

CASE REPORT

Drowning in the desert: family denial of brain death

Mohamad-Hani Temsah (1), Fahad Alsohaim (1), Ayman Al-Eyadhy (1), Fahad A. Bashiri (2), Gamal Hasan (1,3), Bader Almosned (1), Omar Temsah (4)

(1) Pediatric Intensive Care Unit, Department of Pediatrics, College of Medicine, King Saud University, Riyadh, Saudi Arabia

(2) Division of Pediatric Neurology, Department of Pediatrics, College of Medicine, King Saud University, Riyadh, Saudi Arabia

(3) Faculty of Medicine, Assiut University, Assiut, Egypt

(4) Al-Faisal University, Riyadh, Saudi Arabia

ABSTRACT

Drowning continues to be a cause of childhood mortality that is associated with significant psychological distress to the affected families. The unexpected death due to such preventable injury causes excessive grieving responses in these situations. In the present report, we describe a case of a 3-year-old child who was a victim of drowning in a recreational pool, whose family went through severe denial phase following the establishment of brain death. Single-photon emission computed tomography brain scan showed the absence of tracer uptake within brain parenchyma, while the calvarium showed increased tracer distribution, also known as the “halo sign.” She also had electrocerebral inactivity revealed by electroencephalography. We also discuss the magnitude of this family distress that led to total family avoidance of meeting with the treating team, from the time the parents were informed about the established brain death

in the drowning child till the patient had cardiopulmonary arrest 2 weeks later.

KEYWORDS

Brain death; Drowning; Grieving, Parents’ denial; SPECT scan; EEG.

INTRODUCTION

Drowning refers to “the process of experiencing respiratory impairment from submersion/immersion in liquid” [1]. It continues to be a significant source of morbidity and mortality in the pediatric age group [2]. As drowning is preventable through proper use of safety measures, this needs more awareness among parents and caregivers, as well as strict application of these preventive measures [3]. The preventable nature of drowning may be a significant contributing factor to the parental grief reaction, as exaggerated denial may be seen among several family members. We describe a case of drowning event, where

Correspondence to:

Mohamad-Hani Temsah,
Pediatric Intensive Care Unit, Pediatric
Department, College of Medicine, King Saud
University, Riyadh 11424, Saudi Arabia.
Email: mtemsah@ksu.edu.sa

Received: 20 September 2018 | Accepted: 11 December 2018

How to cite this article:

Temsah MH, Alsohaim F, Al-Eyadhy A, Bashiri FA, Hasan G, Almosned B, et al. Drowning in the desert: family denial of brain death. Sudan J Paediatr. 2018;18(2):48–52.
<https://doi.org/10.24911/SJP.106-1537437446>

parents refused cardiopulmonary resuscitation (CPR) at the scene, and how the severe grief reaction among the family led to the avoidance of the whole family of meetings with the medical team. This is the first case report from our region which describes this severe grief reaction among parents, and how it contributed to the extended length of hospital stay for a child with proven brain death secondary to drowning. Knowing more about the proper approach; that is cultural-sensitive and respectful to the parents' emotional status may help both the grieving family and the healthcare providers. Reporting about victims of drowning in desert areas, where there are no natural water bodies like ponds or rivers, this gives more emphasis to the notion that wherever there is water, there is the threat of drowning, even if it is a bucket, bathtub, or pool [2].

CASE REPORT

A previously healthy, 3-year-old girl was found by her family floating in a recreational swimming pool for an unknown time. Her aunt attempted to do CPR at the scene but her parents refused and rushed her to a nearby health dispensary that was reached within 15 minutes according to parents, where CPR was started. She was then transferred by ambulance, with ongoing CPR, to our hospital Emergency Department. She was in asystole, so CPR was continued, with endotracheal intubation. CPR was continued for another 25 minutes to have a return of spontaneous circulation (ROSC). Upon physical examination after ROSC, she had irregular and gasping breathing. Glasgow Coma Scale was 3/15 and pupils were fixed, dilated, and non-reactive to light, with absent brainstem reflexes. Initial arterial blood gas test revealed pH: 6.448 (Ref range 7.35–7.45), PCO_2 : 93.8 mmHg (Ref range 32–45), HCO_3^- : 2.6 mmol/l (Ref range 21–28), and serum lactate was 17 mmol/l (Ref range 0.5–1.6). She was admitted to the pediatric intensive care unit (PICU) and ventilated, with inotropic support to maintain hemodynamic stability. Neuroprotective measures were implemented. On the third day in PICU, with no ongoing sedation and normal body core temperature, her brain stem reflexes were still absent, in line with brain death criteria that are implemented through the Saudi Center for Organ

