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The article you sent to the Commission for the 7th edition of the Nigeria National Human Rights Commission Journal was sent to the Commission's Assessor/Reviewer for review.

The Reviewer has confirmed that your article titled "The Rights to life and the battle over children's life: Baby Charlie Gard in perspective" is publishable. The article will be published in the 7th edition of the Nigeria National Human Rights Journal, 2017.

Congratulations.

Oti Ovrawah

Ag. Executive Secretary

THE RIGHT TO LIFE AND THE BATTLE OVER CHILDREN'S LIFE: BABY CHARLIE GARD IN PERSPECTIVE.

BY

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Abstract

The Convention of the Right of the Child provides that every child has an inherent right to life. This means the child has a right to survival and development. Parents of a child have the responsibility, rights and duties to take "appropriate direction and guidance in the exercise by the child of the rights recognized in the Convention" The Government has the responsibility to ensure that the rights of a child are respected protected and fulfilled. Article 3 of the Convention states that the best interests of the child shall be a primary consideration in all actions taken on behalf of a child. The paper considered the case of baby Charlie Gard, a baby boy, born in the United Kingdom on 4 August 2016, with a genetic defect resulting in a rare disease and the battle between the parents, the hospital where he was being treated for the rare disease and the court. The paper further examined, who amongst, the three, complied with Article 3 of the Convention in the legal battle. The paper also considered who had the right to decide whether Baby Charlie would live or die. The paper provided the position, in Nigeria, under the Childs Rights Act, if baby Charlie were a Nigerian child.

Keywords: Rights, Right to Life, Child, Baby Charlie Gard.

THE RIGHT TO LIFE AND THE BATTLE OVER CHILDREN'S LIFE: BABY CHARLIE GARD IN PERSPECTIVE.

"To defend human life, above all when it is wounded by illness, is a duty of love that God entrusts to all."

- POPE FRANCIS1

The Story of Baby Charlie Gard

Hughes et al.², The Telegraph³ and many other reports gave detailed stories of a child popularly known as Charlie Gard was given. According to the reports, on August 4, 2016, Connie Yates and Chris Gard from Bedfont, London, were delivered of a baby boy and they called him Charlie. At his birth, he was healthy, his weight normal and his parents looked forward to watching him grow. After a month, Charlie's parents noticed that he seemed to have some difficulty in lifting his head and supporting himself more than a normal child of his age, should. They took him to see their general practitioner who had very bad news for Connie Yates and Chris Gard.

The different reports went further to state that the news was that Charlie was very sick. The report of the medical examinations showed that Charlie had inherited some rare genes from his parents which resulted in a terrible disease that caused muscle weakness and severe brain damage. The disease was Infantile Onset Encephalopathy Mitochondrial DNA Depletion Syndrome (MDDS). Charlie had two mutated versions of the gene coding for the RRM2B protein. The Telegraph,⁴ also stated that there were experimental treatments for MDDS, but they had been tried very few times and with very little success. The experimental treatments had never been tried on someone like Charlie, a child with the RRM2B variant of the disease.

Hughes et al.⁵ reported that by October 11, 2017, Charlie was transferred to Great Ormond Street Hospital (GOSH) and placed on a mechanical ventilator because his breathing was shallow and he had become lethargic. By December 2016, Charlie's heart and kidneys were starting to fail. His brain function deteriorated, leading to frequent seizures. He could not move

Pope Francis via Twitter (2017). Available at https://twitter.com/pontifex/status/ 30th June 2017 at 7:32 pm. Accessed 10th July 2017

² Hughes D., Harper P., Wheatstone R. and Christodoulou H. – Charlie's Fight. The Sun News. 26th July 2017. Available at https://www.thesun.co.uk/news/3248426/charlie-gard/. Accessed 30th July 2017 at 6:06pm

³ Telegraph Reporters (2017) 'Who is Charlie Gard, what is the disease he suffered from and what happened in the court case?' The Telegraph, 26th July 2017. Available at www.telegraph.co.uk/news/0/charlie-gard-mitochondrial-disease-suffers-legal-battle/. Accessed 30th July 2017 at 4:25pm
⁴ Ibid.

⁵ Op. cit. 2

by himself, was deaf and could not open his eyes. The doctors could not even tell if he could experience pain or not. They only knew when he was having seizures by tracing it on a machine. In January 2017, the doctors at GOSH decided to try experimental treatment with nucleosides. The Telegraph, and Hughes et al. further reported that before the doctors could get ethical approval to try an experimental treatment, Charlie had another round of severe seizures. This caused the doctors to change their mind and start discussing the withdrawal of life support for Charlie. They decided they would provide palliative care but essentially, they asked Charlie's parents, to let him die.

The Legal Tussle between Charlie's Parents, the Doctors and the Courts

"The parents want to try but it isn't up to them"8

The above quote, introduced the legal tussle between Connie Yates and Chris Gard, the parents of baby Charlie and the doctors in the court of law.

Charlie's parents were not going to give up their son without a fight and they tried to take him out of the United Kingdom to the United States of America for experimental treatment. By the end of January 2017, they launched an appeal on a crowdfunding website, GoFundMe to raise £1.2million for the treatment. Two months later, their target was achieved and by the end of April 2017, over £1.3million had been donated for the treatment of Charlie.

