

CLASSROOM DEBATE ON “COUPLES WITH THALASSEMIA GENES SHOULD HAVE OWN CHILDREN AND NOT OPT FOR ADOPTION “BY ROTATION 1 FINAL UNDERGRADUATE MEDICAL STUDENTS IN MUAR, MALAYSIA

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ABSTRACT

Thalassemia is a public health problem in Malaysia and about 4.5% of the Malays and Chinese are β -thalassemia carriers. (George E 1998). A classroom Debate on “Couples with Thalassemia genes should have own children and not opt for adoption” has been conducted as a Teaching learning activity. The activity has been organized by the 10 students of the rotation 1 Year 5 students during the Pediatric posting of 8 weeks' duration. The aim of this activity is to foster learning with a unique learning strategy; to enable students to develop constructive arguments to support opposing views of the given topic; to encourage critical thinking; to raise students' awareness that most issues are not straightforward and that students should learn to form opinions about their position that they can explain or defend with factual evidence. The students have been briefed on day 1 of the posting and the topic given by the Course Coordinator. The rules and regulations has been presented at start of the Debate session held in 4th week of posting, by the Chairperson Veeramorgan.K.. The speakers are allocated a total of 30 minutes per group strictly managed by the timer Salleh.H.. The 3 speakers each from the proposition and the opposition groups spoke, in alternate turns, to put across the message for or against the motion. A panel of 4 adjudicators scored the performances according to marking scheme template. The other two students did the photography and video documentation. The Best speaker and the Best group are awarded prizes. ALL others are also given participatory prizes; all prizes being sponsored by principal author. Conclusion is according to the winning team message that Couples who have the Thalassemia genes should have own children and not opt for adoption giving sound and concrete reasons.

Keywords: Classroom debate; Thalassemia trait; own children and adoption

INTRODUCTION

Thalassemia is a public health problem in Malaysia and about 4.5% of the Malays and Chinese are β -thalassemia carriers. (George E 1998). It can lead to severe transfusion-dependent anemia, and it is the most common genetic disorder in Malaysia.

Where both parents are carriers of the same trait (α - α or β - β couple), genetic counselling should be performed so as to achieve prenatal diagnosis. The couple should be informed of the possibility (1 in 4 chances) of a Thalassemia Major foetus. The diagnosis is made either by chorionic villus sampling or by amniocentesis. Chorionic villus sampling has some advantages, as it can set the diagnosis earlier during the first trimester (11th week), more DNA is obtained by placental biopsy, and it is perhaps safer to penetrate the placenta than the amniotic cavity. On the contrary, amniocentesis has the drawback of being feasible only after the 16th week. The risk of miscarriage does not differ between these invasive procedures, and is estimated to be less than 1%. (Petraikos G, Andriopoulos P, Tsironi M.2016)

When both parents suffer from a certain hemoglobinopathy, like being carriers of Thalassemia, use of donor gametes screened for hemoglobinopathies – preferably donor sperm, as sperm can be more easily available from sperm banks – seems to be the ideal option, while adoption always remain an alternative (Petrakos G, Andriopoulos P, Tsironi M.2016)

Thus, a classroom Debate on ““Couples with Thalassemia genes should have own children and not opt for adoption”” had been conducted as a Teaching learning activity for Final year 5 students in Pediatric posting, Rotation 1 group of 10 students. The aim of this activity is to foster learning with a unique learning strategy; to enable students to develop constructive arguments to support opposing views of the given topic; to encourage critical thinking; to raise students’ awareness that most issues are not straightforward and that students should learn to form opinions about their position that they can explain or defend with factual evidence. (Soe-Soe-Aye & Noor MAM, 2018).

OBJECTIVE

The objective of this paper is to showcase the presentations made on this topic by the 3 speakers each for Proposition and Opposition group and highlight the Introduction, Discussion and Conclusions made upon the Debate session by the Faculty.

LITERATURE REVIEW

All the students and the Faculty did the literature review relating to topic given by Course coordinator on Day 1 of the posting Please refer to the List of the References

METHODOLOGY

All the 10 students (05/2014) posted to the Paediatrics ward in rotation 1 for 8 weeks, participated in the conduct of the classroom Debate session introduced as one of the Teaching Learning activities. The students elected their own Chairperson and Timer for the session and 3 speakers each for PROPOSITION and OPPOSITION of the topic given by Course coordinator on day 1 of the posting. Each one of them did a Literature review as evidenced by the list of References given. The rules and regulations for conduct of the Debate session and the marking scheme for grading of their performances are given in the students’ guidebook. FOUR adjudicators are the panel comprising of 1 Associate Professor and 2 Lecturers from the respective clinical Subjects at the Faculty of Medicine invited by the principal author (+1 Professor = 4).

