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## Overcoming Autopsy Barriers in Pediatric Cancer Research

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### Abstract

**BACKGROUND**—More than 13,000 children annually in the United States and Canada under the age of 20 will be diagnosed with cancer at a mortality approaching twenty percent [1,2]. Tumor samples obtained by autopsy provide an innovative way to study tumor progression, potentially aiding in the discovery of new treatments and increased survival rates. The purpose of this study was to identify barriers to autopsies and develop guidelines for requesting autopsies for research purposes.

**PROCEDURE**—Families of children treated for childhood cancer were referred by patient advocacy groups and surveyed about attitudes and experiences with research autopsies. From 60 interviews, barriers to autopsy and tumor banking were identified. An additional 14 interviews were conducted with medical and scientific experts.

**RESULTS**—Ninety-three percent of parents of deceased children did or would have consented to a research autopsy if presented with the option; however, only half of these families were given the opportunity to donate autopsy tissue for research. The most significant barriers were the physicians' reluctance to ask a grieving family and lack of awareness about research opportunities.

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#### CONFLICT OF INTEREST STATEMENT

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**CONCLUSIONS**—The value of donating tumor samples to research via an autopsy should be promoted to all groups managing pediatric cancer patients. Not only does autopsy tumor banking offer a potentially important medical and scientific impact, but the opportunity to contribute this Legacy Gift of autopsy tumor tissue also creates a positive outlet for the grieving family. Taking these findings into account, our multidisciplinary team has developed a curriculum addressing key barriers.

### Keywords

Autopsy; childhood; cancer; research; end-of-life care

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Although survival rates have greatly increased over the past decades for some pediatric cancers, other subtypes including high-risk sarcomas and diffuse intrinsic pontine gliomas (DIPG) have an unimproved or near-zero survival rate despite novel therapies [3,4]. This observation highlights the need for improved treatments and new research approaches for rare pediatric tumors. One way to advance knowledge of rare cancers is to study the disease at all stages including the point when treatment has failed and the child has succumbed to the disease. Obtaining quality tumor samples that may be donated directly to a research laboratory or frozen in a biorepository for future research has several important benefits. Autopsy samples allow researchers to collect the most biologically aggressive component of the tumor which has not been eradicated by any treatment administered, to sample multiple sites of disease, and to collect larger specimens than might be possible in a living patient [5]. Fresh samples may provide highly valuable tissue for researchers to study because living cell tumor cultures can sometimes be established; nevertheless, frozen or even paraffin-fixed samples have already proven to be of great value and numerous examples can be cited how such autopsy samples have revealed fundamental mechanisms of tumor progression [5–12].

Despite these significant advances in the understanding of pediatric cancers facilitated by autopsy tissue for research, the number of tumor donations from autopsies remains small. To some extent this reflects a general decline in the frequency of autopsies over the decades in the United States where the autopsy is only performed in 5% of all hospital deaths [13]. This decline has been attributed to physicians' minimal knowledge regarding the procedure, physicians' unwillingness to ask for consent, the assumption that families will not consent, uncertainty of how to approach the family, and the rationale that improved imaging and clinical laboratory tests already shed light on the cause of death [13–15]. However, some studies suggest that autopsy continues to identify unrecognized medical problems even in patients dying of cancer [16,17].

Many physicians currently have not had adequate training in the autopsy procedure [18] and as a result may be insufficiently aware of the benefits. Not only do tumor samples from an autopsy for research offer a potentially important scientific impact, but the opportunity to contribute a Legacy Gift (*i.e.*, the donation of autopsy tumor tissue to science) may also create a small positive aspect for an otherwise devastating event for the grieving family. The goal of this study was to identify barriers to performing pediatric autopsies for research purposes and to develop guidelines that institutions may use to encourage physicians to address tumor donation with families.

