The Barriers and Enablers to Employment: Beta-Thalassemia Major

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2018

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Introduction

What is Beta-Thalassemia Major?

Beta-thalassemia is a type of blood disorder that originates from many different countries such as the Pacific and Mediterranean countries, Asia, Africa, the Middle East and to a lesser degree the White British population. The condition may also be referred to as Mediterranean Anaemia, Cooley's Anaemia or homozygous beta-thalassemia (Bojanowski, 2006). Beta-thalassemia is an inherited blood disorder and should be distinguished from alpha-thalassemia. Alpha-thalassemia is when insufficient amounts of alpha globin chains are produced in the molecules of haemoglobin and is also associated with severe inherited disorders, with some cases involving certainty of a child being stillborn or suffering a perinatal death. This report focuses on beta-thalassemia which is currently expected to have greater service implications (Taher et al., 2018).

Additionally, there are many different forms of beta-thalassemia, with two as arguably the most important forms to be aware of. These two forms include:

- **Beta-Thalassemia Trait,** also known as thalassemia minor, is where people are genetic carriers of thalassaemia, experiencing only slight anaemia and are fairly healthy themselves, although certain conditions can lead to their children inheriting beta-thalassemia major.

People with thalassemia trait have slightly smaller red blood cells than usual and may experience some anaemia and tiredness but are otherwise healthy. Carriers of the trait play a significant role in prevention and having children means they will be faced with two different outcomes:

1. No possibility that children would inherit thalassemia major but could inherit thalassemia trait **if one parent is a carrier and the other has usual haemoglobin.**

2. **If both parents have thalassemia trait,** then *in each and every pregnancy* every child has a one-in-four chance of having thalassemia major; a one-in-four chance of having normal blood and on-in-two or 50% chance of having thalassemia trait.

- **Beta-Thalassemia Major** is a serious inherited anaemia in which children with the condition cannot produce enough haemoglobin. As a result of this their bone marrow produces insufficient quantities of red blood cells, and the red blood cells produced contain almost no haemoglobin. Children born with thalassemia major seem healthy at birth, but symptoms of anaemia begin to show between the ages of three and eighteen months. Other symptoms include paleness, being unable to sleep well, lack of appetite and vomiting their feeds. Without treatment children with beta-thalassemia major would have short life expectancies of about one to eight years old.

Beta-thalassemia major is the more serious condition of the two and is also more likely to have greater implications in the workplace. For this is the reason, the report focuses primarily on beta-thalassemia major.

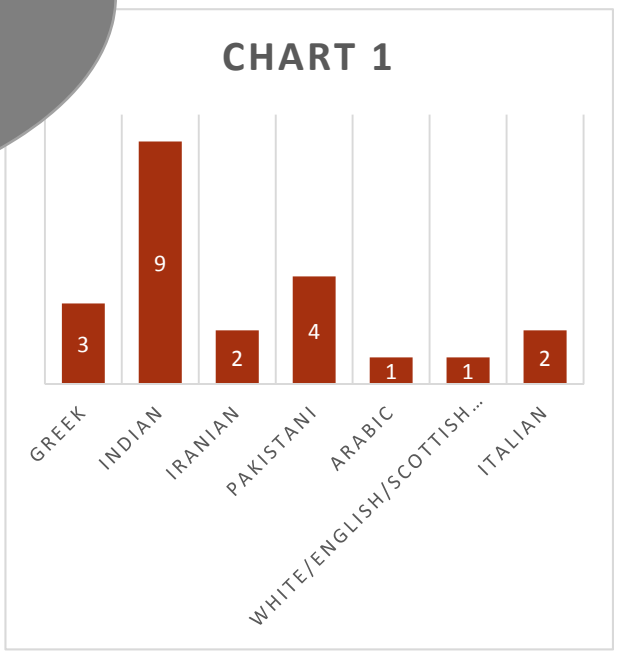
Current Treatment for Beta-Thalassemia Major

There is a fairly successful treatment available with blood transfusions and iron chelation therapy, which in the last three decades have improved survival for people with thalassemia major, allowing them to lead relatively normal and healthy lives. The current treatment for beta-thalassemia major consists of regular blood transfusions every three to four weeks. With this treatment, children with beta- thalassemia major can live into their early twenties. However, to survive beyond this, other treatment is required. People receiving regular transfusions have no means of excreting extra iron therefore, iron chelation therapy is initiated to prevent iron overload, which could be fatal. There are currently three iron chelators used for treatment including: **desferioxamine** in subcutaneous or intravenous injection form, oral **deferiprone** in tablet or solutions form and oral **deferasirox** in dispersible tablets and also, more recently, film coated tablet forms (Taher et al., 2018).