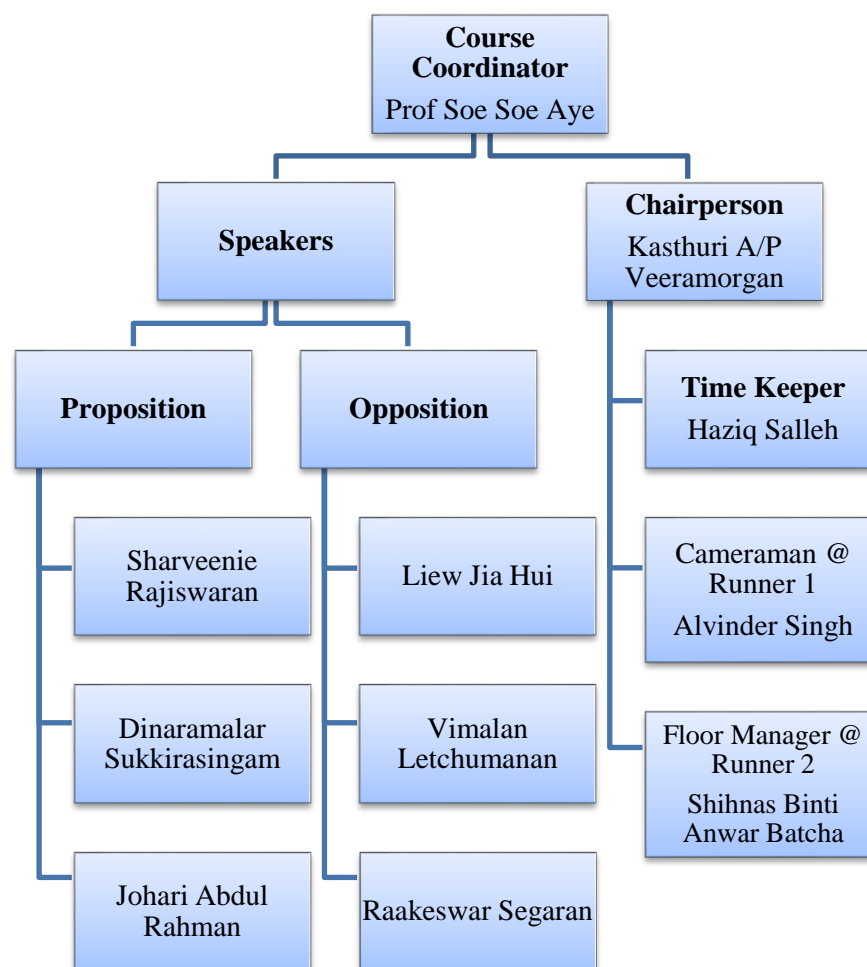


Figure 1. Organizational representation of the 10 students & Course Coordinator

FINDINGS (PRESENTATIONS)

The speakers spoke in turns, one from each group alternating with speaker from other group. However, the 3 presentations from each group are given as below.

PROPOSITION GROUP

1st speaker – MS SHARVEENIE RAJISWARAN

A very good afternoon to the chairperson, Ms. Kasthuri; distinguished panel of adjudicators; cautious time keeper; members of the opposition team and all the members of the floor.

Ben Li, Male, aged 32, a man diagnosed with beta thalassemia major competed in his first New York City Marathon on November 6, 2011. (CFA,2011) As a first-time runner, nothing stopped him from finishing his marathon of 42 kilometres in under 5 hours. Nothing, not even his disease He was placed 35,280 of 47,238 runners, with a finishing time of 4.82 hours.

Today, we the Proposition group, strongly and deeply believe in the motion “Couples who are carriers of thalassemia gene should have their own children and not opt for adoption”. Before I put forward my case today as to why we believe so, let me define the keywords of today’s motion, - ‘Couples, thalassemia, and adoption.’

According the Cambridge dictionary, the word” couples” is defined as two persons who are married or who spend a lot of time together, especially in a romantic relationship. In today’s

context, we're talking about married couples. Next, "Thalassemia" is medically defined as an autosomal recessive heterogeneous group of genetic disorders with defective synthesis of one or more globin chain. This in turn results in defective haemoglobin in our blood. Thalassemia is the commonest human inherited single gene haemoglobin disorder in Malaysia. Lastly, "adoption" is the act of legally taking a child to be taken care of as your own.

Dear members of the floor, why is it that we undoubtedly believe in today's motion? Firstly, let us look at the inheritance of an autosomal recessive disease. If two individuals with thalassemia carrier trait have their own child, the chances of them getting an absolutely normal child is 25%. There is a 50% chance of their child to be a thalassemia carrier and not forgetting to mention, 25% of chances are the child to be born with the disease. This applies to parents who are either both alpha thalassemia carriers or beta thalassemia carrier. Now, this itself goes to show that the chances of the child being normal, and diseased are equal. Am I being oblivious to the fact that the child might have 1/4th probability of being thalassemia? No.

My point is that there is a chance that 25% also have a 50/50 chance of being born without the disorder. Also, there are definite ways to reduce the odds of getting an affected child; close to zero. And against all these odds, even if an affected child is born, there are various promising medical advancements to cope with the disorder today.

Let me summarize a little on alpha thalassemia disorder. If deletion of one α -globin gene occurs, then it results in silent carrier. When deletion of two genes takes place, the individual might be a carrier or have α -thalassemia minor which is usually asymptomatic. Deletion of three genes causes Hb H disease. This cause mild to moderate anemia. In this scenario, some patients may require occasional blood transfusion. Last but not least, a condition called hydrops fetalis occurs if all four of α -globin gene deletion occur. This is the most severe form of α -thalassemia.

Adopting a child is a noble act without second guessing. Please allow me to be clear and state that my team is in no way, shape or form anti-adoption. But we strongly disagree that thalassemia carrier parents have to conform to adoption as being their only option to gain the status quo of parenthood. It is their rights/ autonomy to make informed decision whether or not to bear their own children, and we will stick by it until everyone present here sees our points crystal clear.