### METHODS

This study was performed under approval of the Oregon Health & Science University institutional review board. Parents were informed of this study by the Northwest Sarcoma Foundation (as this study originally focused on pediatric sarcomas) or by other pediatric cancer patient advocacy groups, particularly the pediatric brain tumor community who

participated in unexpected large proportion. Parents who were interested in participating in this study self-identified and contacted the investigators. After a verbal or written consent, interviews were conducted by a single, Master level interviewer who has five years of experience working with cancer patients and their families and interview results were transcribed for analysis. Interviews were conducted from September 2010 through August 2011 in which barriers to autopsy consents for research purposes were identified by parents. Children of the parents interviewed were newly diagnosed, in remission, recently relapsed, in hospice care, or deceased. Emphasis for families who were interviewed was placed on pediatric tumors, such as metastatic rhabdomyosarcoma or diffuse intrinsic pontine glioma, for which outcomes have remained dismal for greater than forty years [4,19]. Questions asked in the survey are given in Table I. Medical professionals were identified by parent-community advocates as professionals with firsthand experience in research autopsies and were also interviewed to identify barriers from the medical perspective. Scientists who have been highly involved in accepting tumor donations were also interviewed to identify barriers from the research side. In addition, medical staff and scientists who had little or no experience in tumor donation were interviewed to identify perceived barriers. Upon completion of the interviews, a multidisciplinary team integrated findings to design a course for medical professionals on how to approach autopsy discussions with parents.

## RESULTS

Eight-four families were self-referred to this study after an initial parent advocate contact, as detailed in Methods. Twenty-three families did not follow up to an email or phone call to schedule an interview, and one family later declined to be interviewed. The other sixty parents, 45 mothers and 15 fathers, were interviewed representing 54 children and more than forty different hospitals across the United States, Canada, and Australia (Table II). At the time of the interview, 70% of the children were deceased while the remaining 30% were alive, among whom one-fourth were on active treatment for relapsed disease. Forty percent of the parents were not aware of tumor donation but would have considered an autopsy for the purpose of research samples in the event of the child's death. All of the families whose child was alive at the time of the interview would consider an autopsy if their child were to die. Sixty-one percent of the families whose child was alive at the time of the interview donated tumor tissue at the time of diagnosis (biopsy) or from surgery.

The attitudes of parents of deceased children in this cohort regarding autopsies for the purpose of research samples were very positive. If the opportunity to donate tumor tissue to research had been presented, 93% of parents state they did or would have consented to a research autopsy and donated tumor tissue to science (7% would not have, whether families were aware of the option or not); however, only half of the families of deceased children who would consider an autopsy were presented with the opportunity to donate autopsy tissue for research. The remaining half of the families of deceased children who would consider a Legacy Gift were not made aware of the option until after the child died or were told there was no benefit to an autopsy and that tumor samples were not needed. In three instances for which a family had made the decision to donate, parents were told tumor tissue was not needed. In 4 other instances, the medical staff was unable to arrange an autopsy requested by the families, thereby adding to the reported grief of the family. Seven percent of the families were aware of tumor donation through other parents but chose not to have an autopsy performed for the purpose of research samples. Informative case histories are provided online which describe what may happen due to poor communication among all parties involved in an autopsy and tumor donation (Supplemental Text I).

Although physicians may routinely ask families about autopsy for the purpose of research samples, none of the families interviewed were approached by a physician requesting an

autopsy; however, parent-driven request for autopsy was frequent in our cohort because of the enriched inclusion of DIPG patients and families. The Children's Oncology Group (COG) D9902 Biology Protocol has for a decade permitted tissue, particularly rhabdomyosarcoma, to be donated to a tumor bank at all stages of disease including post-mortem. In our study, parents of children with rhabdomyosarcoma were asked if participation in D9902 was presented as an option to the family. All 19 children were being treated at a COG affiliated hospital where D9902 was open. Only 2 out of 19 families whose child had rhabdomyosarcoma knew of the protocol and understood when donations could be made to the tumor bank, whereas 8 out of 19 knew of the protocol but thought the protocol was for tumor samples from diagnosis only and did not contribute at a later time point. The remaining 9 out of 19 families reported that the protocol was not presented in any form to the family.

