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Parents' experiences of postmortem tumor donation for high-grade gliomas: benefits and suggested improvements

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Abstract

Background. Pediatric high-grade glioma is a devastating diagnosis. There has been no improvement in outcomes for several decades, with few children surviving 2 years postdiagnosis. Research progress has been hampered by a lack of tumor samples, which can be used to develop and test novel therapies. Postmortem tumor donations are therefore a valuable opportunity to collect tissue. In this study, we explored Australian parents' experiences of donating their child's tumor for research after their child had died.

Methods. We collected qualitative data from 11 bereaved parents who consented to donate samples of their child's high-grade glioma for research postmortem. We asked parents about their perceived benefits/burdens of the autopsy, recommendations for improving consent discussions, and decision regret.

Results. Parents hoped that their donation would help to find a cure for future children with high-grade glioma. They described feeling comforted knowing that their child's suffering may help others. Some parents also felt that the donation would help them better understand their child's tumor. Although some parents described discomfort about procedures leading up to the autopsy, parents reported minimal regret regarding their decision to donate their child's tumor. Parents provided recommendations to improve consent discussions, such as providing more information about the autopsy logistics and why the donation was needed.

Conclusion. Parents consented to autopsy for altruistic reasons, although donation may also assist parents in their grieving. There is a strong need to improve access to tumor donations for any family who wishes to donate.

Key Points

- Parents' consent to an autopsy for their child primarily for altruistic reasons.
- Parents experience little regret and may experience some psychological benefit.
- Autopsies should be considered more regularly for children with high-grade glioma.

Importance of the Study

Our study is the first to describe Australian parents' experiences of postmortem tumor donation for high-grade gliomas (HGGs). Our study suggests that parents' consent to an autopsy for altruistic reasons, but may also experience psychological benefit such as finding purpose to their suffering. Parents reported little-to-no decision regret and provided some recommendations for improving the autopsy consent process. Combined, our findings indicate that autopsies should be considered more regularly for children with HGG.

A diagnosis of high-grade glioma (HGG) in a child is devastating. In particular, diffuse midline gliomas (DMG) harboring the H3K27M mutation present grave challenges for families and clinicians.[1] Even with significant improvements in medical technologies, the prognosis of children with HGG remains poor.[2] For DMG, the median overall survival ranges from 8 to 14 months,[3,4] with 90% of children dying within 2 years of diagnosis.[5] Palliative radiotherapy is the sole standard treatment typically offered, which only prolongs survival for a few months.[6,7] To date, chemotherapeutic strategies offered through clinical trials have not had a significant impact on patient outcomes.[8]

DMGs are diffuse by definition and located within a largely inoperable area of the brainstem.[9] Until recently, biopsies have been rarely conducted, limiting the biological material available for preclinical research. This is largely due to the previously unproven safety and feasibility of conducting a brainstem biopsy, and fine balance between risk versus benefit to the patient/family.[10,11] However, innovative neurosurgical approaches and techniques (eg, stereotactic transcerebellar biopsy, frame-based stereotaxy) allow for biopsies to be performed relatively safely,[12–14] with the potential to identify actionable molecular targets.[15] However, as biopsies carry risks for patients with a lack of established benefit, they are not yet standard practice in many centers.[16] Liquid biopsies, in which circulating tumor cells are collected from the blood, are a promising noninvasive technique. However, they are not yet in routine clinical use as analytical validity and clinical utility is still being determined.[17,18]

With an urgent need to identify effective treatment strategies, tumor samples acquired postmortem are a precious resource that facilitates investigation of novel agents. Autopsies provide abundant tissue for genomic profiling and cell culture for novel drug testing.[19] Research suggests that postmortem tumor collection from children diagnosed with DMG is feasible and provides tissue suitable for extensive molecular studies.[10,20,21] We have shown that samples from DMG autopsy successfully yield cultures in approximately 40% of cases.[22] Moreover, primary cultures obtained from autopsy samples are more likely to engraft in in vivo models than cultures from biopsies.[22]