In an article published by Borneo Post Online in 2016, the Director of Queen Elizabeth Hospital mentioned that 76% of Malaysian are thalassemia carriers. (H.C, 2016)

Just to give you a better picture, that is 22 M of Malaysians. I would like to raise a question of is it even practical that only 24% of Malaysian are allowed to carry their own children, according to the opposition team?

Assuming that the parents are aware of the carrier status, this couple can go in for genetic counselling to learn in depth about their condition. Genetic counselling is the process of providing information to at-risk couple and families about a genetic condition, in particular information about the diagnosis, recurrence risk, burden of disorder and the various reproductive option, together with helping the families coming to terms with the issues in a non-directive manner. This is primary for them to make informed decision about them bearing their own children.

If they decide to take this route, there are many pre-natal investigations that can be done to find out if the conceived child is affected. Prenatal diagnosis of β -thalassemia should be done by DNA analysis of a chorionic villus sample (10-12 weeks) or amniocentesis (16 weeks) to help parents to make informed decisions about whether or not to continue the pregnancy. This is when the option of therapeutic abortion comes in, if the child is diagnosed with the disorder. For those who deem this point as inhumane, in Asia alone, 35M abortions are done annually regardless of the babies' health condition. (SS, 2017) What is your take on that? Gene therapy offers carrier parents to get pregnant through in vitro fertilization. The unaffected ovum and sperm are carefully selected, fertilized into an embryo and then re-implanted back into the mother's uterus. This ensures 100% chance of carrier parents giving birth to unaffected, thalassemia free babies.

A thalassemia carrier, who is also a proud mother to four children of her own; was interviewed by us in the day care centre of HPSF. Two out of her four children have beta thalassemia major. Her first son, is an excellent student academically, plays state level football, and is a national level taekwondo sparing champion. This, is much more than what an average, disorder-free student today achieves. Even though this cannot be set as a benchmark to prove our point, we are here to discuss on how it is indeed very possible for carriers to bear their own children, and for their affected child to lead a normal, if not close to normal life. One main point to note here is that, thalassemia patients' intelligence is not impaired in any way.

As we move on with this session, the opposition are definitely going to make it seem like adoption is the only, practical and rational choice for carriers. And that we the Proposition group, are the selfish, stone cold, sinful monster for choosing the latter. But sorry in advance to burst your bubble.

The process of adopting a child is not as smooth sailing as it may seem. It comes with its own subset of problems, risks and complications. The adopted child, and the parents will have taboos to face. Members of the floor, what gives you the assurance that an adoption child will be disease-free? We are arguing on the parameters of parents who know at least 3 generations of their own inheritance. What about a child who comes with zero family or medical history? Let me give you a clear-cut example. This information was extracted from a senior staff nurse from the day care of HPSF. She was telling us a story of how a thalassemia carrier couple opted for adoption. Unfortunately, the child they adopted was diagnosed with beta thalassemia major two years into the adoption. This goes to show that adoption is not a journey of beds of roses.

With all these concrete points, yet again I would like to emphasize that the Proposition team strongly believes that 'couples who are carriers of thalassemia gene should have their own children and not opt for adoption'.

2ND SPEAKER- MS DINARAMALAR SUKKIRASINGAM.

Good afternoon, Madam Chairperson, distinguished Adjudicators and Opposition team members. The topic for our debate is 'that Couples who are carriers of Thalassemia genes should have own children and not opt for Adoption' We, the affirmative team, believe that this statement is true.

Why don't thalassemia patients have the equal rights to be born and lead a normal life? Do some of these thalassemia patients have success in life? Do you all know about Rabbi Kohan

Shalomim Y. Halahawi? He is the Founder of the African Hebrew Israelite Community Ha' Yisrayli Torah Brith Yahad, and Doctor of Electro-homeopathic Medicine MD(AM), Edenic-Light Natural Medicine Research Foundation, is known to have Thalassemia B+. (www.cs.mcgill.ca/~rwest/wikispeedia/wpcd/wp/t/Thalassemia.htm)

My first point is the medical advancement that has developed in this day and age. Let me quote thalassemia major patient who is also a successful blogger, "For me, the diagnosis and treatment of Thalassemia Major has improved in ways my parents could not have even imagined when I was diagnosed in 1971. I have gone from spending weeks in hospital in the 70's to now visiting every 3 or 4 weeks to have a four-hour transfusion, then I'm home and back to work and all the chores of modern family life for the rest of my time. I am married and have children who are grown up, graduates and all working themselves." (www.quora.com/) This gives a clear picture of medical advancement from 1970s per se as compared to today's reality. Let me just rephrase the quote in simpler terms. As mentioned, it was common for the thalassemia patients in the 70s to be spending weeks per admission. Now, patients who require blood transfusion only need a few hours' worth of day trip.

There are certain transfusion targets set by the Ministry of health where all thalassemia major should be transfused so as to maintain pre transfusion Hb level at approximately 9 -10 g/dl and post-transfusion Hb at 13.5-15.5g/dl. The above targets allow for normal physical activity and growth, abolishes chronic hypoxemia and reduces compensatory marrow hyperplasia which causes irreversible facial bone changes and para-spinal masses. The transfusion interval is usually 4 weekly intervals. (CPG Transfusion Dependent Thalassemia,2014) Time and again, it is proven without fail that positive changes and reinforcements are continually made to enhance the lives of thalassemia patients.

