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Elective intensive care unit admissions for organ donation in patients with terminal brain glioma: Case report

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Abstract

Despite being eligible, only 26 patients with primary brain cancer became organ donors from 2009 to 2018 in Australia. We describe two patients with high grade gliomas who successfully donated their organs after obtaining first-person consent in the outpatient setting by careful multidisciplinary planning and an elective intensive care unit admission for organ donation. Barriers and facilitators were examined based on these experiences and suggestions for future practices are explored. The recommended practices include: 1. Systematic incorporation of organ donation into advance care planning. 2. Integrating organ donation organisation coordinators into advance care planning. 3. Standardization of donor care and clear communication and collaboration between treatment teams. 4. Support and involvement of the medical treatment decision maker. 5. Identification of clinical triggers for admission to hospital and intensive care unit. These two cases illustrate that with careful coordination and involvement from a multidisciplinary team, successful organ transplantation outcomes are possible.

Keywords

Organ donation, transplantation, oncology, palliative care, consent

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Introduction

Active malignancy is generally a contraindication to organ donation; however, The Transplantation Society of Australia and New Zealand guidelines stipulate that donors with primary central nervous system malignancies may be eligible.[1] Despite this, only 26 deceased organ donors had primary brain cancer from 2009 to 2018 in Australia.[2] This accounts for 0.2% of patients who died from brain cancer and 0.6% of total deceased organ donations.[3] There is growing evidence that organ donation is safe in this group with a very small risk of cancer dissemination, except in those with risk factors such as a WHO grade IV tumours, and procedures leading to disruption of the blood-brain barrier such as ventriculoperitoneal shunts and extensive craniotomies.[4–6]

Increasing the pool of potential donors is crucial with 1850 patients waiting for transplantation in Australia in 2021, far exceeding the 421 donors and 1174 recipients in the same year.[7] Approximately 2% of patients who die in hospital can be considered for organ donation but only 40% of these patients become donors with Australia ranked 16th in the world in donation rates, with 21.6 donors per million of the population.[8] One way to improve the donor pool is to increase transplantation rates from under-utilized sources including patients with primary brain tumours. Not only could such an approach benefit recipients, but this may also

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offer patients with terminal brain cancer a chance to provide a meaningful act of altruism upon their death.

Although patients with high grade gliomas are currently able to register as an organ donor via the Australian Organ Donor Register (AODR), this is not legally binding and formal consent is required at the time of donation, usually from the donor's next of kin. The consent rate from the next of kin in this context in Australia is only 58%.[9] There is currently no formal process in place for prospective, pre-emptive, and binding consent for donation by patients with terminal brain cancer – whereby they can be actively involved in the decision making around their own organ donation.

We describe two cases of patients with high grade gliomas who consented to organ donation pre-emptively in the outpatient setting of a tertiary metropolitan hospital. This was coupled with careful multidisciplinary planning and an elective Palliative Care admission with subsequent transfer to the Intensive Care Unit for organ retrieval in the terminal stage of their malignancies. To our knowledge there have been no previous cases reported in the literature. Barriers and facilitators to the process were examined based on experiences gained from these two patients after a formal review of the medical records and discussions with the involved treating physicians.

Cases

Case #1

A patient with a grade 3 anaplastic astrocytoma donated multiple organs to five recipients. A 33-year-old full-time electrician was diagnosed with a right temporal mass in May 2014 after presenting with headache. He underwent a craniotomy and tumour de-bulking which revealed a WHO grade III astrocytoma which was IDH-R132H and ATRX mutation positive.

He received standard management with brain radiotherapy followed by temozolomide chemotherapy. He was working full time until he required further tumour debulking in April 2018. Pathology was unchanged. He then received two further lines of palliative chemotherapy without response.

He was eventually admitted to hospital in May 2019 with behavioural changes secondary to tumour progression. Systemic anti-cancer therapy was discontinued, and he was referred to the palliative care team. The patient was registered on the AODR and expressed an intent to donate his organs. The treating team together with the patient's wife contacted Donate Life, an external Organ Donation Organisation (ODO), requesting more information about the possibility of organ donation.