Transplantation (SCOT) guidelines [4]. Single-photon emission computed tomography (SPECT) brain scan was done on day 4, which showed the absence of tracer uptake within brain parenchyma, while the calvarium showed increased tracer distribution, also known as the “halo sign” (Figure 1). She also had electrocerebral inactivity revealed by electroencephalography (EEG). Her parents were counseled about her very poor prognosis upon admission to PICU and again updated about the progression to brain death by both the PICU and neurology teams. However, the father requested a second opinion, insisting their “child will walk out from the PICU” again. Therefore, a medical report and a copy of the SPECT scan were provided to the parents, with full support for the family during their grieving process. Moreover, other family members were also insisting that she was improving, depending on some sudden spontaneous movements, though these were explained to the family as spinal reflexes, they were not convinced and they started to avoid any talk with the medical team. On day 6, SCOT contacted the father regarding the possibility of organ donation but he declined and refused to talk to any physicians after that. The Do Not Resuscitate (DNR) hospital policy dictates that the patient's family should be informed about DNR but the medical decision can be taken without their consent. Therefore, DNR was applied, with no escalation of life support. She stayed for 3 weeks in PICU and her parents were still refusing to talk to any medical team member and even avoiding answering mobile calls for updates on the child's clinical condition. Eventually, on PICU day 20, when the child developed asystole, the team tried to reach her family for several hours but there was no response until after 8 hours of the child's cardiac asystole.

DISCUSSION

In the present report, we described a case of 3-year-old child who was a victim of drowning in a recreational pool. Preventable injuries such as drowning still occur frequently worldwide, with almost one-third of parents in Saudi Arabia reporting a child injury in the previous year [5]. In that study [5], drowning was reported even