Proper guidelines had been implemented in monitoring thalassemia patients. According to the clinical practice guidelines, during each admission for blood transfusion, the height, weight, liver & spleen size will be assessed. Every year or more frequent if indicated the growth and development is plotted and monitored. Endocrine assessment is also routinely assessed to look for the thyroid and glucose status. Apart from that, pubertal and sexual development is monitored from 10 years onwards according to Tanner staging of breast and genitalia. Hormonal assay, bone scanning, infection screening and cardiac assessment are also done. Splenectomy is indicated when there are increased transfusion requirements which is 1.5 times than usual and evidence of hypersplenism as documented by splenomegaly with persistent leucopenia or thrombocytopenia. (CPG Transfusion Dependent Thalassemia, 2014)

We are aware that iron overload is a known complication in transfusion dependent thalassemia. But there is solution for most of the problems. Have you all heard of iron chelation therapy? Iron chelation therapy is the removal of excess iron from the body with special drugs. The aims of iron chelation therapy are to prevent or reduce iron overload and hence minimize tissue and organ damage. Serum ferritin level should be kept below 1000 µg/L as it is associated with less iron overload complications while serum ferritin level maintained below 2,500 µg/L significantly improve cardiac disease-free survival. Currently 3 approved iron chelators are Desferrioxamine, Defer prone, Defamation. Serum ferritin level are being assessed where the trend of SF would give a good estimate on the risk of complications secondary to iron overload. (CPG Transfusion Dependent Thalassemia, 2014)

Even though, there are complications of iron overload, every problem contains within itself the seeds of its own solution. Let me list out the complications with management one by one. Short stature and growth failure (height less than 3rd percentile for age and gender) is treated with recombinant human growth hormone. The next complication is delayed puberty (complete lack of pubertal development in girls by age 13 and in boys by age 14) and hypogonadism. For the induction of puberty in thalassemia patients diagnosed with probable hypogonadism, ethinyl estradiol had been used in girls and testosterone depot in boys. No obvious clinical signs and symptoms of hypothyroidism despite abnormal thyroid function is treated by levothyroxine. The early and adequate use of iron chelation can prevent DM and major endocrino-pathies. If there is DM, insulin treatment is required. For thalassemia patients with severe cardiac iron overload or symptomatic cardiac disease, continuous intravenous desferrioxamine is the best treatment option. Alternatively, combination therapy with deferiprone can be considered. As for hepatitis B and C patients can be treated with interferon alpha or PEGylated IFN alpha. (CPG Transfusion Dependent Thalassemia,2014) Thus, members of the floor I would like to highlight on my point that positive thinkers have a solution for every problem.

Let us move on to the curative options of thalassemia. Bone marrow transplantation from human leucocyte antigen (HLA) identical family donors is an established curative treatment option for children with thalassemia. There is a one-in-four chance that any sibling will be HLA identical and siblings who are carriers can be potential donors too!!! Apart from that, umbilical cord blood cells are a potential source of stem cells for transplantation. Transplant outcome is good when it is performed on young recipients with early disease status and good HLA match. (CPG Transfusion Dependent Thalassemia, 2014)

So Madam Chairperson, distinguished Adjudicators and Opposition members, in conclusion we Proposition group, strongly agree that medical advancement has enhanced quality of life of thalassemia patient to lead a life which is as near normal as possible. With that I thank you

3RD SPEAKER: MR JOHARI ABDUL RAHMAN.

A very good afternoon to our chairperson Ms Kasthuri, the cautious time keeper Mr Haziq, panel of Adjudicators, the opposition team and my fellow friends. I can understand why the opposition team wants to reject today's notion.

However, we the Proposition, strongly believe that couples who are carriers of thalassemia gene should have their own children and not opt for adoption

Much to our surprise being a carrier of thalassemia actually has a list of benefits. First of all, carrier have a degree of protection against malaria. This is probably by making the red blood cell more susceptible to the less lethal species Plasmodium vivax. (Y.S, 2018). Next, epidemiological evidence from Kenya suggest that the carrier also protected against severe anemia. And finally, did you know that B thalassemia carriers have some protection against coronary heart disease? If we widen our horizon, most things can be looked from a positive approach.

I would like to ask this wonderful hall a question. What does quality of life mean to each member of this hall?? To me it means to have a life (health, comfort, and happiness) which is normal or near normal as possible. Now one might ask why settle for as near normal as possible? The answer is simple, because nothing is perfect in this world.

Today, it is feasible, in fact extremely feasible for a thalassemia patient, be it major or minor, to lead a normal life. Now, as the medical therapy for thalassemia is advancing as mentioned by fellow colleague. The medical field also have been developing ways to increase the quality of life for these thalassemia patients. This development in their quality of life is not solely dependent on medication but how they cope with their problems currently or in the future. One of the examples are VACCINES. (CDC, 2018). Are vaccines important to thalassemia patient? People with thalassemia are more predisposed to some infections. To name a few, Hib, pneumococcal, Meningococcal viruses. So, it is wise that we provide them with the necessary protection to prevent these infections. Prevention is better than cure.

Secondly is NUTRITION. Eating nutritious foods is important for everyone to maintain a healthy lifestyle – a diet, high in fruits and vegetables and low in fats is ideal for gaining the essential nutrients our bodies need. However, for thalassemia patients, due to too much of iron build up in the blood, food that contains high in iron i.e. meat, fish and some vegetables need to be limited. (CDC, 2018) You might say limiting these foods is not a good thing. However, too much diet in meat is also not a good thing even in a normal person. So they can discuss with their doctors should their iron diet be limited or not. We can refer these thalassemia patients to a dietitian to optimize their nutrition intake.

