

# RETRACTION NOTICE: Routine parental request of organ donation in end-of-life care of children in the United Kingdom: Unresolved medical, legal, cultural and religious challenges

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At the request of the Journal Editors the following article has been retracted.

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The Journal Editors have determined the research reported in a publication (Darlington et al. Parents' experiences of requests for organ and tissue donation: the value of asking. *Arch Dis Child* 2019; 104: 837–843) discussed in the above paper was misunderstood and mischaracterised. As a result, this paper has been retracted from publication.

# RETRACTED: Routine parental request of organ donation in end-of-life care of children in the United Kingdom: Unresolved medical, legal, cultural and religious challenges

Mohamed Y Rady

## Abstract

The opt-out system (or presumed consent) for end-of-life organ donation is being widely adopted in the United Kingdom. Since presumed consent for organ donation applies only to adults, commentators have recommended the implementation of routine parental request and integration of organ donation in the end-of-life care of children to increase the donor pool and the supply of transplantable organs. The empirical data for this recommendation originated from a survey of parents of deceased children with severe congenital and acquired brain injuries. The demographics of the surveyed parents were not representative of the diverse ethnic and religious affiliations of British society. Here, it is argued that there are unresolved medical, legal, cultural and religious challenges to the routine integration of end-of-life organ donation that can result in harmful consequences for children and parents. To address these challenges: (1) paediatric practice guidelines should be updated to incorporate new advances in the diagnosis and the treatment of severe brain injuries to eliminate potential clinical errors from premature treatment discontinuation and/or incorrect diagnosis of brain(stem) death and (2) a broad societal debate on the legal, cultural and religious consequences of routine integration of end-of-life organ donation in children.

## Keywords

Presumed consent, organ donation, end-of-life care, children

The opt-out system (or presumed consent) for end-of-life organ donation is being widely adopted in the United Kingdom.<sup>1,2</sup> Presumed consent to organ donation only applies to adults. Several commentators have recommended the implementation of routine parental request and integration of organ donation in the end-of-life care of children to increase the donor pool and the supply of transplantable organs.<sup>3-5</sup> Routine parental request for organ donation may represent a step towards the UK's adoption of presumed consent in children, too. This commentary outlines: (1) the limitations of the empirical data that is driving this recommendation and (2) the contemporary medical, legal, cultural and religious challenges that argue against implementing this recommendation because of potential harmful consequences to children and parents.

## The empirical data

The empirical data driving the recommendation of routine parental request and integration of organ donation

in the end-of-life care of children originated from a multi-centre study by Darlington et al.<sup>3</sup> The study cohort was recruited from neonatal, paediatric and cardiac intensive care units in addition to a children's hospice in the United Kingdom. The study method consisted of telephone interviews of parents of children who died between 2011 and 2014.<sup>3</sup> Most of the children died from congenital or acquired neurological life-limiting illness. The study investigators also interviewed healthcare professionals in focus groups who were involved in the end-of-life care of deceased children. The final study sample was 24 parents and 41 healthcare professionals.<sup>3</sup> The authors concluded that routine

Department of Critical Care Medicine, Mayo Clinic Hospital, Phoenix, USA

## Corresponding author:

Mohamed Y Rady, BChir, MB (Cantab), MA, MD (Cantab), Department of Critical Care Medicine, Mayo Clinic Hospital, 5777 East Mayo Blvd, Phoenix, AZ 85054, USA.  
Email: rady.mohamed@mayo.edu

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parental request of organ donation should be integrated in the end-of-life care of children of all ages.<sup>3</sup> However, an in-depth analysis of the demographics of the surveyed parents did not substantiate the authors' generalisability of the change in paediatrics end-of-life care: (a) only 25% of the parents approached agreed to participate in the study, while the remaining parents were excluded because of difficult interactions with the clinical team, court cases or other difficulties that were sensitive to disclose, (b) the majority of parents were of White British or European ethnicity and (c) the religious affiliations of the surveyed parents were not reported.<sup>3</sup> Previously, the Royal College of Paediatrics and Child Health has emphasised that parental ethnicity and religious affiliations are important considerations when providing children's end-of-life care in a multicultural society.<sup>6</sup>

### Medical challenges

Most children who are eligible for donating transplantable solid organs suffer from neurological disabilities secondary to congenital or acquired severe brain injuries.<sup>3</sup> Over the past decade, neuroscience has advanced contemporary understanding of disorders of consciousness after severe brain injuries.<sup>7-10</sup> Advances have enabled the detection of covert consciousness and facilitated the development of new therapeutic interventions and neuro-rehabilitation programmes to assist neurological recovery after severe brain injuries. Diagnostic and therapeutic advances in the treatment of severe brain injuries were incorporated in the American Academy of Neurology's clinical practice guidelines published in 2018.<sup>9,11</sup> These caution clinicians against making early decisions to discontinue treatment because of the difficulty of accurately predicting the long-term neurological outcome after severe brain injuries. In contrast, the UK practice guidelines for the management of disorders of consciousness were published in 2013.<sup>12</sup> They have not incorporated new diagnostic and therapeutic modalities in the treatment of severe brain injuries to eliminate potential errors from premature discontinuation of life-support treatment.<sup>13,14</sup> The scientific validity of the practice guidelines can have profound clinical implications on discontinuation of clinically indicated therapeutic interventions including life-support treatment and/or withholding potentially beneficial neurotherapeutic interventions.<sup>8,9,13-16</sup> Likewise, the UK code of practice for the diagnosis and confirmation of death was first issued in 1976 and has established the clinical criteria of death after severe brain injuries for organ donation.<sup>17</sup> Since then, neuroscience has refuted the fundamental assumptions underpinning the equation of brain(stem) death criteria with clinical death that is stipulated in the