On 24th February 2017, the doctors at GOSH asked the court to intervene and order that life-supporting treatment should stop as baby Charlie could not breathe by himself and had to be fed through a tube. ¹² A guardian was appointed for baby Charlie by the court and the guardian was represented by an independent counsel. The case of the doctors at GOSH was that, due to the risk that Charlie might be in pain, and the very low chance that the trip to America would be of any use, his mechanical ventilator should be withdrawn in his best interest and based on his right to dignity. ¹³ The arguments of the doctors in the court of law that the option of the

⁶ Op cit 4

⁷ Op cit 3

⁸ Fox News, - 'Charlie Gard's parent's storm out of new court hearing.' Jul 13, 2017. Available at http://foxnews/world/2017/07/13/charlie-gards-parents-make-final-pitch-to-bring-son-to-us-for-treatment.html (accessed September 18, 2017 at 2:15pm

¹⁰ GoFundMeCrowdfunding (2017) - Fundraiser by Connie Yates. Available at https://www.gofundme.com/please-help-to-save-charlies-life/ accessed June 27, 2017 at 12:46pm

¹² The Guardian – 'Charlie Gard's parents say their 'beautiful boy' has died' Available at https://www.guardian.com/uk-news/charlie-gard Charlie Gard, News Feed. The Guardian, 2017 accessed 28 July 2017 at 3:19pm
¹³ Ibid.

experimental treatment might cause more suffering to Charlie did not go down well with the parents of Charlie. At the hearing, Connie Yate, Charlie's mother was reported to have reacted to the evidence of the doctors that Charlie might be in pain that "If he was we wouldn't be up here fighting for that" and Chris Gard was said to have "punched the table". 15

On April 11, 2017, the judge ruled in the doctor's favour after a hearing in the family division of the London High Court. ¹⁶ The ruling by the court was based on the fact that in Britain as in some other jurisdictions, the court is empowered to intervene when there is a disagreement between a doctor(s) and parents or family members on issues relating to the treatment of children or relatives who are unable to speak for themselves. Article 3 of the Convention on the Rights of a Child 1989, states that "In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration" ¹⁷

Furthermore, Article 4 provides that "States Parties shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention"

It suffices to say that the United Kingdom ratified the Convention on 16 December 1991 and it came into force in 1992. As a signatory to the Convention, the right of the child takes primacy and the court was bound to weigh the evidence before. It had to determine whether baby Charlie in his state of health was, in fact, suffering as the doctors stated and the effect or benefit of the experimental treatment on him. This was to be weighed against the submission of the parents that he was not suffering any pain and that the court should give Charlie a chance to live by undergoing the treatment in the United States of America. It is opined that the best interest of the child was the main consideration behind the ruling of the court. According to Bever and Horton 19, the judge was quoted as saying that "based on the unanimity among the

https://www.washingtonpost.com/news/worldviews/wp/2017/07/06/american-hospital-offers-to-admit-charlie-

¹⁴ Op.cit. 8

¹⁵ Ibid.

https://www.judiciary.gov.uk/wp-content/uploads/2017/04/gard-press-summary-20170411.pdf Judiciary of England and Wales (2017). Decision and short reasons to be released to the media in the case of Charlie Gard. (Accessed June 27, 2017 at 10:05am).

¹⁷ United Nations Convention on the Rights of the Child (20, xi, 1989; TS44; CM 1976) United Nations, New York 1989. United Nations/human rights/CRC. Available at http://www.unicef.org/crc/ accessed 1 September 2017 at 1:25pm

¹⁸ United Nations Convention on the Rights of the Child (UNCRC) – UNICEF UK. Available at https://www.unicef.org.uk/what-we-do/un-convention-child-rights/ Accessed September 18, 2017 at 10:22pm
¹⁹ Bever L. and Horton A. 'Charlie Gard may have new hope: Hospital asks court to rehear case of terminally ill infant.' The Washington Post, July 7, 2017. Available at

experts that the experimental therapy Charlie's parents wanted to try could not repair structural brain damage, the life support on baby Charlie should be removed".

The court in taking the above decision was not ignorant of the fact that Charlie's parents had certain rights to take decisions on behalf of their son Charlie. Article 5 of the Convention is very clear about this fact. The Judge in the case, demonstrated his awareness of this provision when he stated in the ruling that "he will consider any new evidence".²⁰

Forster²¹ reported that Charlie's parents taking a chance of their son surviving, appealed to the Court of Appeal on May 3, 2017, asking the Court of Appeal judges to reconsider the ruling of the High Court.²² On the 23rd of May, three judges from the Court of Appeal dismissed the appeal. Connie Yates and Chris Gard further appealed to the Supreme Court.²³ On June 8, 2017, Connie, Charlie's mother, had to be led out of the Supreme Court because she couldn't help screaming at the judges when they gave their decision to the effect that the life-supporting treatment was to be withdrawn.²⁴ The parents of baby Charlie were of the opinion that the 10% chance which the treatment in the United States of America offered was sufficient evidence the court should consider and not withdraw the life support from Charlie. Not satisfied with the Supreme Court decision, Charlie's parents took the legal battle to the European Court of Human Rights and on June 20, 2017, and the European Court started analysing the case after lawyers representing Charlie's parents made written submissions.²⁵ However, by June 27, the European Court communicated its decision not to intervene, upholding previous court rulings in favour of withdrawing life support.²⁶ The court felt that Charlie was exposed to continued pain and that further treatment would worsen his situation. They stated that the application presented by

gard-british-baby-at-center-of-life-support -controversy/?utm_term=.5b9b209eaf3b Accessed 18 September 2017 at 7:43am

²⁰ Op cit. 4

²¹ Forster K. 'Charlie Gard's parents launch fresh appeal over ruling doctors can withdraw life support from brain-damaged baby.' The Independent, May 2, 2017. Available at

http://www.independent.co.uk/news/health/charlie-gard-appeal-high-court-sick-baby-ill-parents-ruling-doctors-withdraw-life-support-a7712806.html. Accessed 5th July 2017 at 12:12pm

²² British Broadcasting Network (2017) 'Charlie Gard: parents to appeal withdrawal of life support.' BBC News, May 2, 2017. Available at http://www.bbc.com/news/uk-england-london-39777073 (accessed June 28, 2017).

²³ Foster A. 'Charlie Gard latest news: Updates as Charlie Gard's parent's fight to bring him home' Express, July 25, 2017, Available at -www.express.co.uk/news/uk/832856/charlie-gard-latest-news-updates-case-high-court-baby-charlie-story/ Accessed 28 August 2017 at 4:15pm

Ibid.Ibid.