Despite the potential benefit of postmortem tumor donation for research, organizing the collection of a child's tumor postmortem is complex. It can be challenging for clinicians to obtain informed consent as parents are highly distressed at their child's end-of-life.[23] Clinicians may also be reluctant to raise the topic of an autopsy with parents, and have difficulty deciding on optimal timing due to differing preferences.[24,25] Clinicians are morally bound by the principles of "beneficence" and "non-maleficence,"[26] which brings ambiguity into whether an autopsy should be conducted. Several small studies have investigated parents' experiences of, or perceptions about, consenting to an autopsy for their child diagnosed with cancer.[20,24,25,27] These studies suggest that most parents would consent to an autopsy should they have given the chance and that parents who do consent to an autopsy typically experience little decision regret. However, these data are largely from the United States or Canada and were conducted before biopsies became more commonly integrated into practice for children with a brain tumor. To our knowledge, no research has published on the Australian perspective in the current era. Therefore, we sought to understand Australian parents' recent experiences of donating their child's tumor via an autopsy. Specifically, we aimed to understand parents':

1. perceived benefits and burdens of donating;
2. recommendations for improving donation consent discussions; and
3. regret about deciding to donate their child's tumor.

Our overall objective was to ascertain whether autopsies could be considered as standard practice for children with HGG, and how to optimize consent procedures for families.

Materials and Methods

Procedure

We received ethics approval to conduct this study (HREC/12/HNE/111). We enrolled families through the "High Through-put Robotic screening Of Diffuse pontine glioma Study" (HoTRODS) from 2012 to 2020, across 5 Australian hospitals. The primary aim of HoTRODS was to harvest DMG specimens and culture new DMG cell lines as neurospheres in order to develop new treatment strategies. Pediatric patients were eligible if they had a clinical and radiologic diagnosis of diffuse brainstem glioma, or DMG not involving the brainstem. We expanded eligibility in 2016 to include HGG in any location due to parental demand. Prior to the child's death, clinicians asked parents to provide consent for an autopsy and tumor donation (to be conducted within 48-hour postdeath). Consent could be signed before or after the child had died (but prior to autopsy). We advised the recruiting health professionals to discuss the option of

participating in HoTRODS at a time, and in a manner, that they felt was most appropriate to each family. We suggested a good opportunity to discuss donation was when there was evidence of tumor progression and arrangements were being made for end-of-life care. We advised health professionals that discussing the autopsy with families as soon as there was evidence of tumor progression allowed for practical arrangements to be put in place that may minimize stress on the family. However, the timing of this was left to the discretion of the clinician. We strongly recommended that these discussions be made in consultation with the child's regular social worker and/or psychologist. The clinician provided parents with a study information sheet (and an age-appropriate information sheet for the child, only to be shared if the parents wish to share it with them) which outlined the purpose of the study and what is involved. Through the research study information statement, autopsy consent form and discussion/s with health professionals, parents were informed about the purpose and value of HoTRODS, what consenting to HoTRODS would involve, the logistics of the autopsy (eg, timing, removal of skull for examination), and the voluntary nature of the study. Parents were advised that the aim of the study was to generate a tissue bank as well as laboratory models (in vitro and in vivo) in order to perform drug screening and identify novel treatments.

Six months after the donation, we mailed parents a single purpose-designed survey. We did not specify whether one parent needed to respond or both (if applicable) could respond together. Contacting bereaved parents at least 3–6 months following the death of their child is recommended in the bereavement research field.[28–30] Parents could return their survey via the provided pre-paid envelope or via email. Aligning with other bereavement research, we did not conduct follow-up calls for missing surveys in order to minimize potential burden on parents.[29] Along with the survey, parents were also send a response card on which they could indicate whether they wanted to receive a report about their child's tumor. The report included the results of the pathological examination of the tumor, whether the tumor was successfully harvested for research, whether tumor cells were able to be successfully grown in the laboratory, and whether there was sufficient tumor material remaining for storage for future, ethically approved research. Parents were also able to opt in to receive an annual newsletter with information on the progress of the research program. In each case, the patient's treatment prior to autopsy was recorded and annotated alongside the pathology specimen. Part of our ongoing research program is to compare the genomics of the autopsy specimens with the genomics of specimens collected by biopsy at diagnosis in order to better understand mechanisms of resistance to radiation and to develop new treatment pathways. However, this is beyond the scope of this manuscript.