Treatment has improved greatly over the years and includes a potential cure for people with beta-thalassemia major. This cure consists of bone marrow transplantation, which is considered a lifelong cure if successful, and more recently stem cell transplantations have been developed (Taher et al., 2018). As with the treatment, bone marrow transplantation comes with considerable drawbacks, which include:

- The difficulty of finding suitable donors, in some cases not finding one at all
- An incredibly risky post-operative stage with many weeks of barrier nursing required. There is also the risk of an unsuccessful operation where the child must return to the regime of transfusions and treatment for iron overload.

The Research Project



The study consisted of two focus groups which took place in London and the East Midlands. There were also four structured telephone interviews and twelve replies to an online survey. Participants of the study were aged between 17 and 59 and represent the diverse range of ethnic groups at risk of thalassemia, as seen in ***Chart 1*** above. The research primarily explored the challenges and problems that people with beta-thalassemia major experience in the workplace as well the adjustments made, or potential adjustments that participants hoped would be made to help them in the work and employment, as well as other activities and daily life. For reasons of confidentiality, all participants quoted in this report are given aliases.

Key Findings

The Challenges in Work and Employment

Table 1 Frequency of Challenges in Employment Reported by People with Thalassaemia

Challenges and Problems	Number of times mentioned
Time off for transfusions and appointments	31
Fatigue felt before transfusions and treatment	23
Lack of awareness amongst employers and colleagues	20
Lack of flexible Working Hours	12
Uncertainty whether or not to disclosure to employers	11
Pain as a result of thalassemia	11
Mobility issues	10

Table 1, above, lists the challenges to employment and how frequently they were mentioned in focus groups, interviews and the survey. The most frequently mentioned challenge in employment appears to be getting the time off for vital monthly blood transfusions as part of the treatment for beta-thalassemia major. Furthermore, the complexity of the condition often leads to other illnesses and complications which need to be monitored closely. Therefore, time off work for additional hospital appointments is also a significant challenge, as multiple days off are required for transfusions and different appointments. Some participants even felt reluctant to take time off when employers were kind and understanding because they did not want to let their employers down. On the other hand, some employers are not so understanding about granting time off.

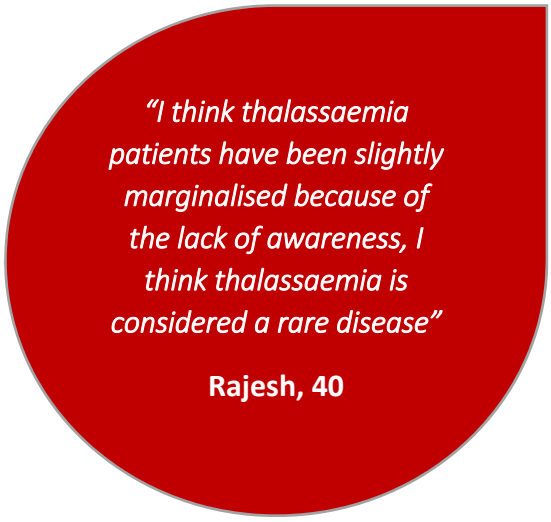
"My employer understands that and has treated me fairly and has assisted me to stay working. I do often find myself working when I maybe shouldn't, I do push myself very hard and will work even when I am unwell. I have to be aware that sometimes it is safer for myself to take time off, but I find this extremely difficult to do as I fear judgement and am frightened to take time off. It is hard to trust my own fatigue levels enough to be brave enough to take time off." - Sally, 38

Fatigue felt by people with thalassemia major is also a significant challenge for people in the workplace. This is also unsurprisingly the second most frequently mentioned challenge in the table above. The level of fatigue and tiredness seems to increase the closer to the time of blood transfusions, with some participants describing their energy levels as a health meter that runs out closer to transfusions. Therefore sometimes there is a need to forfeit some activities as a means of saving energy for work. Fatigue can adversely affect education and physical activities as well as employment, with participants stating that simple tasks such as walking can become very difficult the closer they get to the time of blood transfusions.

