Bioethical Perspective of Charlie Gard Case

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Abstract

This short commentary is about the ethical, rather bioethical, issues of the Charlie Gard case in the United Kingdom. The commentary tries to analyse the case from bioethical perspective and outlines some of the pertinent bioethical issues.

Keywords: Bioethics, Charlie, Ethics

Introduction

On 28 July 2017, Charles Matthew William Gard, popularly known as Charlie Gard, breathed his last at the innocent age of 11 months 24 days in London, England. Charlie, however, did not face the death naturally. His terminal life support system was withdrawn, amidst several agreements and disagreements, to usher him to permanent rest on 27 July 2017. Charlie succumbed to his conditions almost 24 hours after withdrawal of his mechanical ventilation triggering several bioethical issues. In this commentary, some of those bioethical issues would be discussed with the implications for the greater concern.

The Medical and Legal Issues

Charles "Charlie" Matthew William Gard was born at full term and normal weight on 4 August 2016 in London. Although born as a normal baby, Charlie, however, failed to gain weight even after regular breast-feeding and was unable to lift his head even after days of birth. In October 2016, a cranial MRI (Magnetic Resonance Imaging) scan was performed, an ECG (Electrocardiogram) was carried out to detect the source of problem and a nasogastric tube was inserted to help him to increase his weight.
On 11 October 2016, baby Charlie was taken to Great Ormond Street Hospital (GOSH), a 389 bed children’s hospital funded by the National Health Service (NHS), England. Charlie, because of his shallow breathing, was admitted to GOSH to be put on a mechanical ventilator but the intervention of tracheostomy was thought to be unnecessary at this stage. By November, Charlie was suspected to have mitochondrial DNA depletion syndrome (MDDS), a set of rare diseases caused by mutations in genes. In mid-November, a genetic test confirmed that Charlie had two mutated versions of the gene coding for the RRM2B protein because of which Charlie had the potential threat of suffering brain damage, muscle weakness, organ failure, and even death during infancy. Charlie’s parents contacted Dr. Michio Hirano, a New York based neurologist working on an experimental treatment based on nucleoside supplementation with human MDDS patients. Dr. Hirano and GOSH together agreed to proceed with the treatment for Charlie’s interest with funding from the NHS England.

Dr. Hirano and GOSH team came to the decision to work collaboratively for Charlie after checking that Charlie does not have any structural damage to the brain and agreeing that there is only a "theoretical possibility" that the treatment would provide some benefit to Charlie. From mid-December, however, Charlie’s brain function deteriorated and he began having persistent seizures (BBC, 2017). He suffered deafness, gradual failures of heart and kidneys, and was unable to breathe or move independently. By first week of January 2017, Charlie began having epileptic seizures, which continued until end of the month. These were deemed likely considered to be the consequences of epileptic encephalopathy (brain damage). Meanwhile, on 9 January 2017, GOSH team intended to attempt the nucleoside treatment in the next few weeks with the approval from hospital’s ethics committee which was scheduled to meet to discuss the issues and the case on 13 January. And Charlie was provisionally scheduled for a tracheostomy on 16 January (Garrison, 2017; Bailii, 2017). In the meantime, GOSH also invited Dr. Hirano to examine Charlie in January, but he could only physically examine him in July when the legal tension between GOSH and Charlie’s parents had reached the second hearing. (Boseley, 2017). On 13 January the GOSH doctors informed Charlie’s parents that the benefits of the experimental treatment were futile because of the brain damage and it is better to withdraw the life support to minimize Charlie’s sufferings.

As this appeal of GOSH went against the interest of Charlie’s parents, they decided to transfer Charlie to try the experimental treatment in the United States and started raising funds for hospital transfer to New York. As the parents continued to go against the GOSH’s decision to terminate the treatment, on 24 February 2017, GOSH sought help of the England and Wales High Court (Family Divisions) to give the orders in support of GOSH considering the following aspects;

“That Charlie, by reason of his minority, lacks capacity to make decisions regarding his medical treatment; it is lawful, and in Charlie’s best interests, for artificial ventilation to be withdrawn; that it is lawful, and in Charlie’s best interests, for his treating clinicians to provide him with palliative care only; and that it is lawful, and in Charlie’s best interests, not to undergo nucleoside therapy provided always that the measures and treatments adopted are the most compatible with maintaining Charlie’s dignity” (Bailii, 2017).

The court while supported GOSH’s position, the case when further moved to the
European Court of Human Rights (ECHR), ECHR refused to intervene. After several months of tension between court and Charlie’s parents, in July 2017, GOSH applied to the High Court for a new hearing after receiving a letter signed by several international experts defending the potential of the treatment and providing new evidence (GOSH, 2017).