Thirdly, I would like to emphasize on EXERCISE. (CDC, 2018) Did you know that one of the best footballers in history is a thalassaemia patient?? Its Zinadine Zidane. (P.S,2018) Exercise is part of an overall healthy lifestyle and helps lead to better health outcomes. Not all patient with thalassemia will have trouble participating in vigorous activities as pointed out by my colleague. They were able to perform very vigorous exercises with no problems at all and even more than what a normal person can do. Even if these patients having some difficulties, we can also do some moderate activities to help keep their mind active, focus and cope better with stress.

Lastly as a method of increasing the quality of life for thalassemia patients is RELATIONSHIP. Having a warm and supportive relationship is an important part of life whether you are normal being or having a disorder/ disease. Having friends, family members, classmate and so on can offer support in managing their thalassemia as they can remind them of their treatment, healthy diet, exercise and also cope with the daily stress in life. (CDC, 2018) With this loving relationship with the surroundings, patient with thalassemia can cope better in life especially with their mental health status. As we all know depression sets in faster in person with disease or disorder. So it is advised to the family and friends to provide them with love and care so that they won't feel depressed or left out and this is vital in maintaining or improving their quality of life. These are all qualities needed for a child regardless of the health status. To conclude my first point in argument, thru the development of healthy choices for people living w/ thalassemia (in context of vaccine, nutrition, exercise and relationship), we can see that they significantly improve the QOL of thalassemia patients

Since we are talking about relationship. I would like to emphasize my next point that blood is thicker than water. What does it mean and why is this point relevant? Family is an important part of our life whether we like it or not. Continuing that family tree is everyone's wish and everyone hope to have their own lineage in the future. I am sure that everyone here will give love and care to your child whether they are adopted or of your own. But there is a special feeling about having your own child that nothing can compare as I'm sure that all parents here felt in some point in life especially during the birth of your child. Being a thalassemia

carrier is not an indication for you to stop trying to have your own child and opt for adoption “No It Is Not” It is only of your own preference. With all the advancement in the medical field and treatment for thalassemia, we have come so far and how is the advancement in another 10 years’ time? We don’t know but I know for a fact that it is going to get better as mentioned by my colleague. It is all depends on how we counsel the couples and help them to make the right choices. As a parent, making informed decision is their rights. Parents will love their own children nevertheless. I would like to ask this hall a question. Can you be absolutely certain that all parents without gene abnormalities have a 100 per cent chance of getting (in quote) “ perfect child?” Thank you.

OPPOSITION GROUP

1st SPEAKER- MS LIEW JIA HUI

Good afternoon Ms Chairperson, Dear Adjudicators and my fellow friends. I am Jia Hui, the first speaker of the Opposition group and would like to introduce my team members Vimalan, the second speaker and Raakeswar, the third speaker. Today, the topic for our debate is couples who are carriers of Thalassemia should have a child and not opt for adoption. We strongly disagree with the Proposition group’s point of view of thalassemia carriers should have their own child rather than adopt. AND we, the Opposition group, believe that this statement is false.

Today, I as the first speaker would like to talk about how thalassemia affects quality of life of thalassaemia patient and their families.

First of all, I would like everyone to join me in a moment of silence for all the fallen thalassaemia patients.

Statistics taken from CPG of Management of Thalassemia in Malaysia had showed there were 4541 registered patients while 3310 of them was beta thalassemia major and Hb E and was dependent on regular blood transfusion. Besides, 455 of them are diagnosed with Thalassemia intermedia and 410 of them had Hb H. (Ibrahim, 2009)

Is it the child’s fault to be born with Thalassemia? No! It is not. This is a disease that is carried by their parents which imprint to their genetics. Thalassemia is a disease that might cause severe anaemia, jaundice, and growth failure, bossing of skull, maxillary overgrowth, and hepatosplenomegaly. The child might also be more prone to have infections, cardiac or liver disease due to the regular blood transfusion. A child with thalassemia, their physical status might not be as perfect as a normal healthy child. They might not have a normal life as other children. They cannot go for vigorous sports such as basketball or football which may cause injury while playing. For example, I had approached one Thalassemia patient in the day care unit, 2 weeks ago who was active and likes to go for sports. However, he was stopped by his mother from playing football as the medical officer advised him, not to go for any contact sports. Besides, they might not have a chance to play with their friends who have the interest in those contact sports such as basketball and football and thus they lost the chance to spend time with their friend and have less fun. They have lost the most colourful part of their life experience.