"Usually I think when you are closer to transfusion time you get tired more easily, so you are not able to function as well. Not just physically but mentally you can't function as well as you want to. So, we still push ourselves, but I think that's what becomes challenging, when you need a transfusion your body is not really functioning as it should. And with anaemia you have a distinct attack of pain that you get and it's a bone marrow pain throughout (...) So, it's pretty difficult to concentrate when you have that going on (…) when I do have transfusions you tend to feel on top of the world, so you can achieve anything" **- Maria, 59**

The study also found that there is a huge lack of awareness about thalassemia which has significant effects during the initial job seeking process, as well as in work and employment for people with the condition. Some feel discriminated against with respect to how employers and employees have reacted, and most participants were simply tired of explaining the condition repeatedly in the workplace, yet still feeling misunderstood.

Uncertainty whether or not to disclose about the condition has also been a significant issue during job seeking or in employment for people with thalassemia. Many felt that disclosing their condition and the fact that they require time off for monthly appointments and transfusions could lead to a very difficult time whilst searching for jobs. Respondents also felt that disclosing that they could require time off would significantly reduce their chances of getting the job.



"But I have always found I don't need to advertise it (…) I started looking for jobs that's when I realised I was having a problem with this; work life and thalassaemia just didn't work out properly (…) I needed to go for a transfusion every three weeks on a weekday, one working day every three weeks. And the recruiter replied with a "oh", you know shocked, then he said well I don't know if we can give you that sort of time. I even told him I could make up that time any other time (…) unsurprisingly a couple of days later he rang me up and said you have not got the

Adjustments and Suggestions

Table 2 Frequency of Actual/Suggested Adjustments Reported by People with Thalassaemia

Considerations and Adjustments	Number of times mentioned
Mobility issues	11
Time off for transfusions and appointments	10
More awareness amongst employers and employees	7
Support, counselling and training	5
Flexible working hours	5

Most of the participants felt lucky to have accommodating employers and colleagues who understand the requirements of thalassemia, especially in terms of the second consideration in *Table 2* of getting time of for treatment and appointments. However, not everyone seems to be as understanding, especially during the process of seeking employment. This in turn leads to issues with disclosure or reluctance to disclose for fear of being turned down by the employer as seen in ***Table 1*** above. This may be linked to the significant lack of awareness for thalassemia also identified in as the third most requested potential adjustment in ***Table 2*** that could prevent a number of issues in the workplace. Therefore, a more informed work force ought to provide more understanding to the requirements of employees with thalassemia, who regularly need time off to be treated with blood transfusions and other appointments or those who are currently looking for jobs.

"(…) looking at ways to best support people who have thalassaemia and sickle cell is maybe having… a mini booklet (…) to show it to the manager in advance that this is the time off I need for the transfusion, treatments or for the hospital appointments maybe that would be good. Especially people who starting to work to explain to the entry levels. And something that could be used to help them." – Manish, 34

Like fatigue, pain and mobility are the final two issues identified in ***Table 1*** that significantly affect work for people with thalassemia. Consideration for mobility issues also happens to be the most requested adjustment in terms of work and employment as seen in ***Table 2*** above. For people with the condition pain, tiredness, fatigues and other health complications are common and can often affect mobility, especially nearing the time of transfusion. Adjustments in the workplace to ease mobility issues and such as access to lifts, providing car park spaces, and ensuring the comfort and well-being of people with thalassemia could be incredibly helpful in the workplace. Some participants identify that a blue badge to facilitate parking would significantly help them when they experience pain and fatigue and are still required work.