Following his discharge home, an outpatient, multidisciplinary medical review was arranged and attended by the patient, his wife, an intensive care physician with expertise in organ donation, a palliative care physician, and a Donate Life Coordinator. A comprehensive care plan and advance care directive was constructed. The need for pre-emptive invasive treatments such as intubation and mechanical ventilation, as well as other pre-transplant investigations were outlined. The process for assessing medical suitability and the two different donation pathways of Donation after Brain Death (DBD) and Donation after Circulatory Death (DCD) were explored. In actively choosing to proceed on a donation pathway, his venue of end-of-life care would necessarily need to be in hospital instead of at home. His care around death would be a departure from the usual practice incorporating the Care Plan for the Dying Person, with a focus on symptom control during the dying process, with potential life prolongation and life support for organ retrieval.[10] The patient understood agreeing to this could potentially result in prolongation of suffering at the end of his life.

Careful consideration was given to potential scenarios of clinical deterioration in which the patient would need to be re-admitted to hospital. Triggers for an elective admission to the palliative care unit were explored including loss of mobility and uncontrolled symptoms such as pain. A plan accessible to all treatment team members was documented in the electronic record, and communicated to his general practitioner, the community palliative care team, and his local hospital's emergency department. Potential triggers for intensive care unit (ICU) admission once in hospital were also explored. The patient consistently expressed a strong desire to donate his organs as part of his end-of-life care plan.

One week later the patient was electively admitted to the palliative care unit from the community with worsening headache and vomiting. As the care of a potential organ donor was outside the usual scope of practice of a palliative care unit, there was significant support and education provided by the intensive care team. As planned, he was subsequently transferred to the ICU after significant deterioration in his Glasgow Coma Scale (GCS).[11] Mechanical ventilation was commenced, he fulfilled the clinical criteria of brain death and this was confirmed by nuclear medicine single-photon emission computerized tomography. Circulatory support was continued to ensure adequate perfusion of his organs. After family visitation he underwent surgery for organ procurement via the DBD pathway. He successfully donated his heart, right lung, liver, pancreas and kidneys to five separate recipients.

Case #2

A patient with a high-grade glioma donated multiple organs to five recipients and then his whole body for research. A 35-year-old retail manager presented in May 2012 with generalised seizures due to a right parietal tumour and underwent a craniotomy and macroscopic debulking. This revealed a WHO grade III astrocytoma that was negative for 1p/19q co-deletion and was IDH 1 mutant.

He received concomitant radiation with temozolomide with durable control of his tumour. In 2017 he underwent

further debulking and subsequently received two further regimens of chemotherapy. He was then introduced to the palliative care team as part of a standardised early palliative care clinical trial.

He first broached the subject of organ donation at a palliative care outpatient clinic appointment in September 2019. A subsequent appointment with a Palliative Care physician, ICU physician and Donate Life ODO coordinator was organised to discuss this in more detail with his partner in attendance. Based on our experiences with Case #1, a similar discussion was held, and plans were implemented regarding triggers for admission to the palliative care unit and the ICU, and pertinent details were shared with the involved parties.

Several weeks later, he was admitted to the palliative care unit from the community when his functional state deteriorated. A trial of dexamethasone led to no meaningful improvement. Clear parameters were set in the palliative care unit to escalate care and trigger a medical and intensive care review. After an acute drop in his GCS, a Medical Emergency Team call was activated and he was transferred to the ICU, with his carers in attendance.

Mechanical ventilation and circulatory support were commenced to ensure adequate organ perfusion. Brain death was not immediately confirmed as brain stem reflexes were maintained. A DCD pathway was therefore followed, whereby death is confirmed using cardio-respiratory criteria following planned withdrawal of life-sustaining treatments rather than brain death. The patient died within 30 min and successful organ procurement subsequently occurred. The patient's heart, lungs, left kidney, corneas, and multiple tissues were donated to five live recipients, and his whole body for research.