Moving on to my second part, I would like to discuss on the religious aspects. Religion had played a pivotal role in people’s life. I believe everyone have their own religion. Most of the religions prohibit abortion except in certain circumstances. It is considered as committing a sin if you get an abortion done. However, some of the couples who are thalassemia carriers opted for abortion once they noted pregnancy, irrespective the child is healthy or not, as they do not want another child, who has Thalassemia. Here, I would like to share a story of Iqbal

and Khadijah from North America taken from the article Parent's Stories which is the work commissioned by the NHS Sickle Cell and Thalassemia Screening Programme, Public Health England. This couple are both thalassemia carriers, who have married without knowing both of them are carriers. It was first discovered only when their first child born in 1990 was diagnosed as Thalassemia major. Later, her second child was born the following year, also been diagnosed with Thalassemia major making both of them stressed and in distress. Thus, they decided not to have another child which may be a Thalassemia major also. Iqbal and Khadijah both decided to have an abortion with next pregnancy before 20th week of gestation irrespective if the foetus has thalassemia or not. Although the religion does not allow them to have an abortion, in certain circumstances, it does. People think that you are committing a sin if you are having an abortion. Even though misunderstandings are there, some of the couple still insist on having an abortion to prevent another child born to be thalassaemia. Therefore, why should couples who are known to be thalassemia carriers have their own children? They might felt guilty and regret after few years due to the stressful life and seeing their child suffering and later opting for abortion in their next pregnancy. Why not adopt a healthy child, right from the out start? where you could avoid all the prejudice from the others and have a happier life? (Thomas, 2017)

Other than that, although the life expectancy of patient had been enhanced due to the introduction of regular blood transfusion and iron chelating therapy, patient with Thalassemia still face problems in obtaining higher education and securing their employment. Why? As we all know some of the higher education institution have the requirement of qualified medical status. Patient with Thalassemia might not get a chance to enter those institutions to chase their dreams. For example, the National Defence University of Malaysia have the minimum requirement of health status on the students who are enrolling in their university. Therefore, Thalassaemia patient who are physically unfit to the university might not be eligible to enter the university. Moreover, Thalassemia children have been described to show impaired abstract reasoning, deficits of language, attention, memory, constructional/visual spatial skills, and executive functions. These are all based on data by Dr Luigi Mazzone. They might not be performing well in their academic sessions. Besides, due to the regular blood transfusion and iron chelating therapy, children are known to be missing their classes as they need to seek their treatment. It is crucial as almost all the university had set a benchmark for sitting the exams where they need to fulfil the requirements of attendance. A child with thalassemia might face a problem in these circumstances as they are going to miss lots of classes. They also might have loss of focus and lethargy after blood transfusion and iron chelating therapy and thus need more time to rest before regaining energy to study. Nevertheless, the knowledge that had been taught during the session they missed might not be repeated and thus he had lost the chance to gain the knowledge. They need to work really hard to go through this process. Some of them might give up in the mid-way of studying as they cannot cope up with the heavy curriculum.

On the other hand, Thalassaemia patient who need to undergo regular blood transfusion, iron chelating therapy and regular follow up may lead to difficulties in securing their employment. Most of the adolescents would prefer to be financially independent and not cause the burden to their parents after they grown up. However, it is difficult in Thalassaemic patients as they have a lower efficiency than normal healthy people and thus it might cause them having difficulties in securing their employment. This is because the employer prefers to have a healthy employee with higher efficiency in working place rather than having a employee who suffers Thalassemia and need to take regular leaves during working time to receive treatment.

Although the fact is cruel, this is common in all the working places in the world and we cannot disregard this.

Therefore, as the proverb says “prevention is better than cure” while Thalassaemia had no exact cure currently. In my opinion, adoption is a better choice than having own child in couples who are thalassaemia carrier. Adoption is not a big deal in this new era. Lot of people have the experience of adoption. Even having a pet is considered as adoption as we are raising a life and giving them love. Thus, instead of giving a miserable life to yourself and the next generation, why don't we adopt a child who can be healthy and can have a better quality of life for both the parents and the child? We can have a chance to help an orphan who needs love from others as they are not being given care by their own biological parents and family. This is a win-win situation for both the couple who are thalassaemia carriers and the child which is adopted by the couple. Adopting will not change the world, but for the child, the world will be changed. Why can't we give a chance to the child and you to have a better life? So, I think couples who are thalassaemia carriers should adopt a child instead of having their own child.

2 ND SPEAKER: MR VIMALAN LETCHUMANAN

Good afternoon, respected Chairperson, distinguished adjudicators, teachers and students. The topic for our debate is “Couples who are carriers of Thalassaemia should have own children and not opt for adoption.

First and foremost, thalassaemia patients' families are affected financially especially for the low income group people. This is because, even Health care funders including governments, social security funds, and insurance companies are struggling to meet the rising costs of medical treatments and how about the low-income community with thalassaemia problem. Thalassaemia is a disease which needs lifelong management. Parents need to cover the direct cost of financial burden such as medication, blood transfusion which needed monthly transfusion, laboratory test and many more.

Thalassaemia management includes regular blood transfusion, administration of several medications such as iron chelating agents and other concomitant medications. The cost of therapy in these patients as well as any other disease does not only cover medication cost. These extra costs include the cost of medical consultation, laboratory tests, diagnostic tests, cost of preventative or treatments of side effects of therapies and many other indirect costs. The family members sometime need to delay or beg to others for money especially low-income community for their children treatment cost because without money they couldn't admit their child to hospital and seek a treatment as the saying goes ‘no money no talk’.

Other than that, the Indirect costs include travel expenses, the cost attributable to the loss of productivity by the patients or their caregivers, the impairment of well-being and all other related aspects. According to Med J Malaysia Vol 66, all parents were of the opinion that financial burden was an important issue. For some parent's financial difficulty was the expenditure incurred when going to hospital for follow up visits. Also, for some them any loss of working days meant financial loss as well. Being admitted to the ward posed further financial constraints due to additional hospital bills. Adolescence patients felt the need to be financially independent as an important issue.