It is during this time, Dr. Hirano could make time to visit Charlie at GOSH and after examining scans of Charlie’s muscles, Dr. Hirano declared that it’s been too late for the treatment to help Charlie. Dr. Hirano’s declaration obliged Charlie’s parents to abide by the court order and to agree to the withdrawal of life support. The second court hearing, which had been arranged to hear and examine the new evidence then became concerned with the arrangements for the withdrawal of life support. On 27 July, by court order and parent’s consent, Charlie was transferred to a hospice; mechanical ventilation was withdrawn, and he breathed his last on the very next day at the age of 11 months and 24 days.

Charlie’s mother, made an emotional farewell statement with reference to the time. She rightly pointed out about the timely access to the medical care, the time taken for the decision, for the observation. She clarified “Had Charlie been given the treatment sooner he would have had the potential to be a normal, healthy little boy” (The Telegraph, 2017). She also mentioned her son “had a greater impact on and touched more people in this world in his 11 months than many people do in a lifetime.” (The Telegraph, 2017). She was true in her view. At the tender age of few months, Charlie, with the help of the media, attracted widespread attention; became a major concern in Britain and around the world. President Donald Trump and Pope Francis expressed their concerns and assistance to baby Charlie. The case even attracted international media for at the time of Charlie’s death, The Washington Post reminding the difference between American and English healthcare system, wrote the case “became the embodiment of a passionate debate over his right to live or die, his parents’ right to choose for their child, and whether his doctors had an obligation to intervene in his care” (Gaffney, 2017).

Involving several agencies, conflicts of rights and interests, the case gave rise to several ethical issues and opened the scope for the bioethicists to refocus on some of the bioethical concerns. This commentary highlights some of them.

The Ethical Issues

Access to medical care: When GOSH medical team decided to put Charlie out of mechanical ventilation, Charlie’s parents decided to take Charlie to the United States to try for the experimental treatment. And GOSH took refuge to the court for the possible treatments in this case was beyond the scope of long-term medical and social obligations.

However, it took time for the parents, in this case, to accept the fact that nothing can be further done to improve the long-term health and well-being of the baby, for its been late. In short, GOSH’s decision, perhaps, was considered as the denial of access to the high-quality treatment by Charlie’s parents. Charlie’s timely access to high quality NHS treatment, possibly, could have avoided debates and court. The timely focus on the just and fair explanation of health and well-being, rather than consistent focus on suffering and dying with dignity could have shaped the right decisions at the right time.
Balancing rights, harm, benefit, and safety: The case has given rise to the serious debate over the physicians and the court overruling the parents’ decisions on behalf of their child. The reaction in the society turned out to be violent later with the hospital staffs getting threats from the civilians for their paternalistic behavior. Without delving into the depth of the debates, this commentator would like to state that a just medical decision (considering the facts of "medical necessity" and "medical futility" (Ruger, 2010) of the case), balancing the rights of the patients and doctors, could only be undertaken when there is a shared commitment of thoughts and actions- it can commence through the shared responsibility of the parents (if patient is incapable to decide), the hospital staffs, the ethics consultants (not just clinical ethicists working in the hospital setting but ethicists/bioethicists potential enough to work as consultants), medical scientists, social and other medias, and the society collectively. This could also balance the medical harm and benefit with proper consideration of “clinical and economic solutions” (Ruger, 2010); minimize the consequent threats and harms on the physicians and nurses. A joint participation in the decision-making process could also improve the trust and expectation of the people on the healthcare system.

Intervention of Media: The case at hand had witnessed overwhelming coverage of media which captured the attention of the whole world including President Trump and Pope Francis. However, the onus also remains on the media to consider the issue that the coverage should not compel the parents (or the patient), involved in the case, to be stigmatised; that the case is not sensationalised to the extreme for the public to take the law at hand to abuse the physicians and other medical personnels involved in the case.

Conclusion

In the context of Charlie Gard’s case while the debate was about the overruled patient’s rights, balancing harm, and benefit, about the strong involvement of the media, however, the case has been an instance for the discussion of varied bioethical issues in the England. The case, perhaps, has also provoked the discussion of the extent of the involvement of the ethicists- do the cases need to be only within the medical and clinical ethics domain to analyse the moral implications?; or, does it need the involvement of the ethicists, beyond the boundary of the hospital, to discuss the case in bigger context ?; do medical cases always necessarily need to be referred to the court in the England or do they also need an ethical decision from bioethicists before being referred to the court?. While some of these questions are prompted by the case of Charlie Gard, it remains to be seen whether these questions are dealt with great responsibility and obligation in the context of similar such cases in the future.

Conflict of Interest

The author declared no conflicts of interest with respect to the research, authorship and/or publication of this article.
REFERENCES