Discussion

These two cases demonstrate it is possible to prospectively consent and carefully plan for organ retrieval in patients with terminal primary brain cancers. Early and respectful advance care planning and pre-emptive, proactive management of these patients prior to their death increased the likelihood of successful donation. There is clearly a need for further research into this area, and we would like to bring these cases to the attention of the oncology community and explore five key facilitators from our experience.

Systematic incorporation of organ donation into advance care planning discussions, including the correct timing of these discussions

The objective of advance care planning discussions with patients is to establish an individual's beliefs, values and preferences in relation to future care decisions.[10] In cases where organ donation is potentially feasible, we believe advance care planning could incorporate an exploratory, respectful discussion about organ donation as part of end-of-life care. If deemed appropriate, a referral to an organ donation coordinator can be facilitated. To our knowledge there are no studies or publications examining prospective consent to organ donation in patients with advanced malignancies.

Studies have shown that patients respond favourably to discussions about rapid tissue donation (RTD), which involves the procurement of tissue within 2–6 h of a donor's death. Over 85% of patients approached to consent for their bodies to be involved in a post-mortem RTD programme expressed interest with the main motivating factors being to advance research, to find a cure for the disease, to help others, and out of gratitude for the institution.[12–14] In contrast to the positive attitudes of patients, surveys show that healthcare professionals are less likely to ask their patients to participate in RTD programmes, with reluctance to approach the subject of tissue donation as one of the most significant barriers.[14]

Evidence for the preferred timing of such discussions is lacking. McIntyre et al reported that patients preferred discussing tissue donation with their regular treating physician, and later in the trajectory of their illness.[13] In contrast, another study found that patients preferred their treating clinician not be the one to hold discussions about RTD, due to perceived conflicts of interest.[14] One approach, based on our experience, could be to present written or online information to selected patients screened for possible eligibility, after an early introduction to advance care planning. Formal discussions about organ donation could then progress during follow up discussions or if the patient expresses an interest, in the setting of a strong therapeutic relationship and with a carer or support person present.

Integrating organ donation coordinators into advance care planning

We promote involvement of an ODO for further planning and discussion about organ donation if the patient is receptive to the concept. Donation coordinators serve to evaluate donors, obtain consent, coordinate activities necessary for organ retrieval and provide support for donor families.[15] In Australia, donation coordinators are generally specialist registered nurses employed by a central state-based ODO.

The availability of donation coordinators enhances conversion rates for organ donations.[15,16] Several studies have shown significantly higher consent rates and improvement in the experiences of the donor's family after implementation of dedicated donation coordinators within their institutions.[17,18]

The OTA Best Practice Guideline for Offering Organ and Tissue Donation in Australia recommends routine referral to the Donate Life coordinator in the Intensive Care Unit and Emergency Department with planned end-of-life care.[19] We advocate for a similar referral process for patients with terminal primary brain cancers requesting organ donation, but to commence this process earlier in their disease trajectory.

Standardization of donor care and clear communication and collaboration between treatment teams

Standardisation of organ donation planning, and multi-disciplinary team involvement is crucial. We support consistent collaboration between the treating oncologist, donation coordinator, palliative care physician and ICU physician. This team can ensure medical and psychosocial suitability, agree on the roles and responsibilities of the different team members, and develop a personalised care plan. Screening investigations of the donor to exclude distant metastatic disease is required and live donor screening protocols[20] could be applied particularly when existing risk factors such as prior ventriculoperitoneal shunts are present.[1] It would be appropriate for either the medical oncology or palliative care physician to assume a 'lead role' in the overall care of the patient, given existing clinical relationships and disease-specific expertise.

Clear communication of the patient's wishes, and of the individualized care plan to other healthcare staff is also important. This would include external care providers such as general practitioners, community palliative care services, case managers, local ambulance services and emergency departments. Establishing working relationships between oncologists, palliative care physicians and ODO coordinators is likely to drive broader awareness and a positive culture of donation.

