Adherence to Chelation Treatment Among Patients with Beta Thalassaemia Major in Kuwait

Bourusly Maha Jassim, Mustafa Nada Yousef and Asmaa Farag Azab

1Department of Hematology and Oncology, NBK Hospital, Sabah Hospital, Kuwait
2Department of Pediatrics, Faculty of Medicine, Kuwait University
3Pediatric Hematology Unit, Mubarak Hospital

Abstract

Treating doctors are often challenged with patients’ non-adherence to treatment, especially patients with chronic diseases such as beta Thalassaemia Major.

Aim and Method

The aim of this study was to identify some of the factors that might lead to patients’ non-adherence to therapy, as well as their knowledge and insight of their illness, and awareness of their treatment plan. A questionnaire was designed and distributed to a group of volunteers of patients who were registered to the Kuwaiti Thalassaemia society.

Results

More than half of the patients were compliant with treatment. Those who were not complaint with treatment gave several reasons for lack of compliance. Fifty per cent of patients were aware about the importance of regular blood investigation to check for iron overload. Forty five percent of the patients believed that serum ferritin is the only investigation to be checked regularly. There were many reasons for irregular visits to hematology outpatient such as per advice of treating physician, personal decision, transportation problems, and non flexible work conditions; however most of the patients did not give a specific reason. Regarding chelating therapy, 72.2% said that the treating doctor explains regularly the importance of treatment. The majority of patient were on oral chelating treatment (74%), 4.7% on chelating home pump therapy, and 9.5% were on both, 2.8% were not on any chelating treatment. Most patients (56%) were compliant to treatment, the rest were irregular or not compliant to treatment. There was a strong association between nationality and compliance to treatment (p = .000). The treatment type whether oral or pump or both has a direct effect on compliance. Doctor explanations play an important role in adherence to treatment (p=000). Those patients who were keen to follow up at the clinics were keener to do other investigations (p=000). Those patients who followed doctors’ advices were more likely to do other investigations (p=000).

Conclusion

There were many factors which influence patients’ adherence to therapy such as transport and proper doctor patient communication and insight and knowledge of the diseases and complications.

Keywords: Beta-Thalassaemia Major; Compliance; Chronic Disease
their knowledge and insight of their illness, and their awareness of their treatment plan. The questionnaire was distributed among patients with Thalassaemia through the Kuwait Thalassaemia society after their consent. The questionnaire was either filled personally by patients, or through telephone calls to patients by a trained volunteer from the society. The parents of Patients under the age of 18 years were asked to answer the questionnaire after their consent. The results were analyzed using the SPSS software.

**Results**

Among 134 patients who were contacted through Kuwait Thalassaemia society, only 93 patients responded. Those who responded were divided into three age groups: patients below 13 years (27 patients), patients aged between 14-25 years (36 patients), and patients older than 25 yrs (30 patients). The youngest participant was two years old and the oldest was 47 years old. Only 33% of patients were nationals (graph 1). There were 49 females and 46 males, total 95. Half of the patients were diagnosed initially at Sabah hospital, which is the same hospital where most patients of this study are currently following at, and receiving treatment (table 1).

When asked about their adherence to treatment, more than half of the patients said they were compliant with treatment. Those who were not compliant gave several reasons for their lack of compliance (table 2). When asked about their knowledge about the optimum frequency for checking serum ferritin level, fifty percent of the patients said every three months (table 3), and they believed that this was the standard. Forty five percent of the patients believed that serum ferritin is the only investigation which should be checked regularly. The reasons the patients gave for visiting the outpatient department OPD 6 monthly or more were as per the physician advice 23%, personal decision 8%, difficult or could not afford transportation fees 4% and non flexible work conditions 3%; however 43% of patient did not give a specific reason. There were many reasons for lack of compliance to OPD follow up: ten percent had problem with transportation as they do not live in the same health area district and difficulty finding regular transportation, 4% of patients thought the physicians in the OPD were not acquainted with beta Thalassaemia major medical problems, and 3% said there was no hematologist following them in their treating hospital. When asked if they know the importance of the chelating treatment: 72.2% said that the treating doctor explains regularly with details of the importance of treatment, the rest said the doctor either sometimes or never explained the importance of the chelating treatment. When asked about the type of chelating treatment they were receiving right now: 74% were on oral chelating treatment, 4.7% on chelating home pump therapy, and 9.5% were on both, 2.8% were not on any chelating treatment. When asked about the compliance to treatment: 56% said they were compliant to treatment, 28% were irregular or not compliant to treatment, and 1.9% were not on any treatment.