²⁶ Op. cit. 19

his parents was inadmissible and the decision of the United Kingdom Supreme Court was final.²⁷

Charlie's parents believed they needed to do everything to secure the rights of their little boy and that it is their right to be able to make such decisions on his behalf. To them, it starts with the right to life. The doctors, on the other hand, believed his right to dignity should take precedence in this case, as Charlie might be in pain and suffering greatly. There was a legal tussle between the parents of Charlie, the doctors and the courts. It is therefore clear from the decision above that, although the parents of baby Charlie have parental responsibility, the court has overriding control in the best interest of the child.

The intervention of the United States of America Government and the Vatican-The International Dimension

Interest in the issue of Charlie was not restricted to the United Kingdom. All over the world, different individuals including the author of this paper, organisations, medical doctors and government watched and followed the story. According to Rawlinson, 28 the legal battle for Charlie's life turned into "an international Issue." While Collin Yate, Charlie's mother in the course of the legal battle, made reference to a 2014 case of Ashya King, whose parents won the legal battle to take him to the Czech Republic for medical treatment, 29 Bever and Horton in the Washington Post, reported that a New York-Presbyterian Hospital/Columbia University Irving Medical Center, indicated interest in having baby Charlie transferred to their facility. According to the report, it was also suggested that the hospital could ship the drugs to be administered on Charlie and give instructions on the use. A Vatican owned paediatric hospital, Bambino Gesù Children's Hospital, Italy, also indicated their interest to be involved in the treatment of baby Charlie. The international dimension of the baby Charlie's case was further projected with the statement from the Pope, through a spokesman, to Charlie's parents,

July 2017 Available at https://www.theguardian.com/uk-news/2017/jul/10/charlie-gard-pope-and-trump-biggest-help-in-keeping-him-alive-says-mother accessed 19 September 2017 at 2:57pm

29 Ibid.

30 Op. cit 19

 ²⁷ British Broadcasting Network 'Charlie Gard's Parents Lose European Court Appeal.' BBC News, 27th June
 2017. Available at http://www.bbc.com/news/uk-england-40423371 accessed 28 June 2017 at 10:46am
 ²⁸ Rawlinson K. 'Charlie Gard: Pope and Trump biggest help in keeping him alive, says mother.' Monday 10

³¹ Ibid.; Levenson E., Elwazer S. and D'Agostino L. 'Hospital offers to take in baby Charlie Gard.' Cable Network News, 5 July 2017. Available at www.cnn.com/2017/07/04/health/charlie-gard-pope-hospital/index.html. Accessed 10th July 2017 at 9:33am

encouraging them not to give up.³² The Pope also encouraged Charlie's parents via a tweet where he said, "To defend human life, above all when it is wounded by illness, is a duty of love that God entrusts to all".³³

In a report on July 3, 2017, the President of the United States of America, Donald Trump, offered that his government was willing to bring baby Charlie to the United States for treatment.³⁴ The President, through a tweet further showed support for Charlie Gard and his parents.³⁵ According to the tweet, "If we can help little #CharlieGard, as per our friends in the U.K. and the Pope, we would be delighted to do so."³⁶ Baynes,³⁷ stated that President Trump "indicated his delight" to the government of the United Kingdom to help baby Charlie. By these interventions, Baby Charlie was offered both American and Vatican passports.

Focusing more on the intervention from the United States, the doctor who offered to treat baby Charlie, is a professor of neurology. He was the only dissenting voice in the medical field who considered that there may be a benefit to be derived from the new treatment even though he admitted then that the new treatment might not do much for baby Charlie. In his words "I would just like to offer what we can. It is unlikely to work, but the alternative is that he will pass away." Considering the intervention, on one hand, Dr. Michio Hirano, the American doctor, did not examine Charlie before offering help and according to Bosely, some ethicists argued that this is wrong. It has been argued whether it is right for the American doctor to make an opinion without seeing the patient face to face and insist on it, when every other doctor saw the patient and examined his medical history said there was no hope for him. On the other hand,

³² Onyanga-Omara J. 'Parents, Trump and the pope make last-ditch attempt to save a dying British baby.' USA TODAY July 6, 2017, Available at https://www.usatoday.com/story/news/world/2017/07/06/parents-trump-and-pope-make-last-ditch-attempt-save-dying-british-baby/454910001/ accessed 19 September 2017 at 2:18pm
³³ Op. cit 1

³⁴ Jacobs B. and Pidd H. Donald Trump offers help for critically ill baby Charlie Gard.' The Guardian, 3 July 2017. Available at https://www.theguardian.com/us-news/2017/jul/03/donald-trump-offers-help-for-terminally-ill-baby-charlie-gard. Accessed 10th July 2017 at 4:54pm.

³⁵ Dougall S. '"We'li help save Charlie Gard" – Donald Trump wades in row over sick baby.' The Daily Star, 3rd July 2017 Available at www.dailystar.co.uk/news/latest-news/626985/charlie-gard-donald-trump-twitter-britain-great-ormond-street-hospital/ Accessed 11 July 2017 at 8:09pm

³⁶ Donald Trump via Twitter. Available at https://twitter.com/realDonaldTrump/status/ 3 July 2017 at 7:00 am. Accessed 10th July 2017; Foley Elise (2017) 'Donald Trump Tweets U.S. 'Would Be Delighted' To Help Terminally Ill U.K. Infant'. 3 July 2017 the Huffington Post. Available at

www.huffingtonpost.com/entry/donald-trump-charlie-gard_us. Accessed 10th July, 2017 at 5:13pm.

37 Baynes C. 'Charlie Gard: Donald Trump 'to confront Theresa May over terminally ill baby boy' July 6, 2017, Available at http://www.independent.co.uk/news/uk/politics/charlie-gard-donald-trump-theresa-may-g20-summit-terminally-baby-boy-us-uk-court-ruling-pope-a7826291.html. Accessed 28 August 2017 at 38 Deer C. Law, Ethics, and Emotion: the Charlie Gard Case, Available at BML 2017; 358; 3152 doi:

³⁸ Dyer C. Law, Ethics, and Emotion: the Charlie Gard Case. Available at BMJ 2017; 358:j3152 doi: 10.1136/bmj.j3152 (Published 2017 July 04). Accessed July 30th, 2017 at 11:12am.