code of practice.<sup>15,16,18,19</sup> Furthermore, several paediatric cases of false positive diagnosis of death have been reported after applying the diagnostic criteria of brain(stem) death.<sup>15,20-24</sup> Faulty determination of death jeopardises trust in clinicians and healthcare providers because it hastily terminates beneficial treatment in a child with the potential to survive. If routine parental request for organ donation is implemented, the wish to expedite donation and procurement of organs from a child for transplantation can inevitably corrupt the integrity of the clinician-parent relationship. To summarise, the medical challenges originate from outdated practice guidelines for clinically determining treatment futility and diagnosis of death after severe brain injuries in children which may lead to premature decisions to stop treatment and/or to declare brain(stem) death for organ donation.

### Legal challenges

There are legal challenges to the routine integration of organ donation in the end-of-life care of children. The UK judicial system applies the test of best interests to allow initiation and/or continuation of non-palliative interventions and life-support treatment in the end-of-life care of children, irrespective of parental wishes. In the case of *Great Ormond Street Hospital for Children Foundation NHS Trust v NO & KK & Ors* ([2017] EWHC 241 (Fam) (14 February 2017)) and the case of *Alder Hey Children's NHS Foundation Trust v Evans & Ors* ([2018] EWHC 818 (Fam) (11 April 2018)), clinicians successfully argued that the initiation and/or continuation of life-support treatment was non-palliative and inflicts additional pain and suffering at the end of life. In both cases, the court agreed to the discontinuation of life-support treatment without parental consent as in the child's best interests. If we apply the same legal test of the best interests of a child then the initiation and/or continuation of non-palliative interventions that are necessary to facilitate organ donation would be equally prohibited in the end-of-life care of a child irrespective of parental wishes. The goal of medical interventions in organ donation is to maximise the quality of procured organs for transplantation and may include (but is not limited to) initiation and/or continuation of mechanical ventilation, insertion of arterial and venous vascular catheters/cannulas, and administration of systemic anticoagulation and/or other non-palliative medications for organ preservation. These invasive medical interventions are likely to be associated with additional pain and/or discomfort and are of no palliative benefit to the dying child. In addition, as mentioned previously, there are false positive diagnoses of death in children because of poor diagnostic accuracy of brain(stem) death criteria which can raise genuine concerns if certain neurological

functions such as conscious awareness and nociception may have not ceased irreversibly.<sup>18,25</sup> The surgical procurement of transplantable organs without general anaesthesia would likely be associated with additional child distress if the clinical diagnosis of brain(stem) death is faulty. To sum up, the UK legal standard of the best interests could well prohibit non-palliative medical interventions for the retrieval of donor organs in the end-of-life care of children, irrespective of parental consent.

## Cultural and religious challenges

Many cultures and religions are acceptive of the altruistic act of organ donation. However, the logistics and procedures required (e.g. donor preparation, organ preservation, withdrawal of life-support, criteria of death, etc.) are irreconcilable with some fundamental cultural values and religious beliefs.<sup>5,18,26,27</sup> Failing to respect and accommodate these diverse values and beliefs can have a profound negative impact on surviving parents and family members.<sup>6,18,25,27</sup> Although routine integration of organ donation can conflict with religious beliefs, some commentators believe that religious beliefs should not “be allowed to stonewall a secular approach” to the end-of-life care of children in a multicultural society.<sup>28</sup> Other commentators have downplayed the conflict with religious beliefs by claiming that donating a child’s organs can lessen parental bereavement symptoms.<sup>4</sup> There is no good empirical evidence to support this. On the contrary, studies have shown that the grief symptoms of relatives and family members of deceased donors were either unaffected or exacerbated because of uncertainty about the criteria of (brain) death used for organ donation.<sup>29</sup> Researchers advise additional studies should be undertaken to evaluate the long-term psychosocial consequences on family members of a brain(stem) death diagnosis followed by organ donation.<sup>30</sup> In our view, therefore, routine parental request and integration of organ donation at the end of life of children would not take into consideration the cultural and religious diversity and the potential long-term psychosocial consequences on surviving parents and family members.

## Conclusions

The recent recommendation for routine parental request and integration of organ donation in the end-of-life care of children overlooks unresolved medical, legal, cultural and religious challenges, which would require:

- (1) the revision of clinical practice guidelines for the treatment of severe brain injuries and the diagnosis of brain(stem) death in children and

- (2) a broad societal debate of the legal, cultural and religious consequences of mandatory requests for organ donation in the end-of-life care of children.

## Author’s contribution

MYR authorship credit only, based on: (1) substantial contributions to conception and design, or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content and (3) final approval of the version to be published.

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