There was a strong association between nationality and compliance to treatment i.e. nationals tend to adhere to treatment plan in comparison to non nationals (p = .000) (table 4). The treatment type whether oral or bump or both has a direct effect on compliance i.e. as treatment intensify the compliance increase. Doctor explanations and counseling played an important role in adherence to treatment plan which includes regular investigations for iron overload other than monitoring serum ferritin (p=000).
Table 2: The reasons the patients gave for non-commitment to chelation therapy: no benefit of medication as they tried it before, personal belief that they either do not need medication. Other reasons according to patients’ response included the following: multiple medications, difficult timing of the medication, medication side effects, and the need specific Thalassaemia clinic to follow to be convinced of the medication. The last category patients described themselves as compliant.

<table>
<thead>
<tr>
<th>Why not committed to treatment</th>
<th>Number of patients</th>
<th>Percentage %</th>
</tr>
</thead>
<tbody>
<tr>
<td>No benefit</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Personal belief</td>
<td>7</td>
<td>6.65</td>
</tr>
<tr>
<td>Do not want treatment</td>
<td>3</td>
<td>2.85</td>
</tr>
<tr>
<td>Other reasons</td>
<td>58</td>
<td>55.1</td>
</tr>
<tr>
<td>Compliant</td>
<td>24</td>
<td>22.8</td>
</tr>
</tbody>
</table>

Table 3: The frequency of serum ferritin level checking per month

<table>
<thead>
<tr>
<th>Months</th>
<th>Number of patients</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>8</td>
<td>7.60%</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
<td>2.85%</td>
</tr>
<tr>
<td>3</td>
<td>52</td>
<td>49.90%</td>
</tr>
<tr>
<td>6</td>
<td>16</td>
<td>15.20%</td>
</tr>
<tr>
<td>12</td>
<td>5</td>
<td>4.75%</td>
</tr>
<tr>
<td>others</td>
<td>10</td>
<td>9.50%</td>
</tr>
</tbody>
</table>

Table 4: This table represents the results of Pearson chi square of this sturdy

<table>
<thead>
<tr>
<th>Compliance to treatment</th>
<th>df (15) 113.165</th>
<th>P=0.911</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nationality</td>
<td>df (6) 69.739</td>
<td>P=0.000</td>
</tr>
<tr>
<td>Type of treatment</td>
<td>df (6) 88.883</td>
<td>P=0.000</td>
</tr>
<tr>
<td>Patients age group</td>
<td>df (6) 30.91</td>
<td>P=0.004</td>
</tr>
<tr>
<td>Do other investigations to check for iron overload</td>
<td>df (2) 60.986</td>
<td>P=0.000</td>
</tr>
<tr>
<td>Doctor counseling</td>
<td>df (2) 77.244</td>
<td>P=0.000</td>
</tr>
<tr>
<td>Frequency of follow up</td>
<td>df (20) 162.802</td>
<td>P=0.000</td>
</tr>
<tr>
<td>More frequent checking of serum ferritin</td>
<td>df (25) 155.933</td>
<td>P=0.763</td>
</tr>
</tbody>
</table>

Citation: Bourusly Maha Jassim, Mustafa Nada Yousef and Asmaa Farag Azab (2017) Adherence to Chelation Treatment Among Patients with Beta Thalassaemia Major in Kuwait. BAOJ Hematol 1: 003.