"I think car parking is crucial, when I used to work in Leicester the main car park was only for permits and the waiting time for that was about five years. There was another car park but that was about half an hour away (…) So, you do need that because you sometimes struggle. When you have had your transfusion, you can walk days on end and some people do manage to do marathons but when you need your blood it's like you even struggle to walk just a few steps even ten steps are like ten miles." - **Rajesh, 40**

Symptoms of pain and fatigue could mean that some employers wrongly assume that full-time work is unrealistic for people living with beta-thalassaemia major However, this is not the case, as many with the condition have proven these preconceptions wrong and led

incredibly successful and long-lasting careers. As the final consideration in ***Table 2*** suggests, a little extra flexibility in working hours could also help issues of pain and fatigue, as well as getting time for hospital appointments. More considerate and flexible working hours were also significantly mentioned in the study as barriers to work and employment although working part time could be possible if employers could be more flexible and understanding towards the people with beta-thalassemia major.

"Once you also build up your relationship with them with someone who knows you if they know about thalassaemia, I have got a hospital appointment on Monday so that's at 10.20 now I am not going to travel all the way to Warwick and then come back for the hospital appointment and go back again. So, I said I will have the appointment and just work from Leicester and he goes just take the whole day off and don't come back, because this is the type of flexibility they have. Because I make sure whatever he needs gets done for him." **– Rajesh, 40**

Participants also felt that juggling work, home life and treatments can really take its toll. Therefore, mental health and wellbeing is incredibly important, and support to ensure this ought to be available for all people with thalassemia. Participants hoped that support would be provided when required, and that training is available for those new to work, and that re-training can help those who have been out of work for a while and are attempting to return to work. Some participants voiced a feeling of discrimination; whether in being unfairly treated during job seeking or having unfair opportunities to progress their careers., to being denied gym memberships as thalassemia is considered an 'unknown' condition and as too great of a risk during physical activities such as sports and working out using public gym facilities. All of this can produce intense amounts of pressure and stress that affect a person's wellbeing. Consequently, strong emotional and psychological support systems are crucial, and

"We are, I suppose all individuals with this condition some worse off than others…I feel there are quite a few issues that probably affects most sufferers but probably don't realise it but most important is mental health. When your haemoglobin yo-yos up and down I find it can be quite a battle with my state of mind. It's scary that pre-transfusion you can feel so negative and pessimistic and post transfusion very optimistic and positive about everything. This then makes dealing with everyday life pain I suffer and even just interacting with people quite a struggle at times." **– Markos.**

ought to be available to those with thalassemia to ensure a healthy work-life balance.

There were also mentions of electronic documentation to replace writing which can be tiring after long periods of time for someone with the condition. There also appear to be significant gender issues in employment for women with thalassemia. It is already difficult to have children for women with thalassemia and maternity leave appears to be a big issue in terms of employment, getting back to work after having children is also an issue.

Therefore, support and guidance are key as seen in ***Table 2***. Another significant finding is that participants felt that the NHS have a just as much a significant role to play as employers and recruiters in considering the needs of thalassemia patients when it comes to treatments with issues of the lack of options in treatments available in the past, this has since seen improvements however, participants felt that more could be done to help them with work.

"There is only so much a company can do and they are paying you to do a job. I think it's a system where everybody needs to work in harmony with each other and hospitals should offer more services within the NHS putting money towards this because we would be able to contribute much better if they accommodate us." – Rani, 28

Employment is necessary in everyday life and need not be a struggle for anyone with thalassemia. With some simple and considerate adjustments, like those mentioned above the work environment may be improved for people with thalassemia, safe, comfortable and fair opportunities for work can be provided for people with beta-thalassemia major. In fact, many people with thalassemia have already shown perseverance despite difficulties and have gone on to lead successful, long-lasting and meaningful careers as nurses, travel agents, pharmacists, airline pilots, academics, charity workers and much more.

Useful contacts

Most major cities have a centre for Sickle Cell and Thalassemia which can be found on this website: **http://www.sickle-thal.nwlh.nhs.uk/information/nationalsicklecellthalassaemiacentres.aspx**

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Acknowledgements

This research was conducted under De Montfort University's *Graduate Champions* Internship as part of a larger study funded by the Big Lottery and Disability Research on Independent Living and Learning (DRILL) under Professor Simon Dyson and Dr Maria Berghs. We would like to thank all the participants and all of the people in the voluntary sector who helped at short notice to make this possible, in particular the UK Thalassemia Society.