³⁹ Bosely S. 'US Doctor's Intervention in Charlie Gard Case Raises Ethical Questions'. The Guardian, 25 July 2017. Available in the Guardian News https://www.theguardian.com/uk-news/2017/jul/25/. Accessed 30th July 2017 at 11:23am.

for Charlie Gard, it can be said that the doctors in the United States and even the Vatican who offered to treat him have offered some hope. Like his parents, the Americans believe that Charlie has a right to life and this should be exhausted before he is deprived of life-supporting treatment. To the parents of Charlie, the intervention of President Trump gave them hope. However, the Daily Mail reported that certain experts were of the opinion that the "interference" by President Trump and the Vatican were "cruel" and offered "false hope." The issue of baby Charlie, while it transcended governments, also sparked several debates.

The Rights of Baby Charlie

A right is that to which one has a valid claim. It is the liberty to enjoy a certain privilege, act in a certain manner or refrain from acting in a certain manner.⁴² Human rights may, therefore, be defined as those rights to which every human being may justly claim. They are rights which may be enjoyed by anyone and are not to be dependent on the will of another human being.⁴³ The right to life, is the most basic and fundamental of all human rights as all other rights depend on the existence and enjoyment of this right by an individual.⁴⁴ Article 3 of the Universal Declaration of Human Rights, states that, everyone has the right to life, liberty and security of persons.⁴⁵ Article 4 of the African Charter, also guarantees, the right to life in stating that, "human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right."

The Constitution of the Federal Republic of Nigeria, ⁴⁶ in section 33(1), guarantees the right to life in the following terms, "every person has the right to life and no one shall be deprived intentionally of his life, save in execution of a sentence of court in respect of a criminal offence of which he has been found guilty." Since it has been established that everyone has a right to life, it goes without saying that this right to life extends to children. It is unanimously agreed that this right, which is applicable to children includes a day-old baby. However, it is still

^{40&#}x27;Op. cit 19

⁴¹ http://www.dailymail.co.uk/video/news/video-1495855/Very-cruel-Expert-blasts-Vatican-Trump-Charlie-Gard.html (2017) 'Very cruel: Expert blasts Vatican and Trump over Charlie Gard' (accessed September 18, 2017 at 2:05pm).

⁴² Ogbu O. N. (2013) Human Rights Law and Practice in Nigeria, 2nd Revised Edition. (Enugu, Snapp Press Ltd, 2013)

⁴³ United Nations Department of Public Information (1998) The Universal Declaration of Human Rights: A Magna Carta for all Humanity.

⁴⁴ Op. cit. 42

⁴⁵ Op. cit. 43

⁴⁶ Constitution of the Federal Republic of Nigeria, 1999 (As Amended)

controversial whether unborn children should also enjoy a right to life but the right of a nonautonomous child to life no matter how young is unquestionable.

Some of the laws that define the right of the child to life, include the following;

- The Children Act (England and Wales—1989 and 2004). This Act generally makes
 provision for the care of a child and the duties of parents and guardians. There are no specific
 instructions for end of life decision making but like all child laws, it emphasises the following
 principles as important;
 - a. All decisions to be made about a child should be in his best interest.
 - b. Where the child is of age, efforts should be made to accommodate a child's feelings and wishes and regard made to any harm which may have been suffered by that child.
 - c. Parental rights and duties must be exercised in the child's best interests.
- The United Nations Convention on the Rights of the Child. The United Nations Convention
 on the Rights of the Child (UNCRC) applies to every child and young person under the age of
 18 and was ratified by the UK in 1991. Although, it cannot be used by UK courts directly, the
 UK government is by the ratification, bound to honour it and make all the child laws compatible
 with it.
- The Human Rights Act (HRA) 1998⁴⁷ incorporates and gives effect in the UK to the rights
 and freedoms guaranteed under the European Convention on Human Rights (ECHR). Articles
 of the Convention that deal with the withdrawal of life-supporting treatment, especially with
 regard to children are:
- a. Article 2: the right to life and the positive duty to protect it
- b. Article 3: the prohibition of inhuman and degrading treatment
- c. Article 5: the right to liberty and security of the person
- d. Article 8: the right to respect for private and family life
- e. Article 9: the right to freedom of thought, conscience and religion
- f. Article 14: the prohibition of discrimination in respect of enjoyment of the other rights

As observed by Larcher et al,⁴⁸ "Although there is a positive obligation to protect life, in certain cases, treatment can be withheld or withdrawn, where it is in a child's best interests to do so, even if this will result in the child's death. When tasked with intervening in disputes which

⁴⁷ UK Human Rights Act (UKHRA) 1998.

⁴⁸ Larcher V, Craig F, Bhogal K, et al 'Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice.' Archives of Disease in Childhood 2015;100:s1-s23. http://adc.bmj.com/ on July 21, 2017 - Published by group.bmj.com

have arisen over the withholding or withdrawing of treatment, judges seek to balance the duty to respect and protect life (Article 8) against the duty not to inflict inhuman and degrading treatment (Article 3), whilst attempting to respect the provisions of Articles 8 and 9."

Can the right to life be the most important life of Charlie or the right to dignity? His parents insisted on the right to life and for this reason, they fought in court to the highest level. His doctors, on the other hand, feel that his right to dignity should be protected and be treated as more important. Both sides were engaged in court in this debate. It is opined that no right is more important than the other as they are intertwined.

Patient Autonomy versus Beneficence

A major dilemma in the medical world is the fight between autonomy and beneficence. Beneficence means to do good. It is that branch of medical ethics that obliges the doctor to seek the good of others. It involves preventing the infliction of harm by others and promoting good. This also very well, describes the relationship and responsibility of a parent to a child. Therefore, basically, the doctor has the same intentions as the parents. However, doctors are also bound by the Hippocratic Oath. According to Hippocrates, the purpose of medicine is, "To do away with the sufferings of the sick, to lessen the violence of disease and to refuse to treat those who are overmastered by their disease." To most doctors, this would include withdrawing life-supporting treatment from patients when there is no other possible treatment for them. According to Wilkinson and Savulescu, of it is ethical for doctors to decline to provide treatment that is judged to be medically inappropriate or futile, either when such treatment is contrary to the interests of the patient, or when there are insufficient resources to provide treatment.