Discussión

There are many factors affecting adherence to treatment when it comes to management of patients with Beta Thalassaemia major. Oral chelating agents are known to be safe and convenient, therefore it was anticipated that these agents may improve compliance, and would be cost effective [4,5] and the initial studies supported this thought [6,7,8]. Our study proved that many patients are not adherent to treatment, and management is suboptimal [9]. Availability of the state of the art oral chelating agents is not the only factor for better adherence to treatment or management plan. The Kuwaiti government was keen to provide thalassaemic patients with all the medications and investigations required for management of iron overload free of charge for the nationals. The non nationals have to pay an affordable amount for treatment. Investigations might be expensive for non nationals; however there are many nonprofit organizations that provide full sponsorship. Despite that it was noticed in this study that the availability was not the issue, as patients expressed that other factors affect their compliance, such as transportation, or lack of communication with the treating physician, which need to be the focus for a follow up study, or perhaps a quality of life study (Haghpanah I S, Nasirabadi II S, Ghaffarpasand III F, et al) [10], or a study for adjustment and adaptation with treatment [11]. It was noticed also that nationality was strong risk for adherence to treatment, as adherence to treatment was best in nationals in comparison with non-nationals. This may indicate that there are other factors affecting compliance such as feasibility or accessibility to treatment as well as the patient’s social and economic status, which need to be studied in depth. Unfortunately premarital screening clinics for hereditary diseases in Kuwait were only established in 2009. Most patients were diagnosed initially in Sabah hospital, where the oldest pediatric hematology unit is situated. Half of the participants of this study were initially diagnosed at Sabah hospital. This unit continued to follow patients well into adult life; only recently all adult patients were referred to adult hematology units. Most of the referred patients preferred to stay at Sabah hospital to support each other through the journey of their treatment; therefore, three quarters of the participants in this study are still receiving treatment at Sabah hospital. Although hematology units or departments are available in each governmental hospital in Kuwait, it is shame that there is no specific tertiary center for the management of hereditary blood diseases in Kuwait, as seen in other regional countries. This study showed that patients are not necessarily following at the hospitals where the diagnoses were initially made. Results showed that some patients may receive treatment in two or more hospitals...
simultaneously, as there is no registry currently in Kuwait, and patients may receive blood transfusion in one hospital and follow out-patient clinic in another according to their convenience. Not to mention following up at other non-hematology clinics for other thalassaemia complications in again a different hospital. This may be one of the factors that lead to lack of adherence as the treating doctor in the out-patient hematolgy clinic might not be aware of the transfusion history of the patient, as well as be able to follow the patient’s uprising problems, and do the necessary adjustment of treatment. Hence this might lead to patients' lack of adherence to treatment. We believe in order to raise the level of adherence to treatment, patients with Beta 'thalassaemia Major should be receiving their management in a specialized tertiary center and not to be distributed to different hematolgy units in accordance to their area of residence, as patients do support each other and compliance may improve as a result.

Half of the Thalassaemia patients are aware of the disease and the plan of treatment, and were compliant with treatment. This means that more effort should be directed into increasing awareness and improving communication with the patients. Doctor explanation plays an important role in adherence to treatment, which means as communication improves, adherence to treatment improves [12].

As expected patients who are keen to follow up at outpatient hematolgy clinic are keener to do other investigations; however that does not mean that they are following with serum ferritin regularly as an indicator for iron overload, which might have increased adherence to chelation treatment [9]. However there is a possibility that they are doing other investigations such as imaging studies for iron overload. Perhaps in the future the availability of modern technology such as an application or software might help in providing the treating physician and the patient with all the results of the patient's investigations and transfusions, and to follow the progress of chelation. This might help to increase adherence to treatment [13].

The treatment type whether oral or infusion bump or both has a direct effect on compliance [14], which means those who are on both oral and infusion bump are more compliant to treatment as they are more concerned of the complications related to chronic transfusions and iron overload, and this was seen in another study [15]. Compliance tend to improve as the patient gets older; however chelating treatment for iron overload should start at an early age [16], and continuous education should be more emphasized all through patient's life starting at early age.

