families are 'changing gears' in their minds, this may help them to find some meaning and consolidation."

Other parents provided reasoning for why early preparation for this conversation would be useful, including opportunity to discuss with the child and acceptance of the inevitable. The overriding sentiment provided was that discussing autopsy after their child dies is too late: "*After death you don't want to think about anything. Need time to talk and prepare and to think about it.*"

Reasons for discussing post-death—The few parents who felt discussion about autopsy should occur after their child's death referred to the emotional impact of the conversation: *“After the child dies there is nothing else the doctor can do, so it is more humane to ask then. That is showing more caring. It would make me angry to ask before.”*

Reasons for discussing at multiple time points—Several participants endorsed that more than one time point would be appropriate for discussion of autopsy to take place as parents' outlooks on the illness change: *“I think you should ask at 3 times: 1. During treatment. 2. When death is near. 3. After the death of the child. A parent's outlook changes from diagnosis [to] loss of their child.”*

What do Parents Want to Know About an Autopsy?

The majority of participants wanted to know how the autopsy could help other children (90%, n = 27 of 30). As one father wrote, *“[Tell me] that my child's body will be respected, my loss will be appreciated, and that this is an opportunity to create a change for the positive for someone else.”* Topics that parents endorsed as important to include in discussion of autopsy are presented in Table 3 in order of frequency endorsed. Overall, parents most commonly wanted the autopsy conversation to include: 1) how the autopsy can potentially help other children, 2) how the medical team can learn more about their child's cancer, 3) how they can learn about the findings of the autopsy, and 4) how the autopsy will help their child's doctor. All of these were included as important topics to cover by at least 80% of the parents in this study. Differences in responses between parents who recalled having a discussion about autopsy as compared to those who did not recall are also presented, though none of these differences were statistically significant. In examining gender differences in information preferences, interestingly, a smaller percentage of men than women reported that they would want to know details on how an autopsy is performed (14.3%, n = 1 of 7, and 74.9%, n = 17 of 23, respectively; Fisher's Exact Test, $p = .009$). Participants' responses to an open-ended item about information that physicians should consider covering when discussing the autopsy with parents are provided in Table 4.

Discussion

To the best of our knowledge, this is the first investigation with bereaved parents of children with a variety of malignancies that explored the timing and specific topics that should be addressed during discussion about an autopsy. While the literature reports that physicians often choose not to discuss autopsy with parents in order to avoid further distress,¹⁴ the majority of parents who were not offered the option of an autopsy in the current study would have seriously considered consenting to one. Further, parents who consented to an autopsy did not report decisional regret, similar to findings by Baker et al. (2013).¹⁷ The literature has also shown that consent to an autopsy is typically sought after the child's death, though it may be discussed earlier when death is expected.¹ The majority of participants in this study indicated their preference to have the first conversation about autopsy when it becomes clear that cure is no longer possible. Parents provided poignant examples of the emotional challenges they had in processing their child's poor prognosis and in making rational decisions before and around the time of their child's death. Given there may be discrepancies

between when physicians and parents come to accept that cure is no longer possible, it is key to carefully assess where parents are at in terms of their child's disease status before initiating an autopsy discussion. Parents did note the role that autopsy and related research might play in making meaning of their child's illness, yet few parents were interested in learning how the results may assist them with grieving. This may speak to how painful a parent's anticipatory grief is and how resentful they often feel when someone who has not experienced the loss of child tells them how to cope with their loss.

Over 80% of participants reported wanting to know whether autopsy findings could potentially 1) help other children, 2) help their child's medical team learn more about their child's cancer, and 3) whether parents can obtain the findings. Importantly, they want their loss to be appreciated. Though our cohort includes bereaved parents from across the USA, each of whom have lost a child to cancer, this study is limited by the small sample size, under representation of ethnic minorities, and in some cases, having both parents from the same family participate. The latter was also a study strength, as it provided us with an opportunity for a preliminary comparison of mothers' and fathers' preferences and perspectives about post mortem examination. The cross-sectional design of the study prevented us from examining whether feelings about autopsy or what should be included in discussions about autopsy with parents change over time. It is also difficult to determine the impact of time and grief on parents' retrospective reports about autopsy discussions.