Family-related and medical professional-related barriers were identified and frequency of each barrier was recorded (Table III). Parents most frequently cited the physicians' reluctance to ask (52%) and the lack of educational information available for families (47%) as major barriers. Medical professionals cited logistics (71%) as the major barrier, and similar to the family-reported barriers, also cited the physicians' reluctance to ask due to the prospect of having an uncomfortable conversation with a family (50%). Additional barriers identified were the lack of awareness of tumor donation and the value of tumor samples to research, the uncertainty as to when to discuss tumor donation with a family, the absence of a motivation to ask (*e.g.*, a current COG or institutional protocol), the lack of an immediate reward or recognition for the physician, the uncertainty about protocols and hospital tissue collection procedures, and the coordination with the research institution who would obtain the samples.

Interviewed parents were asked which member of the medical team should approach families about tumor donation and when the best time would be to discuss the possibility of donating tissue to research via an autopsy. In most cases (90%), parents preferred that the primary physician initiate the discussion but felt that subsequent questions could be answered by anyone on the medical team. The remaining 10% of families suggested a nurse, a hospice care provider, or anyone who showed compassion and understanding of the situation.

Acknowledging that the time may be different for each family, parents identified two times as the most appropriate and conducive to gaining consent. Although the majority of parents felt that the time of a child's initial diagnosis can be overwhelming, 43% felt that exposing parents to the general concepts of tumor donation and research at diagnosis is valuable (Supplemental Figure 1). Second, 73% of parents suggested that the subject of an autopsy for tissue donation might be usefully broached after the discussion changes from curative treatment options to palliative care options. Uniformly, parents felt that after death was the least desirable time to initially discuss a research-related autopsy.

Families also articulated what they considered to be the most appropriate forms of follow-up once a donation has been made to science. Although families vary in the amount of details they wish to receive, parents felt that information provided by the researcher when the family was ready to receive this information would be valuable and would honor the child. In particular, learning of medical advances made through research from the tissue donated would be a positive experience and validate the child's Legacy Gift. Fifty-eight percent of parents reported that even if the donation does not result in the establishment of a cell line [10], emphasis should be placed on the positive contributions of how a donation that resulted in frozen or fixed tissue still contributed to the knowledge of science and that particular type of cancer [7,11].

Religious beliefs identified by the families are shown in Table II. For our interviewees, religion would not have forbidden an autopsy for the purpose of research samples for any family. Many families (72%) stated that tumor donation was seen as a positive way to give back to another's life and was felt to be supported by the family's religious and spiritual beliefs.

## DISCUSSION

While we acknowledge that our study has an inherent bias due to the method in which families were non-randomly self-referred to us to be interviewed, with a large representation of pediatric sarcoma and brain tumor families, much can be learned from these interviews. The current study sheds light on a paradigm of particular interest: while a national protocol is in place for tissue donation for rhabdomyosarcoma, eligible families were not aware of the option to donate resulting in low autopsy rates. In contrast, the community of parents with children diagnosed with DIPG is peer-educated about the need for tissue for research because tumor tissue is not otherwise routinely biopsied or resected at any point during the standard treatment in the United States. Families in this DIPG community thus advocate for donation individually despite the lack of a formal protocol, thereby leading to a high autopsy rate. In our study, the autopsy frequency was ten-fold higher than other reported contemporary rates [13], which we attribute to the presence of families of patients with DIPG among our interviewees.

Medical teams often believe grieving parents are reluctant to consent to an autopsy but the real barrier may be that parents are not given the opportunity to consent. The literature reports that many physicians will not ask for an autopsy because the physician believes that the family is already emotionally distraught, the cause of death is known [20] and that asking will only upset the family more [21]. Nevertheless, an autopsy for the purpose of research samples may offer great benefits to the bereaved family [22,23]. This altruistic act can give the family a sense of empowerment and control over the child's death and provide the family with hope that something good might come from their devastating experience [6,24]. In addition to the benefits to families, an increase in autopsies might also increase the range of tumor samples available and lead to a new understanding of pediatric cancers or even new therapies.