Survey

We used open-ended questions to ask parents why they decided to consent to the tumor donation, their hopes for their family or others, any perceived benefits or burdens, and any recommendations to improve discussions around the autopsy (Supplementary Appendix A). We also measured parents' regret about deciding to donate their child's tumor via the validated "Decision Regret Scale."[31] The Decision Regret Scale includes 5 statements that measure distress or remorse after a healthcare decision. Respondents rate each item along a 5-point Likert scale ranging from "*strongly agree*" to "*strongly disagree*." At this 6-month survey, parents also indicated whether they would like to receive the autopsy test results and/or annual research updates. The autopsy test results were communicated to the family by written report provided by the treating clinician, either in person or by mail, according to the parents' preference.

Analysis

We used NVivo (Version 12, QSR International) to conduct a directed qualitative content analysis. Two authors (E.R., C.W.) coded all responses independently to ensure rigor. E.R. and C.W. discussed any discordant coding and revised the coding structure appropriately. We used this analysis approach given the small sample size and limited responses.

We analyzed quantitative data descriptively in Microsoft Excel. In accordance with the Decision Regret Scale User Manual, we converted scores to a scale of 0–100. A score of 0 indicates no regret and 100 indicates high regret.[32]

Results

Fourteen families participated in HoTRODS. We were unable to determine a study consent rate as families were typically only introduced to the study if the clinician felt that they would consent or if the family approached the clinician to participate themselves. Of these, 11 families completed the survey (76%, Figure 1). Most children (9/11) were diagnosed with DMG. Children/adolescents were diagnosed between 0 and 20.5 years of age (median = 6.2 years) and died between 1 and 11 months after diagnosis (median = 8 months).

Perceived Benefits of Participation

Parents' reasons for consenting to the autopsy appeared to align with their hopes for their family and their hopes for future children. All parents expressed an altruistic reason for deciding to donate their child's tumor postmortem—they wanted to help future children diagnosed with cancer and their families by helping researchers/scientists to find a cure. They hoped that donating their child's tumor would contribute to finding a *"treatment protocol that is not just a delay tactic"* (ID:1) for children around the world. Donating provided parents with a sense of hope for the future and helped them to feel that there was a positive to arise from their suffering.

> "We did not want her death to be for nothing. If she can help in any way to find a cure, that would be amazing. ID:10"
> "Our hope is that there will be time when no other family has to experience the suffering we have.

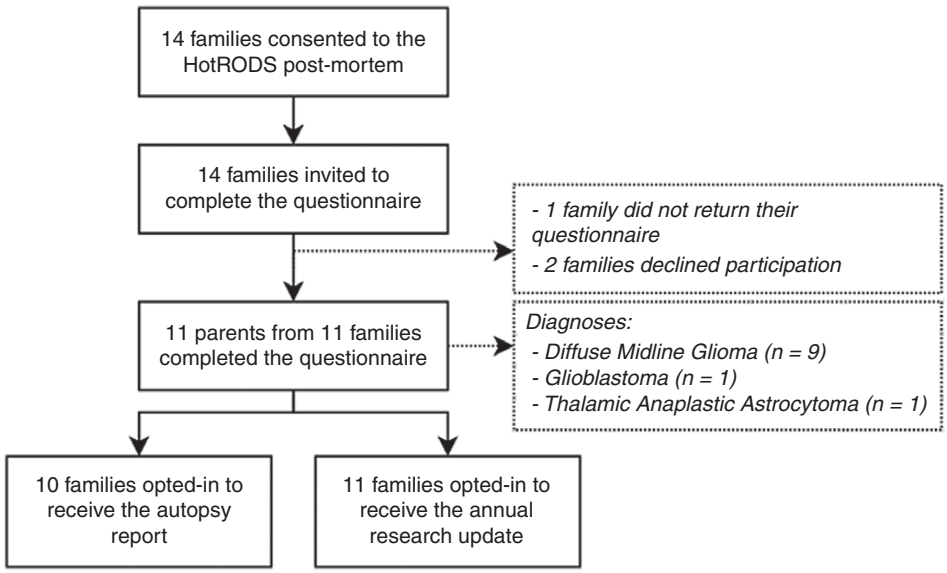

Figure 1. Study participation.