In making end-of-life decisions, a patient usually has the utmost say. This is because doctors would usually respect the wishes of an autonomous patient. Where a patient for whatever reason is unable to make such important decisions for himself, it falls to a surrogate who is usually a close relative and is expected to know what would be in the best interest of the patient. Whatever the case may be, a patient is entitled to make certain decisions concerning his treatment. Where the patient is a child who is not old enough to make decisions for himself, the parents or other caretakers such as a guardian would usually make the important decisions.

⁴⁹ Street K. et al. 'The decision-making process regarding the withdrawal or withholding of potential life-saving treatments in a children's hospital.' Journal of Medical Ethics 2000;26:346–352, Published by group.bmj.com ⁵⁰ Wilkinson D. and Savulescu J. (2011) 'knowing when to stop: futility in the ICU.' *Current Opinion in Anaesthesiology* 2011, 24:160–165

The doctors would always have the opportunity to offer advice on what they consider to be in the best interest of the child.

In determining the best interest of a child who is on life-supporting treatment, there are many factors to be considered such as the child's comfort, the extension of life and even the possibility of a cure. While a patient has the right to make decisions concerning his or her treatment, the doctor is obliged to do what he/she thinks is in the best interest of the patient. Sometimes, there is a clash between the decision of the patient and the opinion of the doctors. Where the patient is an adult, this might not pose much of a problem as both parties may come to a consensus and at the very worst, the doctor would respect the wishes of the patient.

However, where the patient is a baby or a child who is non-autonomous, the issue of decision-making get a bit more complex as the clash is now between parents and doctors. This is usually the case when the treatment the parents insists on would keep the child alive but leave the child with a poor quality of life like complete paralysis or a completely vegetative state where the child is basically brain dead as in Re J.⁵¹ This, unfortunately, happens quite often. The case of Charliè Gard is one of the numerous examples of this clash. On the other hand, as in Re B⁵², there are some cases where the parents are the ones who want to pull the plug and the doctors or health commissioners are insisting that there are other forms of treatment which may be beneficial to the child.

Wilkinson and Savelescu, 53 believe there are two reasons why a doctor would refuse treatment or life-sustaining treatment or judge a treatment to be medically inappropriate. According to them, the first is that the doctor believes that, further treatment is contrary to the patient's interests and would harm the patient. They further stated that it is a type of paternalistic judgment about the value of treatment and life. Wilkinson and Savulescu, 54 went on to say that either the quantity of life (duration of survival) is so short or improbable, or the quality of their life so reduced, that the pain, suffering, distress and indignities of treatment outweigh the benefits. It is believed that this is the opinion of the doctors at Great Ormond Street Hospital who so far, have been Charlie's treating physicians.

The second reason according to Wilkinson and Savelescu, why a doctor would refuse treatment or life-sustaining treatment or judge a treatment to be medically inappropriate, and which is a

⁵¹ Re J (a minor) (wardship: medical treatment) (1991) Fam 33

⁵² Re B (a minor) (wardship: medical treatment) (1981) 1 WLR 1424

⁵³ Op. cit. 50

⁵⁴ Ibid.

more controversial reason or justification, is that, providing treatment would be harmful to other patients. This justification has nothing to do with Charlie Gard's case.

Savulescu⁵⁵ in a paper titled, "Is it in Charlie Gard's Best Interest to Die", referred to an earlier paper⁵⁶ where he said, "Having spent 20 years in medical ethics, I do believe some lives are intolerable and not worth living, but this is extremely rare." Savulescu,⁵⁷ further stated thus, "The best example is severe dystrophic epidermolysisbullosa. In this condition, the skin relentlessly peels off, causing extreme pain and infection. In the most severe form, the child often dies of infection in the first year of life, even with medical therapy. Severe pain is an intrinsic part of the syndrome; this situation is not the case in Charlie Gard." He went on to explain the concept of distributive justice with regards to Charlie's case. In some cases, treatment may be withheld on the grounds that not only would it be futile but it would deprive another person to whom it would be more beneficial. However, this is not the case with Charlie Gard as his parents have been able to raise money through a GoFundMe project to pay for his treatment. As such, the right thing to do would be to allow his parents to take him to the USA for treatment.

Wilkinson and Truog et al,⁵⁸ opined that parents should be allowed to make such decisions if there is any hope and cost, poses no problem. They stated thus, "When it comes to experimental treatment, there can be different reasonable views among health professionals about how to weigh up the chance of benefit against the burdens of the treatment. They went further to state that in the face of such disagreement, the decision properly belongs to the parents." Wilkinson⁵⁹ in a later write-up suggested that "Assuming the treatment is affordable, and the parents want it, it should be provided. However, when no health professionals think that the experimental treatment is worth pursuing, parents' request for treatment should not be granted" In the case of Charlie Gard, the doctor in the United States of America, though they were in the minority, believed that there was some hope for Charlie. It is opined that though the chances of the experimental treatment being successful were very slim, it was still worth trying.

⁵⁵ Savulescu J. 'Is it in Charlie's best interest to die?' Available at www.thelancet.com. May 5, 2017, http://dx.doi.org/10.1016/S0140-6736(17)31204-7

⁵⁶ Savulescu J. (2006) End-of-life decisions. Medicine 2006; 33: 11-15.

⁵⁷ Op. cit. 55

⁵⁸ Wilkinson D, Truog R, Savulescu J. 'In favour of medical dissensus: why we should agree to disagree about end-of-life decisions.' *Bioethics* 2016; 30: 109–18.