Although some institutional and national tissue banking protocols to collect autopsy tumor tissue exist, the literature reflects that very few autopsies have been performed for research purposes [5]. Currently only two COG protocols exist that includes postmortem samples to be donated to a biorepository. In order to increase tissue donation and sample availability, additional COG autopsy protocols will likely need to be written and physician awareness increased. Contributing to a centralized tissue bank, such as the COG Biorepository that has a scientific oversight committee, could be one approach to establishing a national tumor tissue bank of autopsy samples.

One of the barriers identified by both the family and medical staff was the medical professional's lack of awareness of tumor donation options and the potential value of an autopsy. Education on the practical aspects of autopsy and the communication skills required to obtain autopsies can begin in medical or nursing school and continue throughout a medical professional's career so that the value is understood and the approach to obtaining autopsy consent is not forgotten [13,15]. Emphasizing the value of tumor tissue to science from the beginning of the child's diagnosis and throughout the course of disease is an important step in educating a family about research opportunities. Families who have contributed tumor tissue during the child's biopsy or resection may be better prepared to have a Legacy Gift discussion.



A family may request as little as a postmortem biopsy or may permit a partial or full autopsy to be performed that would benefit both the medical and scientific communities. In an even less invasive approach, circulating tumor cells collected from a postmortem blood draw within 3–6 hours can also be used to establish a viable cell line [12] for research. Although offering such limited autopsies is appropriate and may result in higher consent rates, the physician should emphasize the potential value of a full autopsy and the additional investigational and educational benefits an autopsy offers [5,14].

In our study, the lack of educational information for families about tumor banking and research opportunities was identified as a barrier. Parents whose child had undergone autopsy for research had learned about tumor donation through online avenues including listservs, blogs and foundation websites. To address the lack of information available for families and provide guidelines for medical professionals, we have designed handouts for physicians, including pathologists, and the families ([www.ccurefast.org](http://www.ccurefast.org)). Providing guidelines for a researcher is challenging as each scientist will have different needs for tissue acquisition and shipping. Similarly, providing guidelines for funeral homes are also beyond the scope of this report as such guidelines will depend on individual state laws.

One of the major barriers identified was physician reluctance to ask. The physician might begin by assessing the family's understanding and engagement in the child's treatment, and whether or not to include the patient in the conversation. The religious or cultural beliefs of a family are important issues to be considered even though the majority of religions allow autopsies to be performed as an individual choice or under special circumstances that benefit the living [25](Table IV). Parents may ask how quickly the autopsy needs to happen after the child expires. Logistically the time limitations for burial (*e.g.*, within 24 hours for Judaism) are consistent with the most successful timeframe for collecting the most valuable tissue (*i.e.*, less than six hours [8,26] after death) although valuable tissue has been obtained at 14 hours postmortem [10].

Some flexibility may exist in deciding which medical professional is the best person to discuss tumor donation and an autopsy with the family (*e.g.*, if available, a palliative care team member or social worker could be present with the physician during the discussion to help answer questions a family may have about the process). In order to elicit the family's wishes, one may ask questions about what is important to the family about remembering and honoring the child. Conversations may be most productive when the medical professional can convey the benefits to the family, future families, and medical science, and if families are given examples of how tissue donated by other families have contributed to a better understanding of pediatric cancers. Families noted that when the physician informs parents that curative options have been exhausted, a family may be in denial about the child's prognosis and may not wish any further procedures to the child before or after death, resulting in lower consent rates. Nevertheless, parents preferred that the option be presented well prior to the child's death, allowing them to discuss the idea and make proper arrangements in advance. Empathy and a willingness to address the questions a family may have about the autopsy procedure are important, although answers need not be especially graphic.