Finding a cure is the answer and that can only be achieved through research. ID:6"
"There can only be positive things to come from continuing to offer anything we can. Doing nothing gives no hope. ID:2"
"To spare others the horror of watching your child die...To make a difference, create the silver lining, create hope... ID:1"

Parents' desire to contribute to research was affirmed by the fact that all parents requested to receive annual research updates for the study. Although most parents described the benefit of donating their child's tumor was to "*assist in furthering scientific understanding of this horrible tumor*" (ID:7), some specified that the benefit of donation was irrespective of the present research studies' outcomes or progress in therapeutic advancements (ie, the direct contribution of their child's tumor in developing a cure).

"Knowing that we have attempted to assist the research as best we can. ID:7"
"Something positive was that we were given a chance to maybe help other kids in some way. ID:9"

However, 2 parents expressed that perceived benefits would be less if the tumor could not be grown in the laboratory and was not found to be *"useful"* in finding a cure.

"I sincerely hope that the tumor survives and can be grown for research. I think it would be hard to hear if it was not a success. ID:2"
"We'll feel some disappointment if his tumor is not useful to this study, but we won't regret it as it was done postmortem. ID:6"

Some parents described psychological benefit from the autopsy, in addition to, and because of, the altruistic nature of the donation.

"It would give us comfort knowing her body was buried without much or all her tumor that she so hated. ID:8"
"I don't hold religious beliefs, yet somehow I feel that a small part of her has been preserved. I know it's not her, but it's like a tiny bit lives on. ID:2"
"I hope that we can find peace in mind that our boy is helping others with the research they need from his tumor. ID:5"

Parents also perceived benefit from finding out more information regarding their child's tumor. The desire to find out this information was affirmed by 10 of the 11 parents requesting to receive the child's autopsy report.

"I am actually interested in the specific details of [child's name] tumor so I can try and understand and wrap my head around what happened. ID:10"
"Participating in this study was good because we [will] clearly understand what he died from by investigating post mortem—"bleeding or dead tissue." ID:11"

Two parents also expressed benefit in making a decision that they felt their child would have wanted.

"I believe that she would have wanted to help others with her cancer. If our pain can in any way help others, then we would like to share what we can to help find a cure...We hope only that our loss may help others. ID:3
It was my son's wish to assist other humans. He had no use for his brain when dead! ID:11"

Perceived Burdens of Participation

Parents showed minimal regret regarding their decision to donate their child's tumor, with 7 parents reporting no regret at all (Figure 2).[33,34] All parents strongly agreed that the decision "*was the right one*," which was reinforced by all parents reporting that they would make the same choice if they had to do it again ($n = 9$ "strongly agree," $n = 2$ "agree").

Although parents reported minimal regret, a few parents expressed some burden from consenting to the autopsy. Two parents shared that it was distressing that their child's body was kept overnight in the hospital mortuary. Another parent described that, in hindsight, their child's body was taken away from them too quickly.

> "How quickly our child had to be taken away from us. We were given a few hours before she was taken but in hindsight that was not enough. ID:3"

Two parents mentioned that it was challenging to manage the organizational aspects of the donation, including encountering uncertainty regarding how to manage autopsy on a public-holiday or weekend to align with the 48-hour window needed after the death. They indicated that potentially not being able to donate due to a pathologist being unavailable weekends was a distressing thought.