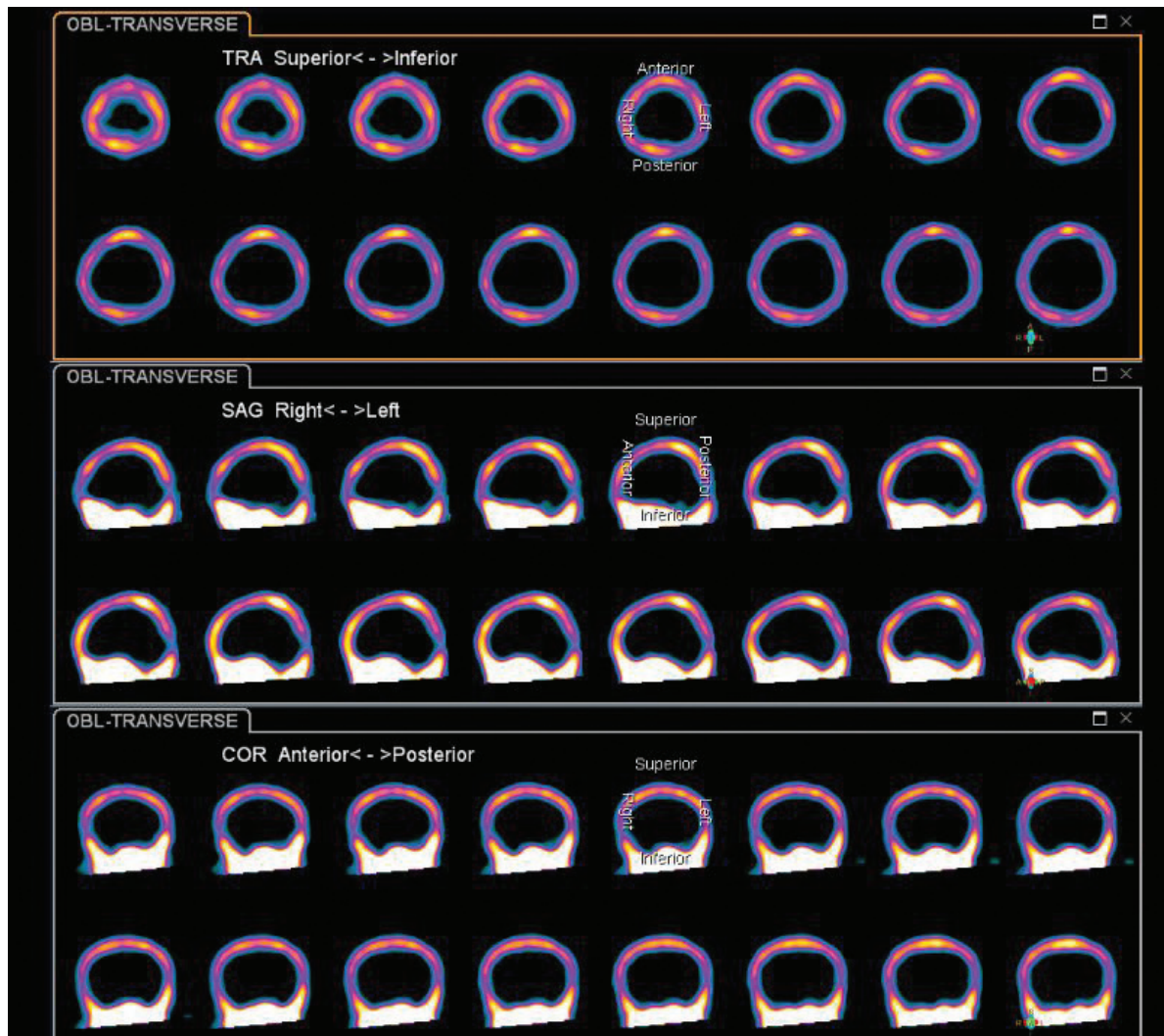


Figure 1 - SPECT brain scan showing the absence of tracer uptake within brain parenchyma and increased tracer distribution in the calvarium: "halo sign."

more than choking, though Riyadh is situated in a desert environment. Changing trends in the prevalence of drowning are observed in different parts of the worlds. According to the World Health Organization and other reports, the trends are decreasing in the developed countries whereas it continues to be an ongoing problem in others [3,6]. The prevention of such devastating injury must aim at minimizing the exposure to risk through enforcement and standardization of pool fencing, developing public and parental education, emphasis on swimming skills, and supervision by parent or caregiver all the time [2,3,7].

In this case report, the child's family went to a severe denial phase following the establishment

of brain death. Determination of brain death in children depends on the clinical diagnosis, which is evidenced by the absence of neurologic function which includes cerebral and brainstem function, and when the cause of the coma is irreversible [8]. At least two expert physicians should make this diagnosis, and some countries require one of them to be specialized in neurology [9]. It should be done twice, for infants and children 12 hours in between the examinations. Apnea test must be performed in addition to the clinical examination [8]. Ancillary studies such as EEG or radionuclide cerebral blood flow is not required to establish brain death unless clinical examination and apnea test were not completed [8]. These criteria were applied to our case, doing ancillary testing, in this

case, gave supportive measures to convince the parents, especially since they were in the denial stage.

The sudden death of an infant or child is one of the most difficult, traumatic, and devastatingly painful experiences a family member, especially a parent, can face during their lifetime [10]. Because of the intracranial nature of this injury, being drowning and thus cerebral anoxia, it is often difficult for parents to grasp the reality of this situation, as brain-dead patients usually look as if they are just sleeping, and even though the patient is considered legally dead in some countries, it is often not perceived as such by families [11].

Family members grieve in different ways and at different speeds, and it is critical that healthcare providers provide ample time and support for them to accept the death of their beloved child. Family members should also be provided with privacy and the opportunity of spending time with body, as many parents would like to cry, to touch and talk to the child, to lie with and hold the child, which can sometimes be difficult in the setting of the PICU but should be set up and accommodated by the PICU staff as much as possible. Clinicians and families alike may, therefore, struggle with cognitive dissonance, on the one hand, understanding the ethical and legal ramifications of the diagnosis of brain death while emotionally relating to the patient as a living being [12]. Parents of a brain-dead child experience even more intense grief when compared with parents whom children died by other means, most significantly when referring to feelings of despair and detachment [13]. These parents suffer through the Kübler-Ross model, otherwise known as the five stages of grief: denial, anger, bargaining, depression, and acceptance. However, the order through which a parent experiences these stages and the duration of each varies significantly from one parent to another. Most prominent of these observed phases was the denial phase, during which the parent firmly refuses to believe that their child has been declared brain-dead [14].