Better assessment of psychological challenges that the patient might be facing might shed the light on yet another factor affecting adherence to treatment [17]. Unfortunately this was out of the scope of this study.

**Conclusion**

Developing and adapting new treatments in the management of chronic diseases such as Beta Thalassaemia major should not be taken for granted. Issues such as compliance or positive adherence to therapy should be anticipated, and studied in depth in order to improve patients' medical conditions and then their quality of life.

**Acknowledgment**

The authors would like to thank the Kuwait thalassaemia society for their valuable contribution to this study.

**Appendix**

**How Adherent Patients with Beta Thalassaemia with Their Medication**

Name: 
(optional )

Age or date of birth:

Nationality :

Diagnosis :

Were diagnosis of beta thalassaemia was first made:

The first hospital where you received your treatment:

The second hospital:

The third hospital:

Currently you receive your treatment at:

Outpatient treatment currently I am following at:

a. Sabah hospital
b. Mubarack hospital
c. Amiri Hospital
d. Farwaniya hospital
e. Addan hospital
f. Jahra hospital
g. Ahmedi Hospital
h. Other

I follow outpatient clinic every:

a. Month
b. 2 months
c. 3 months
d. 6 months
e. Year
f. I do not follow outpatient clinic

If you are Following Every 6 months or More, the Reason is

a. Doctor advice
b. Personal belief
c. My job difficult timing
d. Hospital distant from my residence , transportation difficulties’
e. Other reasons

I Check Serum Ferritin Level Every

a. Month
b. 3 months
c. 6 months
d. Year
e. Other

Are There Other Investigations You Should do Regularly Same as Ferritin Level?
- a. Yes
- b. No
- c. I do not know

Has Anybody Discussed Treatment Plan Personally and did the Necessary Changes to the Dosed of Chelating Treatment?
- a. Yes
- b. No

Are You Following in Other Non Hematology Clinics?
- a. Yes
- b. No

How Many Other Clinics you are Following with?

The Reason for not Commitment to Outpatient Clinic Follow Up
- a. no hematologist available in the hematology clinic
- b. the doctor has no experience in following patients with Beta thalassaemia Major
- c. difficult transportation
- d. difficult to get appointment
- e. I can afford visit fees
- f. Other

Do the Doctor in the Clinic Explain to you how to use or the Importance of Chelating Medication?
- a. Yes
- b. No
- c. Sometimes

Type of Chelating Treatment
- a. Oral
- b. Home Infusion pump
- c. Oral + infusion pump at hospital
- d. I am not taking any treatment currently
- e. Other

How Adherent are you to Treatment
- a. I take medication regularly
- b. I take medication irregularly
- c. I take medication sometimes
- d. I do not take any medication

I am not Adherent to Treatment for the Following Reasons
- a. Medication not available
- b. Transportation difficulty
- c. Outpatient Fees are not available
- d. Difficult to leave my job to attend
- e. Treatment difficult

My Body does not Respond to Oral Chelating Therapy Because
- a. I am not adherent to treatment
- b. I am not taking the correct dose
- c. The medication has side effects
- d. Lack of availability
- e. The medication does not suit me
- f. Others

If you are Receiving Infusion Pump, Poor Response to Therapy is Due to
- a. I am not committed to oral treatment
- b. I do not have the pump at home
- c. I do not have the medication
- d. Difficult treatment
- e. Medication side effects
- f. Others

If you are Receiving the Medication Inside the Hospital (Inpatient), the Reason for Poor Response to Therapy is
- a. Difficult to reach the hospital
- b. In availability of the proper place to receive my therapy
- c. The hospital timing to receive the treatment does not suit me
- d. Treatment is not important
- e. Other

What is the Importance of Treatment?
- a. To get rid of excess iron
- b. To avoid precipitation of iron to vital organs
- c. Others

Are you Committed to Treatment?
- a. Yes
- b. No

The Reason for Non Commitment to Treatment?
- a. No benefit of treatment
- b. Personal belief
- c. I do not want any treatment
- d. Other reasons
- e. I am committed
References