⁵⁹ Wilkinson D. 'Beyond resources: denying parental requests for futile treatment.' Available at www.thelancet.com. Published online May 4, 2017, http://dx.doi.org/10.1016/S0140-6736 (17)31205-9.
Accessed 19 July 2017 at 1:34pm

End of Life Decision Making: Parents versus Doctors

It may be argued that the parents of a sick child have a right to take the child elsewhere for treatment and must be allowed to do so, unless it puts the child at significant risk of harm. According to Carnevale et al, 60 in England, patient autonomy is not given as much importance as beneficence, while in countries like America and Canada, patient autonomy and by extension, parental autonomy is more respected. As a result, court battles like the case of Charlie Gard, are more likely to occur in England which may remain more paternalistic in treatment decisions for children

Because non-autonomous children lack the ability to make decisions for themselves, they rely on their parents or caregivers to make such decisions for them. It is agreed that in any situation, the best interest of the child should be of the utmost importance. The dilemma arises, when it is time to determine who should decide what is actually in the best interest of the child. Should it be the parents or should it be the doctors? In cases where there is a conflict between the doctors and the parents of the non-autonomous child, should the court be allowed to intervene? Laws in some countries like England and Nigeria, agree that the child becomes the ward of the court in such situations and the court is allowed to appoint a guardian ad litem, who would be able to determine what is in the best interest of the child from an objective point of view.⁶¹

It may be argued that the parent of a child is in the best position to know what is best for their child. On the flip side, it may also be argued that a parent of a sick child cannot be trusted to make logical decisions to prevent the child from suffering. If the child is so sick that they have to be placed on life support in the first place, such parents have grief and even a bit of selfishness to deal with at a time when the child's best interest should be of the utmost importance. Carnevale, 62 opined that based on experience, superior medical knowledge and objectivity, doctors would be in a better position to make decisions about pulling the plug on a non-autonomous child.

Schneider and Rice,⁶³ discussed a case similar to Charlie's case. Joseph Marachli, a Canadian baby was diagnosed with a rare progressive and incurable neurological disorder known as

⁶⁰ Carnevale F. A., Canoui P., Cremer R. et al. 'Parental involvement in treatment decisions regarding their critically ill child: a comparative study of France and Quebec'. 2007, *Paediatric critical care med*; 8:337-42.
⁶¹ Children Act of England and Wales, 1989, 2004; Child's Right Act of Nigeria 1991

⁶² Carnevale F. A. 'The birth of tragedy in paediatrics: A phronetic conception of bioethics'. 2007 Nurse ethics 14:571-82 (PubMed)

⁶³ Schneider M. and Rice S. (2017) 'Baby Joseph, focus of treatment dispute, dies in his sleep.' Cable Network News, 28 September 2011. Available at www.cnn.com/2011/09/28/health/baby-joseph/index.html. Accessed 28th July 2017 at 10:41am.

Leigh's disease. His parents wanted a tracheotomy performed. They admitted that while their son's disease was terminal, the procedure would extend his life by some months enabling him to die at home where his parents could care for him. The Canadian doctors refused. In their opinion, the treatment would be futile. It was also reported that his parents then fought to have him transferred to the United States and with the support of pro-life groups such the Catholic group, Priests for Life which funded the entire surgery, they succeeded According to Hutchison's report with the ABC News Medical Unit,64 Joseph Marachli's life was extended by several months and he was able to die at home. While the Canadian doctors were right about the terminal nature of Joseph's disease, his parents made the better choice. After the surgery, he was able to respond to both parents and make some movements. Considering the fact that the parents of a child are the ones who would live with the consequences of whatever decision is made, this writer poses a question whether it would not be more appropriate to let parents make decisions, they believe, they can live with? However, on the other hand, it is relatively safe to also argue that when parents are allowed to make such decisions, what they consider to be in the best interest of the child, are most times, inseparable from their own interest or the interest of the family at large.

The above case of Joseph Marachli goes to show that parents would always want to be involved in end of life decisions concerning their children and cannot be expected to readily agree with doctors who say that death is the best option. They would do anything and might make rash decisions in the process. Another case relevant to this discourse is that of Ashya King whose story was followed closely by The Guardian. Ashya's parents were not ready to wait for the court or even doctors to decide on the mode of treatment for their son. Against, the advice of the doctors handling their son, they desired proton therapy over conventional chemotherapy for their son who had just had a brain tumour removed. Khomamai and Doward, for eported that on August 28th, 2014, the parents took Ashya and absconded by ferry to France. However, they were found and arrested in Spain while their son was rushed to the hospital for urgent

⁶⁴ Courtney H. and ABC News Medical Unit (2011) 'Baby Joseph dies at home after long treatment battle.' ABC News, 28 September 2011. Available at http://abcnews.go.com/Health/Wellness/baby-joseph-dies-home-long-treatment battle/story? Id=14623722 Accessed July 15, 2017 at 11:02am

⁶⁵ The Guardian. 'Parents of Ashya King put him at risk, report says' https://www.theguardian.com/uk-news/2015/sep/24/parents-ashya-king-put-him-risk-report-says Accessed 3 November 2017 at 11 30 pm 66 Khomami N. and Doward J. 'Parents arrested as missing Ashya King found by police in Spain'. The Guardian, 31 August 2014. Available at https://www.theguardian.com/society/2014/aug/31/ashya-king-found-spain-parents-arrested. Accessed 30th July 2017 at 6:22pm

treatment. However, as reported by Bosely,⁶⁷ the High Court in Britain on September 5th, 2014 ruled that Ashya could receive proton treatment in Prague. Ashya received his treatment on September 9th, survived and by March the next year, Davies⁶⁸ reported that according to his father, new scans had shown that Ashya was cancer-free. After his case, the NHS decided to start paying for children with medulloblastoma to travel abroad and receive proton therapy.