Once a family has decided to donate the child's tumor to research the medical professionals should arrange for the donation to happen in a seamless manner. Communication between each specialty involved will be the key to a successful donation. Identifying one member of the team who will be the single point of contact and who will ensure that the family's wishes are met regardless of the obstacles was reported as an important aspect of relieving the family of logistical responsibilities and improving the quality of the end of life experience. For example, when a child's death is imminent, the pathologist could work with the

Decedent Affairs office (if available) to coordinate the logistics of the autopsy, as well as contact the researcher to inform them of the current status of the patient and ensure that the samples are obtained correctly.

Whether a child who dies in hospice or outside of hospital care can be transported to the autopsy facility will be institution specific and ideally should be explored with the help of the pathologist well before the time of death. Upon the child's death, it should be possible for the family to be provided with complete assurance that the donation has been seamlessly prearranged so as to relieve any additional stress to the family. Information from the autopsy becomes part of the child's medical record and is available to the family whenever they are able and willing to receive the information. Finally, if a family chooses to donate to a specific laboratory and request an ongoing dialogue, the researcher should communicate with the family that the tumor samples have been received. Later, if the family requests, the research findings derived from the donated samples might be shared. However, this dialogue requires consideration of the Health Insurance Portability and Accountability Act privacy regulations as well as state and local ordinances. If the Legacy Gift is donated to COG, tracing the results is not possible.

In conclusion, while acknowledging that any conversation about an autopsy is emotionally challenging, physicians should recognize that many families wish to be presented with the option of postmortem donation. Research autopsies are indeed possible in many cases and are often valuable to not only the pediatric cancer research field but the families as well.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**TABLE I**

**Questions Used During Phone Survey to Assess Views on Autopsies and Tumor Banking.**

|   |
|---|
| <b>For Family Interviews:</b>   |
| Did your child’s medical team present the option to donate samples to research to you?            |
| If so, did you and your child ever donate tumor samples? When?                                    |
| If not, how did you find out about donating to research?  |
| In the event that your child’s health fails, would you consider an autopsy for research purposes? |
| What barriers may exist in obtaining consent for an autopsy for research purposes?                |
| Did you and your child decide to leave a Legacy Gift when he or she passed away?                  |
| If an autopsy was performed, was it suggested by the doctor or requested by you?                  |
| If you approached the medical staff about donating, were they receptive to your request?          |
| When and how would you like to be approached about the Legacy Gift opportunity?                   |
| Who would you like to speak to you first about tumor donation?                                    |
| Would your child be part of the decision making process?  |
| Would your religion or cultural beliefs play a role in deciding to donate?                        |
| Why would you consider a Legacy Gift?   |
| What would be the best way to educate families about tumor donation?                              |
| Would you want to know what research was being done with your child’s Legacy Gift?                |
| If so, what would be the best way to communicate this information to you?                         |
| For rhabdomyosarcoma families: Are you aware of COG’s D9902 protocol?                             |
| <b>For Medical Professional Interviews:</b>   |
| In your training, were you exposed to autopsies?  |
| How often do you request an autopsy?  |
| Do you consider autopsies for research purposes?  |
| What are the current challenges of tumor donation?  |
| How do you think these issues could be addressed?   |
| Would you consider tumor banking if existing protocols were established at your institution?      |
| When would you approach the family/patient to discuss this option? When is the best time?         |
| For an adolescent patient, who would you approach first, the patient, family or both?             |
| What have been some of the outcomes from having an autopsy discussion?                            |
| Do you think religion/culture plays a role in asking a family or the decision the family may      |
| What tools would be helpful for you to have when you approached a family about autopsies? make?   |