Conclusion

It is not surprising that given the sensitivity of the issue, physicians are often hesitant to discuss the option of autopsy, particularly when the patient is a child. These findings provide important insights from parents bereaved by cancer and suggest that such hesitancy is not warranted as long as discussions are led sensitively, timed appropriately, and address both questions and future outcomes about which parents want to know. While all participants in this study felt it was appropriate to approach parents about autopsy, this paper is not intended to imply that parents 'should' consent, but rather to provide data suggesting parents would like information to make an informed decision. Moreover, given the range of responses to parents' desired timing and content of autopsy discussions, it is clear that there is not yet a one-size-fits-all method for approaching this situation and individually tailored conversations are most appropriate.

Educating parents about the clinical and potential research benefits of autopsy and tissue procurement while respecting religious or personal beliefs will ultimately help them make informed decisions. Several educational brochures have been developed, such as The College of American Pathologists' "Autopsy: Aiding the Living by Understanding Death," which may be helpful to facilitating discussions about autopsy. Furthermore, researchers should apply this study's findings to develop effective and sensitive methods to facilitate communication between physicians and parents. To this end, our team is currently developing a communication skills module to assist with training frontline clinicians. Future studies should attempt to recruit larger samples of both mothers and fathers to determine if the current study's findings are robust and to further explore gender differences in

preferences. Finally, barriers to conducting an autopsy, such as financial cost and communication challenges, should also be explored.

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Table 1
The Autopsy Questionnaire

-
1. During your child's illness or when your child passed away, was autopsy discussed?
 - Yes, autopsy was discussed with me (*Please continue to Question 2*)
 - No, but if autopsy had been discussed I would have considered it for the following reasons (*Please check all that apply, then go to Question 7*)
 - To learn more about the disease my child has, in order to help others
 - To learn more about the disease my child has, in order to help me try to make sense of my child's death
 - To learn more about my child's specific type of cancer for my own knowledge and understanding
 - To learn more about my child's response to treatment
 - To learn more about why my child passed away, in order to make sense of my child's death
 - For closure
 - Other
 - No, but I would not have chosen it even if asked for the following reasons (*Please check all that apply and continue to Question 7*)
 - It would be against my religious beliefs
 - I felt my child had gone through enough already
 - I'm not sure what kind of benefit there would be
 - I wouldn't have been able to think about autopsy during my child's illness or right after his/her death
 - I don't think my child would have wanted an autopsy
 - Other
 2. Were you asked in a respectful, culturally sensitive way?
 - Yes
 - No
 - Not sure
 3. Did you feel pressure to agree to the autopsy?
 - Yes
 - No
 - Not sure
 4. When were you asked about the possibility of performing an autopsy?
 - During treatment
 - When death seemed near
 - After my child's death
 - Other (please specify)
 5. Did you agree to have any autopsy done?
 - Yes (*if yes, why? Please check all that apply*)
 - To learn more about the disease my child has in order to help others
 - To learn more about the disease my child has in order to make sense of my child's death
 - To learn more about my child's own illness
 - To learn more about my child's response to treatment
 - To learn more about why my child passed away

- For closure
 - Other
 - No (if no, why not? Please check all that apply)
 - It was against my religious beliefs
 - I felt my child had gone through enough already
 - I wasn't sure what kind of benefit there would be
 - I wouldn't have been able to think about autopsy during my child's illness or right after his/her death
 - I didn't think my child would have wanted an autopsy
 - Other
6. Was the autopsy helpful to you?
- Yes
 - No
 - Not sure
7. In the past, when a family has lost a child, we have struggled to choose the best time to talk about performing an autopsy. From your perspective, when do you think is the best time to discuss this?
- During treatment
 - When death seems near
 - After the child's death
 - Parents who lose a child to cancer should not ever be approached about this
- 7a. Can you please tell me a little more about why you chose this answer?
8. In thinking about giving consent for an autopsy to be performed on your child, which of the following would you have wanted to know?
- Details about how an autopsy is performed
 - If there are different types of autopsies
 - Will the body be handled respectfully?
 - How will the autopsy help my child's doctor?
 - Will the autopsy delay the funeral and by how long?
 - Will guests at the funeral be able to tell an autopsy was done?
 - Is the pathology done like that for any operation?
 - Can I learn about the findings of the autopsy
 - Will my doctors meet face to face to help me understand its findings?
 - Will this information help me grieve?
 - Can the medical team learn more about my child's cancer from this autopsy?
 - Can the autopsy potentially help other children?
 - Other items doctors should consider when talking to parents.
-