The Place of the Court in Making End-Of-Life Decisions

In situations where children are unable to make decisions, it is accepted that parents have the responsibility to make decisions on their behalf. It is assumed that parents with the love and commitment towards their child's welfare, while sharing religious, cultural and family beliefs with the child, are in the best position to make sound decisions on behalf of their child. It is not in doubt that parents in certain cases may be too emotionally involved to make objective decisions that are in their child's best interests. The concept of parental responsibility which enables an individual to make decisions on behalf of his or her child, in the child's best interests is recognised. This is the position in Nigeria under the Child's Right Act, 1991. Further discussion on the Nigerian position is in the latter part of this paper. In certain circumstances, the court can take on parental responsibility or it can be sought by external persons, such as social workers and healthcare providers.

In some jurisdictions like England, where there is a disagreement between the parents or caretakers of the non-autonomous child and doctors, the court gets to be the decision maker. It does this by appointing a guardian for the child, who is supposed to make decisions in the best interest of the child, regardless of the parents' feelings or the doctor's opinions. The child's guardian is expected to be objective and unbiased. However, in most cases, the court has ruled in favour of the doctors. There are however rare exceptions where the court rules in favour of the parents against medical professionals. In *Child MB*,⁶⁹ the court ruled against fourteen (14) doctors to sustain life-supporting treatment for a child.

This paper poses that question - whether the court has the right to give a ruling to remove a life-supporting machine on a child, when all the treatments available have not been thoroughly explored and exhausted. At this juncture, it is important to know the place of the court. The

⁶⁷ Bosely S. 'Ashya King given legal go-ahead for cancer treatment in Prague'. The Guardian 5 September 2014. Available at https://www.theguardian.com/uk-news/2014/sep/05/ashya-king-prague-proton-beam-therapy-court-ruling. Accessed 30th July 2017 at 6:30pm

 ⁶⁸ Davies C. 'Ashya King's parents say he is cancer-free after proton therapy.' The Guardian 23 March 2015.
 Available at https://www.theguardian.com/uk-news/2015/mar/23/ashya-king-now-free-of-cancer-after-proton-therapy-say-parents. Accessed 30th July 2017 at 6:35pm
 ⁶⁹ [2006] EWHC 507 (FAM)

court falls into the judicial arm of government. The involvement of the court in taking a decision where there are conflicting positions between the doctors and relatives takes this discussion in the paper to the question raised by Taylor⁷⁰ as to "who is ultimately responsible for the health and well-being of our children" and "who decides on what is best for them" Taylor cited in his article several cases and advocated for parents freedom of choice in the healthcare of the child. It is opined that the overriding stand on this issue should be the best interest of the child. The effect is that nobody should make any decision to take away the life of a child neither should a child be made to continue to be on a life support except it is in the best interest of the child.

Charlie to Die or Not To Die

On July 10th 2017, Charlie's parents having, gone to the European Court of Human Rights at heard from a doctor in the United States of America, gotten messages from the Pope and having the American President involved and offering support went back to the High Court and asked the judge to review the case. 71 The judge gave them less than 48 hours to provide new evidence that the experimental treatment would work.⁷² Judge Francis, the judge who first heard Charlie's case referred to the U.K Court of Appeal's decision in the case of Wyatt v Portsmouth NHS Trust⁷³ and said "In our judgment, the intellectual milestones for the judge in a case such as the present are, therefore, simple, although the ultimate decision will frequently be extremely difficult. The judge must decide what is in the child's best interests. In making that decision, the welfare of the child is paramount, and the judge must look at the question from the assumed point of view of the child. There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable. The term 'best interests' encompasses medical; emotional, and all other welfare issues."74 In situations like this, the court has two issues to consider. First, will new treatment help the child in any way or will it only cause more pain? Where treatment might be burdensome, financially or otherwise, the other issue to consider is if the burden outweighs the benefit. For Charlie, his doctors are of the opinion that he is in pain, pain that won't go away even with nucleoside treatment and "when, as in his case,

⁷⁰ Taylor Paul Anthony 'Who knows what's Best for your Children? You? Or the Government' 13 April 2017 Available in www4.dr-rath-foundation.org Accessed on 19 September 2017 at 5:29pm

⁷¹ Op cit. 28; op.cit. 31

⁷² Op. cit 28

⁷³ Wyatt v Portsmouth NHS Trust. 2005: EWHC 117

⁷⁴ Op cit. 16

the consensus of all the doctors who have examined him is that the treatment would be futile, there are no benefits to put on the scale."⁷⁵

On July 24th, 2017, Greene and Clarke, ⁷⁶ reported that Charlie's parents decided to stop fighting after new scans showed that the damage that had been done to his brain and muscles were unalterable. Robinson and Greenhill, ⁷⁷ stated that these new scans showed no benefit to weigh against the risk of flying baby Charlie to the United States for treatment. Yate and Connie made a decision to take Charlie home so that he could die there but his ventilator could not fit into their house. Mendick ⁷⁸ said that the parents decided to spend Charlie's last hours with him at a hospice where he was being given palliative care which relieved him of whatever pain might be feeling. Baby Charlie died on the 28th of July, 2017, a day after the court ordered him to be moved to the hospice and life support to be withdrawn. ⁷⁹

The fight put up by Charlie's parents is considered, not out of place. Yate and Connie were in constant contact with an American couple whose baby survived due to the experimental treatment offered by the American doctor. They might have encouraged them and given them a reason to fight on. Smith-Squire and Robert, 80 reported on Arthur and Olga Estopinan's baby, Arturito, who was the first to receive the new experimental treatment in the United States. They, however, pointed out that while the Estopinan baby has MDDS, he suffered from a different variant. Arturito survived and said to be alive. Smith-Squire and Roberts, 81 are of the opinion, that if Arthur and Olga Estopinan had not tried, Arturito would have been dead.

Another compelling case in favour of trying all available treatments is the case of Haleigh Poutre, 82 another child whom doctors concluded would die due to health-related issues.