> "There were issues with organizing that post mortem study on a public holiday—the day after [child name] died. I was very stressed when I knew we only had until lunchtime to get [child's name] tumor to the hospital. I felt like we were the only ones pushing for the sample to make it in time. There was no urgency on that morning for the staff and it was a horrendous feeling knowing we possibly missed the cut-off point. ID:9"

Recommendations to Improve Consent Discussions

Parents provided several suggestions on how to improve the autopsy discussions. Parents expressed that a lack of information caused them distress and worry. They suggested that parents should be given more information about why the tumor sample was needed, what the sample would be used for, the autopsy itself, and what would happen shortly following their child's death. There also appeared to be some minor confusion about the size of sample/incision which indicates a need for clearer information regarding this.

> "I suggest to be open and honest upfront with the journey. I guess you cannot kill hope…To know the options, possibilities and outcomes. ID:11"

Two parents felt that they needed to advocate for the autopsy and drive the information exchange, rather than the clinician freely providing this.

> "Our oncologist approached us in an appropriate, sensitive way. However, in terms of the logistics following our son's death in relation to harvesting the tumor, I felt we had to ask questions to find out how this would occur, e.g. How long could we keep his body before they needed it to access the tumor. We also found out that if he died at a time when there was no pathologist [available], the tumor would not be part of the study. I found this distressing. Perhaps some written information to give to parents once they agreed to the study. Many of questions came to me as my son was approaching his death and all the logistics around death were in our face…Just provide more information about the process. ID:6"
>
> "I know my original "picture" of the autopsy didn't help initially...My mind was settled a little to hear [how] the procedure was conducted…. ID:2"

One parent felt that reassuring parents that their child was not just a *"nameless number"* and that study updates would be available might "*help them choose [to participate]*" (ID:4).

Parents also provided suggestions regarding how to improve the delivery of information. They suggested having the support of a social worker during the consultation and for a debrief postconsultation. They also suggested that having another parent who had experienced the process describe their experiences might be beneficial. One parent felt that the autopsy should not be discussed in the first postdiagnosis meeting. However, another parent suggested that consent be obtained as early as possible (even prior to tumor progression), with the opportunity for withdrawal at a later stage.

> "The communication about the post mortem trial was appropriate, I just wish it had not been raised at the first post-diagnosis meeting with the oncologist—I wanted to talk about treatments/cures at that point. ID:7"
>
> "Have a social worker brief the family that the discussion is coming and have them there for the discussion, and a debrief later—Some doctors are better than others at talking about sensitive information. Sometimes it feels like a sledgehammer. ID:9"

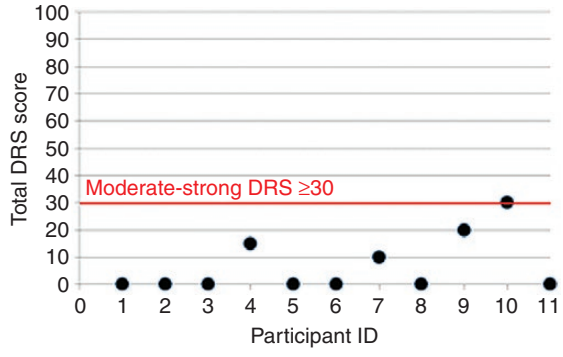

Figure 2. Parents' Total Decision Regret Scale (DRS) scores. We considered ≥30 for the total DRS as "moderate–strong regret," in line with previous research in the field.

Discussion

Postmortem tumor donations of HGG provide an opportunity to investigate tumor biology and novel therapeutics in a way that has not been previously possible. Improved access to tumor samples has already led to the identification of important genomic mutations, providing greater insight into potential treatment options.[3] However, an autopsy can be challenging for the parents of a child who has just died from cancer.

In our study, parents chose to donate largely for altruistic reasons, but also to have the tumor removed from their child's brain, and to feel that there was purpose to their families' suffering. Finding meaning from tumor donation was a benefit reported by parents in our study and previous studies.[10,20,27] Our parents also perceived that they would benefit in finding out more about their child's tumor. Parents' desire for information about their child's tumor has been reported as a common facilitator for consent.[35] Combined, these findings suggest that consenting to an autopsy is not purely an act of selflessness, or altruism, as previously suggested.[8] Consenting may be a type of "reciprocal altruism," where parents experience benefit from their donation such as finding purpose to their suffering.[36] This is important information for clinicians to consider—offering an autopsy may not purely be to facilitate research but may be of psychological benefit to parents following the death of their child. Indeed, the broader literature suggests that organ and tissue donation acts as a coping strategy for some bereaved parents.[37,38] Future research should consider the role of consenting to an autopsy on parental adaptation in bereavement.

