Ethical Issues And Challenges Of Managing Severe Anaemia In Jehovah Witness Paediatric Patients: 2 Case Reports.

Oyapero O[1] Diaku-Akinwumi I N[1] Ubuane PO[1]

ABSTRACT

The Jehovah's Witnesses are a rapidly growing religious group in the Western world and in Nigeria with an estimated 7 million members worldwide. Procedures generally regarded as unacceptable by Jehovah's witnesses include transfusion of whole blood, packed red cells, white cells, plasma, platelets and preoperative autologous blood collection with storage for later reinfusion. In the event of a refusal when seriously indicated, it creates an ethical dilemma for the health care professional, as well as being a frustrating experience. Central to modern medical ethics is a respect for the patient's autonomy, while the Physician respects this, he also must abide with the principles of beneficence, non-maleficence and Justice.

In the case of minors of Jehovah's Witnesses requiring blood transfusion, a standard of care procedure should be designed for use in emergency care and elective procedures. Standard steps of procedures must be agreed upon by management as well as the ethics committee of every hospital. This report examines two cases of Jehovah's Witnesses minors whose parents refused a much needed blood transfusion for emergency procedures due to religious reasons.

Key words: KEYWORDS: Jehovah's Witnesses; Blood Transfusion; Anaemia.

INTRODUCTION

The Jehovah's Witnesses are a rapidly growing religious group in the Western world and in Nigeria with an estimated 7 million members worldwide in over 230 countries.[1] They receive most forms of medical care, including surgery, but are deeply committed to the teachings of their church and the prohibition of blood their church and the prohibition of blood transfusions even at the point death. Treatment generally regarded as unacceptable by Jehovah's witnesses include transfusion of whole blood, packed red cells, white cells, plasma, platelets and preoperative autologous blood collection and storage for later reinfusion (pre-deposit). When a patient refuses a treatment option and could die in a potentially *treatable* situation creates an ethical dilemma for the health care professional, as well as being a frustrating experience.[2] The basic common law right of bodily

Correspondence: Dr. Oyapero O.

Email: oyejoke_ba@yahoo.com

Department of Paediatrics, Lagos State University Teaching Hospital, Ikeja, Lagos.

self-determination establishes that every person of sound mind is master over his own body. Central to modern medical ethics is a respect for the patient's autonomy and the fundamental principle of informed consent. While the Physician respects this, he also wants to abide with the principle of *beneficence, non-maleficence and the* principle of *Justice.*

The children of Jehovah's Witnesses requiring blood transfusion present the most difficult management problem. Legal and ethical standards regarding the autonomy and rights of minors have evolved over time. Due to this evolution, confusion still exists within the medical community regarding the appropriate response to a minor whose parents refuse medically necessary treatment.[3] This report examines two cases of Jehovah's Witnesses minors whose parents refused a much needed blood transfusion for emergency procedures due to religious reasons.

CASE 1

J.F., an 11year old boy whose parents were Jehovah's witnesses, was admitted to the Paediatrics Emergency ward of the Lagos State University Teaching Hospital on account of a 2/52 history of severe headaches that was not relieved by any medication. He also had a low to moderate grade fever, alteration in consciousness and deteriorating neurological function which was rapidly progressive. There was no history to suggest otitis media or any infection from a distant source. On physical examination, he was noted to be pale, febrile, lethargic and drowsy with focal neurologic deficits and a Glasgow coma scale of 11. There was no evidence of spinal disraphism anywhere in the body nor any portal of entry of infection.

Blood investigation showed 6 gm% haemoglobin with leukocytosis while plain and contrast-enhanced CT scan of the brain revealed a ring enhanced lesion in the temporal lobe region with oedema of the surrounding tissues. A diagnosis of meningitis with intracranial abscess was made. Antibiotic regimen with supportive therapy was continued for the patient while Neurosurgical review indicated an urgent need for surgical intervention. The patient's packed cell volume (PCV) was adjudged sub-optimal for

neurosurgical intervention to drain the brain abscess.

The parents of the patient clearly refused a blood transfusion after detailed counseling by health workers and also refused to sign the informed consent form to allow the operation. The church representatives remained supportive of their members and insisted that transfusion must not be involved in the Neurosurgery. A multidisciplinary team involving the paediatric haematology unit, neurosurgery unit, social workers, Church medical representative, the hospital lawyer, and hospital management worked closely together to ensure optimum care for the patient. Artificial blood was requested but could not be provided by the parents and the church team on account of cost and scarcity of the product in Nigeria. The patient was commenced on Erythropoietin to optimize his PCV. When the Hospital initiated a legal move to have the patient treated in line with best practices due to a decline in his neurological status, the parents obtained a voluntary discharge after stating that they had contacted a center that would do bloodless surgery. After several efforts to reach the Church liaison officer, he informed us that the patient pulled through after going through a difficult surgery. He however gave no information about the present neurological status of the child.