⁷⁵ Op. cit. 38

⁷⁶ Greene R. and Clarke H. 'Charlie Gard's parents give up battle to take son to US.' Cable Network News, 24 July 2017. Available at www.edition.cnn.com/2017/07/24/health/charlie-gard-decision/index.html

⁷⁷ Robinson M. and Greenhill S. (2017) 'High Court judge to rule TODAY on whether to allow Charlie Gard's parents to take him home to die as doctors say his ventilator 'cannot fit through the family's front door" Daily Mail, 25 July 2017. Available at http://www.dailymail.co.uk/news/article-4728210/Charlie-Gard-s-parents-endure-High-Court-case.html Accessed 28th July 2017 at 7:30am

Mendick R. 'Oreat Ormond Street wants Charlie Gard moved to hospice to die by Friday, court hears'. The Telegraph, 26 July 2017. Available at http://www.telegraph.co.uk/news/2017/07/26/charlie-gard-judge-decide-babys-life-will-end-parents-legal/. Accessed 29th July 2017 at 3:44pm

⁷⁹ Bever L. 'Our beautiful boy has gone' Parents of Charlie Gard say he has died.' The Washington Post, 28th July 2017. Available at www.washingtonpost.com/news/worldnews/wp/2017/07/28/parents-of-charlie-say-he-has-died-reports. Accessed 29th July 2017 at 4:02pm

⁸⁰ Smith-Squire A. and Roberts S. 'If we were British, our son would be dead.' The Sun News 13th April 2017. Available at https://www.thesun.co.uk/living/3318065/arthur-olga-estopinan-arturito-charlie-gard-court-case/. Accessed 10th July 2017 at 8:00am

 ⁸¹ Ibid.
 ⁸² Wen P. 'Timeline - the case of Haleigh Poutre'. The Boston Globe, 3 August 2014. Available at https://www.bostonglobe.com/2014/08/02/timeline-the-case-haleigh-poutre/9j3BhnkLrA8AxlYo4PZWoN/story.html Accessed July 15, 2017 at 9:27am.

According to Wen's timeline, 83 the child was born in 1994 a healthy child. By the time she was four, she was adopted and lived with an aunt. At age 11 in 2005, she was rushed to the hospital, diagnosed to have suffered severe brain injury from frequent abuse and the doctors involved in her treatment claimed she was virtually brain dead and if left on life support, would be in a persistent vegetative state. On October 5th, 2005, a judge approved a request from the Commissioner of the Massachusetts Social Department, to withdraw life-supporting treatment. Her guardian appealed but the appeal was dismissed. On January 17, 2006, the Court of Appeal, ruled in favour of the doctors that life support should be withdrawn. The very next day, she woke up from a coma shortly before her scheduled removal from life support breathing on her own and responding to commands. 84

Were Baby Charlie a Nigerian child: The position of the law

Section 1 of the Nigerian Child's Right Act, 2003, states that the best interests of the child shall be of the utmost importance. The best interest of the child would be considered to be that which is for the child's good and would keep the child away from undue suffering and harm. It does not refer to physicians but it does state that all individuals and institutions, which would include hospitals and medical personnel, must act in the best interest of the child.

The Act recognizes that there would be situations when decisions would have to be made on behalf of a child. To this effect, sections 82-91 provide for the guardianship of a child including occasions when a guardian may be appointed. Section 83 gives the guardian of a child parental responsibility unless he is appointed a guardian ad litem. Appointment of a guardian may be done whether the parents of a child are present or not if the court feels that the parents may not be able to make the right decisions for a child.

Section 59 of the Act empowers the court to order a care or supervision order in proceedings in which a question arises as to the welfare of a child. In the case of life-supporting treatment, the court would obviously rely on doctors and other healthcare providers to provide support for or against sustaining life-supporting treatment. The Child's Right Act does empower the court to settle disputes affecting the welfare of a child which may arise between parents or between other joint guardians in section 88

⁸³ Wen P. 'Missed warning signs nearly killed Haleigh Poutre' *The Boston Globe*, August 3, 2014. Available at https://www.bostonglobe.com/metro/2014/08/02/missed-warning-signs-nearly-killed-haleigh-poutre/fgTaEv2QlbSUxCnKAFhbXJ/story.html. Accessed July 15, 2017 at 9:44am.
⁸⁴ Op. cit 80

The Act in Section 4 gives the child a right to survival and development, provisions which are related to section 13(1) which states that a child is entitled to the best attainable state of physical, mental and spiritual health. The Act, therefore, implies that it is the right of a child to be treated when ill, especially when it can be afforded and it would not cause undue harm or disadvantage to another. From this it can be inferred, that while doctors may have more experience and superior medical knowledge than the parents of a child, it is the right of a child that all options in his/her best interest be explored first before a decision is made to let him/her die.

If baby Charlie were a Nigerian child, his parents would be his guardians by section 82 and would have primary responsibility for him. They would be the ones making all the decisions based on the advice of his doctors. If baby Charlie was a Nigerian child, his case might still get to the court, and by the Child's Right Act, it is safe to believe that the court when taking a decision, the best interests of the child shall be of the utmost importance

RECOMMENDATION

It is posited and recommended that should be a standard for surrogate decision-making that has to do with life-supporting treatment and end of life decisions. This will provide some sort of guidance for decision makers, be they doctors, parents or the court as the case may be.

It is recommended that before a claim is made, that a child has a right to die with dignity and be protected from inhumane treatment, the right to life should be placed first.

It is also recommended that in considering the right to life and any other right, that a child is entitled to, the best interest of the child should take primacy.

CONCLUSION

The law seems to stick firmly with making decisions which are in the best interest of the child. For a child on life-supporting treatment, what is in the child's best interest would be seen to have been done when all options have been explored, all treatments and therapies tested. This will be so, especially, when it is not going to expose the child to significant harm or cause significant harm to another before a decision is made to pull the child off life-supporting treatment.

When everything has been done and there is no way forward, then the right to die with dignity can come in. It is easy to agree that life-supporting treatment may be withdrawn when there is no way forward. It is opined that Charlie's parents were easier to convince, to allow the removal

of the life-supporting machine, when they saw that they had done everything humanly possible, to save their son Charlie and that the new treatment would be of no use.

Every person, including a child, has a right to life. It is trite to note that all other rights including the right to dignity are based on the right to life. In the battle over children's life, decision makers should keep this in mind.