TABLE II

## Demographics of Interviewees

| <b>Patients/Families</b>                      |  |       |        |
|---|--|-------|--------|
| Age of Child at Diagnosis                     | Median: 6 years; Range: 3 weeks-15 years old | n= 51 | (85%)  |
| Age of Adolescent or Young Adult at Diagnosis | Median: 20 years; Range: 16–40 years old     | n=9   | (15%)  |
| Time from Diagnosis to Interview              | Median: 39 months; Range: 9–208 months       | n=60  | (100%) |
| Time from Death to Interview                  | Median: 19 months; Range: 1–70 months        | n=42  | (70%)  |
| <b>Country of Origin</b>                      |  |       |        |
|   | United States                                | n= 57 | (95%)  |
|   | Canada                                       | n= 2  | (3%)   |
|   | Australia                                    | n= 1  | (2%)   |
| <b>Diagnosis</b>                              |  |       |        |
| Brain Tumors:                                 | Diffuse Intrinsic Pontine Glioma             | n= 20 | (33%)  |
|   | Medulloblastoma                              | n= 8  | (13%)  |
|   | Glioblastoma Multiforme                      | n= 1  | (2%)   |
| Leukemia/Lymphomas:                           | Hodgkins Lymphoma                            | n= 3  | (5%)   |
|   | Acute Lymphoblastic Leukemia                 | n=1   | (2%)   |
| Solid Tumors:                                 | Rhabdomyosarcoma                             | n= 19 | (32%)  |
|   | Osteosarcoma                                 | n= 3  | (5%)   |
|   | Ewings Sarcoma                               | n= 1  | (2%)   |
|   | Intimal Sarcoma                              | n= 1  | (2%)   |
|   | Undifferentiated Sarcoma                     | n= 1  | (2%)   |
|   | Mesenchymal chondrosarcoma                   | n= 1  | (2%)   |
|   | Teratoma                                     | n=1   | (2%)   |
| <b>Religion</b>                               |  |       |        |
|   | Christian/Catholic                           | n= 20 | (33%)  |
|   | Jewish                                       | n= 5  | (8%)   |
|   | Mormon                                       | n= 1  | (2%)   |
|   | Spiritual (Unspecified)                      | n= 2  | (3%)   |
|   | No Religious Belief                          | n= 20 | (33%)  |
|   | Not Identified                               | n= 12 | (20%)  |
| <b>Medical Professionals</b>                  |  |       |        |
|   | Physicians *                                 | n= 8  | (57%)  |
|   | Scientists *                                 | n= 2  | (14%)  |
|   | Pediatric Nurses                             | n= 2  | (14%)  |
|   | Social Workers                               | n= 3  | (21%)  |
|   | Other  | n= 1  | (7%)   |

\* n=2 (14%) Interviewees were both Physicians and Scientists

**Table III**

## Frequencies of Identified Barriers to Autopsies for Research Purposes

|  |
|--|
| <b>Family Identified:</b>  |
| Physician's reluctance to ask  |
| Lack of educational information for parents  |
| Medical staff unaware of tumor donation option and/or value                          |
| Uncertain when is an appropriate time to discuss tumor donation                      |
| Logistics ( <i>e.g.</i> coordination, location of death, transportation, cost, etc.) |
| No motivation or immediate reward for the physician                                  |
| <b>Medical Staff Identified:</b>   |
| Logistics ( <i>e.g.</i> coordination, location of death, transportation, cost, etc.) |
| Physician's reluctance to ask  |
| Medical staff unaware of tumor donation option and/or value                          |
| Uncertain when is an appropriate time to discuss tumor donation                      |
| Lack of educational information for parents  |
| Coordination with research scientists  |
| Lack of protocols  |
| No motivation or immediate reward for the physician                                  |

**TABLE IV**

## Autopsy Perspectives in Major World Religions

| <b>Religion</b> | <b>Strictest view or doctrine regarding autopsy</b>  |
|-----------------|--|
| Buddhism        | Body should be undisturbed for 3 days following death to allow soul to continue on to the next life. |
| Christianity    | No official doctrines prohibiting autopsy, except in Christian Science.                              |
| Hinduism        | Autopsy may upset the immortal soul.   |
| Islam           | Burial should occur immediately and autopsies are generally not allowed.                             |
| Judaism         | Burial should occur as soon as possible and with the body in its entirety.                           |