Parental denial of neurologically determined death and subsequent DNR decisions could be changed through repeated counseling, especially if families are better aware of the futile role of CPR

in changing the disease outcome [15]. However, parental avoidance of the medical team may be particularly challenging and reestablishing these communications may be occasionally impossible, especially if the family is potentially having some internal guilt feeling for failure to protect their child from such preventable injury or denial to provide CPR at the scene.

CONCLUSION

Parental denial may lead to prolonged hospitalization of brain-dead patients and should be anticipated and well-managed. Family bereavement needs special support from all healthcare providers. Appropriate interventions can save resources from the unnecessary prolongation of PICU stay for these patients, as well as decreasing the length of prolonged family suffering.

ACKNOWLEDGMENTS

The authors thank the dedicated pediatric staff at King Khalid University Hospital, Riyadh, Saudi Arabia, and Professor Mustafa A. Salih for his valuable guidance.

REFERENCES

1. van Beeck EF, Branche CM, Szpilman D, Modell JH, Bierens JJ. A new definition of drowning: towards documentation and prevention of a global public health problem. *Bull World Health Organ*. 2005;83(11):853–6.
2. World Health Organization. Global report on drowning : preventing a leading killer. Geneva, Switzerland: World Health Organization; 2014. Available from: <http://apps.who.int/iris/handle/10665/143893>
3. Peden M, Oyegbite K, Ozanne-Smith J, Hyder AA, Branche C, Fazlur Rahman AKM, et al., editors. World report on child injury prevention. Geneva, Switzerland: World Health Organization; 2008.
4. National Committee for Death Documentation; Saudi Center for Organ Transplantation. Diagnosis of death by brain function criteria. *Saudi J Kidney Dis Transpl*. 2011;22(2 Suppl 1):1–25.
5. Al-Zahrani MA, Temsah MH, Al-Sohime F, Al-Mosned BS, Al-Soliman MA, Abaalkhail MS, et al. Self-reported unintentional injuries in families

- visiting the childhood safety campaign in Saudi Arabia. *Egypt J Hospital Med.* 2018;71(1):2280–6. <https://doi.org/10.12816/0045304>
6. Felton H, Myers J, Liu G, Davis DW. Unintentional, non-fatal drowning of children: US trends and racial/ethnic disparities. *BMJ Open.* 2015;5(12):e008444. <https://doi.org/10.1136/bmjopen-2015-008444>
 7. Bose A. Drowning—the preventable killer. *J Trop Pediatr.* 2015;61(3):153–4. <https://doi.org/10.1093/tropej/fmv031>
 8. Nakagawa TA, Ashwal S, Mathur M, Mysore M. Clinical report-Guidelines for the determination of brain death in infants and children: an update of the 1987 task force recommendations. *Pediatrics.* 2011;128(3):e720–40. <https://doi.org/10.1542/peds.2011-1511>
 9. Jan MM. Brain death criteria. The neurological determination of death. *Neurosciences (Riyadh).* 2008;13(4):350–5.
 10. Lima L, Goncalves S, Pinto C. Sudden death in paediatrics as a traumatic experience for critical care nurses. *Nurs Crit Care.* 2018;23(1):42–7. <https://doi.org/10.1111/nicc.12326>
 11. Truog RD, Christ G, Browning DM, Meyer EC. Sudden traumatic death in children: “we did everything, but your child didn’t survive.” *JAMA.* 2006;295(22):2646–54. <https://doi.org/10.1001/jama.295.22.2646>
 12. Lock MM. *Twice dead: organ transplants and the reinvention of death.* Berkley, CA: University of California Press; 2002.
 13. Youngblut JM, Brooten D, Glaze J, Promise T, Yoo C. Parent grief 1–13 months after death in neonatal and pediatric intensive care units. *J Loss Trauma.* 2017;22(1):77–96. <https://doi.org/10.1080/15325024.2016.1187049>
 14. Kubler-Ross E, Wessler S, Avioli LV. On death and dying. *JAMA.* 1972;221(2):174–9. <https://doi.org/10.1001/jama.1972.03200150040010>
 15. Tamsah M-H. Ethical considerations about changing parental attitude towards end-of-life care in twins with lethal disease. *Sudan J Paediatr.* 2018;18(1):76–82.