Table 2
Demographic Characteristics for the NCI Sample

<i>Gender</i>	Frequency	Percentage
Female	23	76.7
Male	7	23.3
<i>Race and ethnicity</i>		
White	23	76.1
Black	5	16.7
Asian or Pacific Islander	1	3.3
Other (Puerto Rican)	1	3.3
<i>Child's type of cancer</i>		
Sarcoma	16	53.3
Brain tumor	5	16.7
Neuroblastoma	4	13.3
Leukemia	2	6.7
Other (e.g., hepatoblastoma, melanoma)	3	10.0
<i>Age and time since death in years</i>		
Age of parent (m/sd/range)	48.6/6.1/33 to 58	
Age of child at death (m/sd/range)	15.4/6.3/4 to 24	
Time since death (m/sd/range)	2.1/1.2/0.5 to 5	

Table 3
Information Most Important to Include in a Discussion about Autopsy

Autopsy topics about which parents wanted to know	All parents (N = 30)		Parents who...			
	Frequency	Percentage	Recall being asked about autopsy (N = 11)		Do not recall being asked about autopsy (N = 19)	
			Frequency	Percentage	Frequency	Percentage
How the autopsy can potentially help other children	27	90.0	10	90.9	17	89.5
How the medical team can learn more about their child's cancer	27	90.0	9	81.8	18	94.7
How they can learn about the findings of the autopsy	25	83.3	8	72.7	17	89.5
How the autopsy will help their child's doctor	24	80.0	8	72.7	16	84.2
Whether or not their doctors will meet face to face to help them understand the findings	22	73.3	6	54.5	16	84.2
Whether or not their child's body will be handled respectfully	21	70.0	9	81.8	12	63.2
Details on how the autopsy is performed	18	60.0	7	63.6	11	57.9
Whether or not the autopsy delays the funeral, and if so, by how long	18	60.0	5	45.5	13	68.4
Whether or not there are different types of autopsy	16	53.3	8	72.7	8	42.1
Whether or not guests at the funeral will be able to tell that an autopsy was done	16	53.3	5	45.5	11	57.9
Whether or not the pathology is done like that for any operation	8	26.7	5	45.5	3	15.8
Whether or not the information from the autopsy will help them grieve	6	20.0	2	18.2	4	21.1

Table 4
Responses to Open-ended Item on Information Physicians Should Consider in Discussing Autopsy with Parents

Parents' thoughts on discussing the procedure

- “Be forthcoming. Speak in layman's terms.”
- “Where will the autopsy be done?”
- “Don't discuss ‘incisions.’ Too much of a visual comes to mind and no one wants to visualize their child being ‘dissected.’”
- “Do I have to be there to see it done?”

Parents' thoughts on discussing what can be learned from the autopsy

- “Can you tell me what was really going on in his/her body?”
- “Can they tell me exactly how my child died? (We suspect a brain hemorrhage but we don't know the immediate cause of death.)”
- “It would be helpful to get an understanding of what my child was going through and to know that he was in no pain.”
- “I think most parents want to help find a cure. Those who don't want an autopsy, I think have just had enough and can't do anymore and that's okay too.”
- “I would like the doctors to have asked if I had considered whether I would want to have my son's tissues preserved to help other down the road with the same diagnosis.”

Parents thoughts on discussing what happens after the autopsy is completed

- “Can I see photos of the tumor?”
 - “Will other institutions have access to [my child's] samples and/or data collected?”
 - “Can I designate who receives the samples?”
 - “If I change my mind and decide later that I want to learn about the autopsy results, can I?”
-