It is also possible that organ donation could be planned for a patient undergoing voluntary assisted dying, in which case a VAD clinician and coordinator would need to be part of the treating team. The feasibility of organ donation following VAD in an Australian context has been explored in a recent article by Bollen et al.[21]

Support and involvement of the medical treatment decision maker

Consultation and communication with the medical treatment decision maker, and wider family ensures that the patient's wishes can be respected and followed.

In Australia, there is no first-person authorization to legalise donation decisions, meaning the patient's preferences can be over-ridden and the ultimate decision on consent is made posthumously by the substitute decision maker or the next-of-kin.[22,23] Multiple studies show that knowledge of the donor's preferences is a leading predictor of consent.[24–26] In a study by Siminoff et al.[26] it was found that having knowledge of a patient's preference to donate increased the likelihood of donating with an odds ratio (OR) of 6.90, and having enough information about the patient's wishes increased satisfaction with their decision to consent with an OR of 3.32. In addition, one of the leading causes of withdrawal of consent is conflicting family opinions surrounding donation.[27,28] These studies suggest that it is important to involve not just the medical treatment decision maker but also the wider family. Studies show that describing the processes involved, and the benefits of donation can reduce or improve a family's experience of grief.[29,30] In both of our cases, there was strong involvement and advocacy from the medical treatment decision maker from the beginning of the planning process.

Identification of clinical triggers for admission to hospital and ICU

There are various symptoms that herald terminal deterioration in patients with high-grade glioma – such as worsening headache and nausea, new neurological deficits, and alterations in mental state or functional deterioration.

Close communication with the patients' main carer and the community palliative care team is required to establish clinical triggers to prompt hospital admission for intubation and circulatory support and planned organ retrieval. A formally documented action plan developed by a multidisciplinary team should be available widely to families, community health providers and hospital departments. One advantage with this pathway compared with patients that present unexpectedly with devastating brain injury after a motor vehicle accident or stroke is that patient's caregivers have had time to discuss organ donation with the patient.

The overall process of organ procurement is highly complex and must include clinical expertise, health-care team education and streamlined protocols surrounding organ recovery, distribution and transplantation. It involves medical optimization of a critically ill patient, decision to withdraw life-sustaining therapy and declaration of death, and optimization of end-organ function as well as support for family members of prospective donors. There are well-established institutional guidelines for management of patients being considered for both the DBD and DCD pathway.[31–33]

These guidelines can be utilised in patients prospectively consenting to organ donation. However, one key difference is that terminal high-grade glioma patients may present from a palliative care ward or community palliative care service, where the emphasis of care is supportive rather than life preserving, and emergency management is infrequent unless there are clear directives. Education, training and support of palliative care nursing staff caring for these unique patients to underscore the importance of clinical monitoring and early recognition of terminal deterioration will be required.

One key consideration is the organisation of the palliative care services within the health service. Although some hospitals have on-site palliative care units, others are off-site where access to other specialties and emergency care facilities are limited. Patients who are being considered for organ donation must be located at sites where access to rapid

emergency care and ICU support is available. Management of deteriorating patients with advanced brain tumours must be pre-emptively discussed with the medical treatment decision maker. There is a need for specific medical criteria which when met should result in urgent ICU assessment – these clearly defined criteria need to be based on empirical evidence and developed by an expert panel.

Conclusions

These two cases illustrate that successful organ transplantation in carefully selected patients with advanced primary brain cancers is possible with advance care planning, careful coordination and clear communication between a multidisciplinary team involving palliative care, intensive care, medical oncology, transplant services and external community care providers.

Further research is required to enable more terminal glioma patients the opportunity to donate their organs. We advocate for the development of an optimal care pathway for first-person pre-emptive organ donation consent and planning underpinned by a multidisciplinary collaborative approach involving the patient and their medical treatment decision maker. These guidelines should be evidence-based and should be developed with the input of patients and their families.

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Author contributions

All of the listed authors:
- Made substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND
- Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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