They prefer to be independent and not cause burden to their parents. In this case, they can't work independently as there will be complications of the treatment as well as the disease

itself which will decrease their efficiency at work. So, most of the time, they will always depend on the parents or any others for money. Here I want to stress again that adopt a child way better than having a thalassemia child which we can clearly see them suffering. Moreover, the parents are so burden with the transportation fees to the hospital especially whoever don't have transport in their house. I am agreeing in this modern world we have Grab and other public transport service but how about the illiterate who don't know how to use internet service for the cab service.

Next, I would like to talk about complication that thalassemia patient facing. They face complications due to the disease itself and also the treatment. People who receive a lot of blood transfusions are at risk for iron overload. Red blood cells contain a lot of iron, and over time, the iron from all of the transfusions can build up in the body. When it builds up, the iron collects in places like the heart, liver, and brain, and can make it hard for these organs to work properly. To prevent iron overload, people with thalassemia may need chelation therapy, which is when doctors give a medicine either a pill or a shot under the skin to remove excess iron before it builds up in the organs. This is not something to take it simple as the consequences can lead to death sometime.

Every time a person gets a blood transfusion, their risk for a problem called "alloimmunization" goes up. Alloimmunization happens when a person's body reacts to blood from a transfusion because it is seen as harmful by their immune system, and tries to destroy it. Persons with alloimmunization can still receive blood transfusions, but the blood they receive has to be checked and compared to their own blood to make sure that it won't be destroyed by their immune system. This takes time and can mean that persons with alloimmunization have to wait longer for blood, or may have a harder time finding blood that won't be destroyed by their body.

Another concern for people who receive a lot of blood transfusions is the safety of the blood they receive. Some infections, like hepatitis, can be carried in blood. In the United States, the blood supply is screened and monitored for safety, and the risk of getting an infection from a blood transfusion is very low. Nevertheless, there is still a very small risk of getting an infection through a blood transfusion. So here other than thalassemia they might have a new disease which they going to suffer more in their life treating both the disease.

Furthermore, the patient will have Skeletal Changes due to bone marrow expanding the available space to improve production of red blood cell which is inadequate for thalassemia patient. This most notable occurs in the bones of the skull and face. People can develop what is called "thalassemia facies" chipmunk like cheeks and prominent forehead. So, when they already enrolled in school there are for sure going to be teased by everyone with nicknames which will cause the patient to look down even at himself. According to J Abdul Wahab 2011 About one third of the parents (9 of 24) claimed that their diseased children did not have many friends and were virtually housebound. They believed that generally it was the normal children that did not want to befriend the patients. Patients attributed the illness as an obstacle for them to integrate socially.

Moreover, Osteopenia (weak bones) and osteoporosis (thin and brittle bones) can occur in adolescents and young adults. This 2-bone disease really effects the physical status of the children with good interest in outdoor activities because they can easily have fracture in their limbs. Other than that, they also can have endocrine problems where in future they might face

consequences like reduce libido, weight gain, thyroid problems and many more. So all these are just can be controlled but never a stop for them.

So Madam Chairperson, distinguished adjudicators, and all , in conclusion Proposition group, please pack your things up and leave the room now or else you will anyhow but a bit later. Thanks, and have a nice day.

3rd SPEAKER: MR RAAKESWAR SEGARAN

Good afternoon, Ms Chairperson, distinguished Adjudicators and Proposition team. Today I would like to talk about psychological impact and time constraints faced by thalassemia patient.

Thalassemia children feel different from their peers and elaborate negative thoughts about their life, guilt senses, increased anxiety and low self-esteem; their behavioural profile is similar to normal subjects, but many of them can manifest severe psychosocial problems due to difficulties in complying with the painful chelation; male patients, in particular, show oppositional defiant disorder(ODD). ODD is a childhood disorder that is defined by pattern of hostile, disobedient behaviour at adult. Various authors have reported that up to 80% of children with thalassemia are likely to have psychological problems e.g. oppositional defiant disorder, anxiety disorders and depression. Patient also would be a victim of bully because of the physical appearance such as thalassemia facies, depressed nasal bridge and protruding maxilla. They would lose interest in life because they always get bullied. They would not have positive outlook in life.

Within the family, concerns for the future of the thalassemia child may contribute to worsen the relationship between members, and to increase marginalization and isolation. Children with chronic physical illnesses exemplified by thalassemia are vulnerable to emotional and behavioural problems. The onset of symptoms, the rigors of treatment, and frequent absence from school make huge demands on the emotional and interpersonal resources of the children and their families. The emotional and cognitive needs of a child with thalassemia are patently different from those of the adolescents striving for independence and identity.

Imagine, how the parents would feel at the time, when their child was diagnosed with thalassemia? Will they fell guilty as it as an autosomal recessive disease that runs in family? They might think that their child is suffering this disease because of them and might lead to depression. Studies by Dr Afghan Shargi shows that parents of the thalassemia patients have higher prevalence of psychiatric disease. Parents might think the disease may present in next pregnancy. This may cause depression of mother during pregnancy.