CASE 2

6 year old boy A.F. whose parents were Jehovah's witnesses, presented in the paediatrics emergency room with a 7 days history of fever, pallor and weakness. He was a known patient of the hematolology/sickle cell unit who was diagnosed at 3years of age and had been registered for care at the clinic. He was the last child in a family of four children. Two of his siblings had sickle cell anemia and he had lost a sibling with sickle cell anaemia due to severe anaemia when their parents refused blood transfusion for religious reasons in spite of counseling and appeals from the health worker.

On physical examination, he was found to be severely pale, extremely weak, with tachycardia and in heart failure. His packed cell volume (PCV) was 9% and he needed to be

urgently transfused. Supportive therapy and blood substitutes were commenced but his parents strongly refused blood as a treatment option even though the precarious nature of his situation was explained to them. He died the next morning from the complications of severe anaemia before any arrangement could be made to declare him a ward of the state. Efforts to have the deceased's parents bring his other siblings with sickle cell anaemia to the clinic for evaluation of hydroxyurea treatment to reduce the need for blood transfusion has so far been unsuccessful.

DISCUSSION

Brain abscess is a focal, intra-cerebral infection that begins as a local area of infection and develops into a collection of pus surrounded by a well-vascularized capsule. It requires an urgent Neurosurgical intervention. Sickle cell anemia (SCA) is similarly a life-long debilitating disease often requiring multiple and frequent hospital admissions. Patients that present with either of these conditions may require the transfusion of blood or blood products as part of their management regimen especially when their haematocrit is extremely low. Medical or surgical treatment in Jehovah's Witnesses however presents complex ethical and legal issues to the physician when the transfusion of whole blood or blood products is indicated.

Jehovah's Witnesses have absolutely refused the transfusion of blood and primary blood components (red cells, white cells, plasma and platelets) ever since these techniques became universally available. It is deeply-held core value to them, and they regard a non-consensual transfusion as a gross physical violation.[4] Many of the adherents' beliefs are based on literal translations of the Bible. Genesis 9 and Leviticus 17 state that one cannot eat the blood of life; these passages are interpreted to include the exchange of blood products. For the Jehovah's Witness, receiving blood products may lead to excommunication and eternal damnation. Understanding these facts is crucial when caring for patients who are Jehovah's Witnesses.[5,6]

In the case of minor children, however, the U.S. Supreme Court in Prince vs. Commonwealth of Massachusetts has ruled that, "Parents may be free to become martyrs themselves, but it does not follow that they are free, in identical circumstances, to make martyrs of their children." The court determined that the right to practice religion freely does not include liberty to expose children to ill health or death.[7] Medical ethics include the virtues of professional self-respect, collegiality and competence, as well as the principle of respect for patient's confidentiality, beneficence, *non-maleficence*, respect for life and classless treatment.[8]

Patients due for elective surgery have a number of alternatives to blood transfusion. Agents that increase red cell production such as erythropoietin, iron, and B-complex vitamins are important sources for erythropoesis.[9] Folic acid supplementation and an iron-rich diet can also be useful both pre- and postoperatively.[10] In the management of sickle cell anaemia, hydroxyurea has been found promising in reducing the blood treatment needs and disease complexity. Intraoperative techniques involved in the abatement of haemorrhage such as normovolemic haemodilution, controlled hypotensive anaesthesia, sedation, and muscle paralysis could also be helpful. Emergency treatment may however require that patients are urgently transfused especially if their haematocrit is very low. Blood transfusion with blood and blood products may be the only lifesaving option for a child with severe anaemia that is haemo-dynamically compromised and at the brink of death.

Social and health workers have statutory duty to investigate and take appropriate action to safeguard a child's welfare. The wellbeing of the child is paramount and if, after full parental consultation, blood is refused, the medical practitioner may have to make use of the law to protect the child's interests'. If the court is convinced that a child's life or health is in jeopardy because of a parent's refusal to consent to blood transfusion, they may grant a court order for the transfusion when it has been proven that there are no alternative non-blood treatments available.

CONCLUSION

Time is of essence in the management of Jehovah's Witnesses presenting at a hospital emergency. Early diagnosis and onset of comprehensive care as well as hydroxyl-urea use may reduce complications and transfusion needs. Jehovah's witnesses and their relatives that attend out-patients clinics should be educated about the need to have an appropriate response in case a medical or surgical emergency arises. The Ethics Committee of every hospital must also formulate policy concerning the Jehovah's Witnesses and blood transfusion.[11]

Medical doctors that are Jehovah's witnesses can be incorporated into this committee and a standard of care procedure should be designed to have a prompt response to patients requiring both emergency care and elective procedures. A clear organogram should be designed outlining clear steps to take, both legal and otherwise. The medical department of the Jehovah's witnesses should also make available a list of hospitals that they have identified that undertake bloodless surgery for prompt referral of their patients when indicated.

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