Our data indicate that parents strongly believed they had made the right decision to consent to the autopsy. Parents' responses suggest that they may experience distress if there are barriers that prevent an autopsy from taking place. Although we were unable to report on the response rate for the HoTRODS study, previous studies have reported that over 40% or more families consent to an autopsy if asked.[25] However, many families are not given the opportunity to consent.[10,24,39] Indeed, 2 parents/families in our study indicated that they had to advocate for postmortem tumor donation, rather than this information being proactively given by their clinician. Studies have indicated that most bereaved parents report that they would have been willing to donate their child's tumor if it had been discussed with them.[10,20,24,25] Health professionals may choose not discuss an autopsy because of uncertainty regarding the benefit of the investigation, perception that the family is too distressed,[10,24] or their lack of training on how to communicate with families about autopsies.[26] Although one study has indicated that parents may deny consent due to emotional distress,[20] previous literature[27] and our study found that parents' reported little decision regret. Strikingly, parents in our study reported less regret about their decision to donate than parents who consented their child to a Phase III clinical trial.[33] Future research should consider exploring Australian health professionals' attitudes toward autopsies in more depth, and any facilitators and barriers to consenting families in a sensitive and family-centered manner. Attention needs to be paid to improving resources to facilitate the consent procedures, recognizing the potential for both parent distress and psychological benefit.

Although parents in our study showed little regret, they felt that receiving further information regarding the autopsy and donation may have improved their experience. A lack of information for families regarding the procedure/logistics has been reported in previous research.[24,27] Ensuring that families understand logistical considerations, such as limitations around location of death (ie, that the deceased need to be in close proximity to the hospital to permit the autopsy to occur), is integral, given that location of death has a significant impact on parents' grief.[40] Despite the challenging nature of these conversations, parents should be sensitively informed about the opportunity for tumor donation, research protocols, and the process of the autopsy.[26] Parents also want to know how the autopsy may potentially help other children, how it may help them learn about their child's tumor, and how it may help their child's clinician.[25] A study of 297 families in the United States who were asked to donate a deceased adult family member's brain for genomic research found that unwillingness to donate was associated with (1) unwillingness to donate their own tissues for research, (2) concern with for-profit use of donated tissue, (3) feeling squeamish about tissue donation, and (4) discomfort with consenting even if the patient had signed a donor card.[41] Providing more information about the purpose and use of tumor donations may increase comfort with donations, and further reduce decision regret.[42] This is especially important for culturally and linguistically diverse families who are at increased risk for decisional regret regarding treatment for their child with cancer.[43] Future research exploring what parents and young people understand about autopsies, and what facets of information cause additional distress, may illuminate areas for intervention.

As with any procedure, children should be involved in decision-making if they have the capacity, and if they so wish, as mandated in the "Convention on the Rights of the Child"[44] and the "Charter on the Rights of Children and Young People in Healthcare Services in Australia."[45] In our study, no parents spontaneously mentioned that their child needed more information but we are uncertain whether any parents provided their child with the child information sheet. We did find that 2 parents in our study and 2 children (of 10 families who consented to an autopsy) in another study[20] indicated that the young person wished to donate their brain, highlighting the need for more child/adolescent patient information and a family-based approach to decision-making.