Furthermore, thalassemia patient would face time constraints. We all are similar with the quotes time and tides wait for no man. In today's world many of us wish to have 48 hours a day because there is lot of work and commitment to fulfil. In thalassemia patient time is just a luxury for them. Homework or social gathering would get delayed. Their Parents time also are affected. They need to take time off from their work to bring their children to hospital. Thalassemia patient uses most of their time for treatment and recovery. Each time 4 hours spent for blood transfusion. So think about in a month? Year? They would not be able to enjoy time and do works as a normal people. Last week I had a privilege of interviewing a patient at a day care in Hospital Pakar Sultanah Fatimah. Patient's mother told me that they are living in Pagoh. They travel about 1 hour daily for 2 days every 2 weeks to get treatment. She also complained her child would be so tired from the treatment that he would dose off and he always to submit his schoolwork later than his friends. In addition, as a worrying

parent you tend to do some research or enquire other places to seek better treatment for your children. Time are spent on finding good medical facilities.

I also would like to talk a bit about adoption. There is a NGO group called Cooley's Anemia Foundation in USA. They have these adoption program called CAF Adoption Support Program. These programs help to adopt thalassemia patient that has been abandoned by their families. I have a question to ask here. Why don't we just adopt? Why do we have to produce them and later on abandoning them because we don't have enough strength to take care of them

So Ms Chairperson, distinguished adjudicators, and Proposition team, Family is more than bloodline and foster care is risky, adoption is risky and love itself is always risky. In conclusion we believe that couple who are carriers of thalassemia should not have own children. Thank you and have a nice day.

DISCUSSION

Each of the 3 speakers from each of the 2 groups have presented the messages to support their side of the motion. All of them have done their best not only in presenting facts and figures and their sources but their attire, usage of words, intonation at time of delivery at the Debate are commendable. The members of the panel of adjudicators had a tough time deciding which one of the six speakers is the best and also which group is the winner of this debate session.

Table 1 Scores of the six speakers by the 4 Adjudicators

Adjudicators	P1	P2	P3	O1	O2	O3
1	77	75	54	55	71	51
2	81	87	77	77	66	64
3	82	78	91	78	79	78
4	87	86	73	75	67	59
Total score	81.75	81.5	73.75	71.25	70.75	63

Best Speaker: **MS SHARVEENIE RAJISWARAN (P 1)**

Table 2. Scores of the two groups by the 4 Adjudicators

ADJUDICATORS	PROPOSITION GROUP	OPPOSITION GROUP
1	246	201
2	245	207
3	251	235
4	206	177
Total score	948	820

Best Group: Proposition group consisting of the speakers: , **MS SHARVEENIE RAJISWARAN MS DINARAMALAR SUKKIRASINGAM. MR JOHARI ABDUL RAHMAN. (P1,P2,P3)**

The Proposition group had emphasized that

- (1) Gene therapy offers carrier parents to get pregnant through in vitro fertilization. This ensures 100% chance of carrier parents giving birth to unaffected, thalassemia free babies.
- (2) Medical advancement has enhanced quality of life of thalassemia patient to lead a life which is as near normal as possible. It is indeed very possible for carriers to bear their own children, and for their affected child to lead a normal, if not close to normal life. One main point to note here is that, thalassemia patients' intelligence is not impaired in any way.
- (3) Blood is thicker than water. There is a special feeling about having your own child with nothing in comparison. As a parent, making informed decision is their rights. Parents will love their own children nevertheless. I would like to ask this hall a question. Can you be absolutely certain that all parents without gene abnormalities have a 100 per cent chance of getting (in quote) a "perfect child?"

The opposition group had highlighted the following:

- (1) Having a child with Thalassemia means, child cannot play "contact sports "basketball and football" and thus lose the chance to spend time with their friends and have less fun. They have lost the most colourful part of their life experience
- (2) Management is for lifelong. Thalassemia patients 'family are affected financially especially for the low income group people.
- (3) Risk of blood transfusion infections
- (4) Bone changes altering the physical features and affecting the strength of the bones. The characteristic chipmunk facies, may be an embarrassing stigma in childhood and later in adolescence.
- (5) Thalassemia patients have serious emotional and behavioral issues
- (6) Time and Tide waits for no man- Thalassemia patients may be faced with Time constraints
- (7) Adoption is the solution to all the challenges and issues in children with Thalassemia.

More highlights from the Faculty:

* Couples with genetic thalassaemia traits should consider avoiding pregnancy or at least equip themselves with necessary knowledge about the disease and its treatment before even thinking about having children.

*Couples are reminded to take a blood test to ensure they are not thalassaemia carriers before planning to have children. (Borneo Post On Line 2012)

*Couples with genetic thalassaemia traits should consider avoiding pregnancy or at least equip themselves with necessary knowledge about the disease and its treatment before even thinking about having children.

*State Health Department director Datuk Dr Yusof Ibrahim said knowing how to manage thalassaemia disorder was essential to ensure children suffering from the disease could grow up healthy and have a normal life.

"Thalassaemia children can still have a normal healthy life provided proper treatment is given from the start.

"It is a long-term and continuous treatment that requires dedication and sacrifices from both parents," he said when officiating at the Parents of Children with Thalassaemia Workshop.

State Health Department director Datuk Dr Yusof Ibrahim said knowing how to manage thalassaemia disorder was essential to ensure children suffering from the disease could grow up healthy and have a normal life.

In most cases, he said parents diagnosed with thalassaemia traits would opt to adopt instead of having their own children, or in cases where pregnancy had already occurred, go for abortion.

CONCLUSIONS

To the Debate on whether to have own children or opt for adoption, the answer maybe:

- (1) Flip of the coin and trust your destiny
or
- (2) Give the parents their RIGHTS for INFORMED DECISION MAKING

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