In our study, parents provided mixed advice on when the first discussion about an autopsy should occur. One parent felt it should be delayed until any treatment discussions had shifted to only end-of-life care. This perspective was also shared by 73% of parents in Alabran et al.'s (2013) study.[24] Parents in that study felt that the discussion/s regarding the autopsy should not be done after death as it does not allow time to discuss the idea or make practical arrangements.[24] This closely aligns with the findings by Wiener et al. (2014), who found 77% of parents felt that discussion was appropriate when death seemed near,

with few agreeing it should be done after the child died.[25] In contrast to these 2 studies, one parent in our study felt that the discussion should occur as soon as possible, even prior to tumor progression, as part of standard practice when a child is diagnosed. Our findings and the literature indicate that timing for discussions may need to be determined on a case-by-case basis. Although many families will prefer this discussion near the end-of-life, this may not suit all. Clinicians should also be mindful of the potential incongruence between when health professionals and parents accept that cure is no longer possible, and where possible, align with the needs and preferences of each unique family.[27] Regardless of timing, the involvement of a social worker or psychologist in discussions regarding an autopsy is warranted. It may also be appropriate to involve other professionals such as child life therapists or chaplains from the families' faith.[20,26] Providing families with anticipatory guidance regarding an autopsy may also prove beneficial when making complex decisions such as postmortem tumor donation.[46]

Although our study contributes to the minimal literature on parents' perspectives of postmortem tumor donation, it is not without limitations. We expanded our inclusion criteria from DMG to "*a HGG in any location*" due to parental requests for participation. However, we still only recruited 14 families to HoTRODS, 11 of whom completed the survey that this manuscript reports on. We did not record the number of families who were approached to participate in HoTRODS and declined, although anecdotally this was very few given that most parents proactively requested to donate their child's tumor. In addition, we did not collect further family sociodemographics, which would have provided greater context to our findings. Although we provided clinicians with clear study eligibility criteria and guidelines/recommendations for discussing an autopsy with the family, we left the decision to approach a family to the discretion of the clinician. We also did not capture the demographics of respondents, or whether the survey was completed by one or both parents. As such, we are unable to determine whether there were differences found between mothers and fathers. The eligibility of our study and study design also limited involvement from non-English speaking families. Although waiting 3–6 months postbereavement is recommended when conducting research with bereaved parents,[28–30] this may have resulted in some hindsight bias.

Clinical Implications

Our findings indicate that parents are often willing to consent to an autopsy should they be approached. Using the feedback from parents in our study, combined with the literature and our clinical expertise, we propose several tangible suggestions for clinicians to improve the practice of approaching families for postmortem tumor donations:

- The decision to discuss/not discuss a postmortem, and timing of when to do so should be made in consultation with the family's regular social worker and/or child psychologist.
- Provide parents with a clear understanding of the logistics of the postmortem, including the procedure, where it takes place, timing, and where the child's body will be. Parents should be made aware of the timing of the autopsy following their death.
- Provide parents with a clear understanding of what information they will have access to whether they consent to the postmortem, including when this information will be available. This information should be communicated in a sensitive manner, through both written and face-to-face formats.
- Written information should be delivered at a Grade 8 readability or less, be well-presented under logical headings, and be supplemented with at least 2 face-to-face conversations. The use of visuals and infographics may be especially useful for families from a culturally and linguistically diverse background.
- Families should be provided with the opportunity to be updated of the research progress.
- Earlier discussion of the tumor donation will allow practical arrangements to be put in place to facilitate the procedure with less stress on the family.
- There may be rare occasions where it may be appropriate to discuss the possibility of tumor donation with the patient themselves. There are no definitive rules to suggest which children should be told about the option of tumor donation, and this must be decided on a case-by-case basis. It is important to take into consideration the child's age, maturity, and emotional functioning. Parents/guardians must always be consulted before discussing the concept of tumor donation with their child. Even if a parent discusses death and dying with their child, this does not mean that they would want to or should discuss postmortem tumor donation.
- If it is decided to discuss tumor donation with the child, then a parent, social worker, and/or child psychologist should always be present to support the child during the discussion.

Conclusion

Our study contributes to an important field that will hopefully have a significant impact on the survival rates for children with HGG. The minimal regret and potential psychological benefit also suggest that postmortem tumor donations should be considered more routinely for children with HGG, and barriers to routine donations need to be addressed.

Supplementary Data

Supplementary data are available at *Neuro-Oncology Advances* online.

Keywords

childhood cancer | DIPG | glioma | qualitative| tumor donation

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