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Iron Overload Diagnosis and Management Among Clinicians: International Survey Showing Gaps in Knowledge and Need for Continuing Education Programs

INTRODUCTION

• Iron overload (IO): can occur with a variety of conditions, including thalassemia, myelodysplastic syndromes, sickle cell disease, hereditary hemochromatosis, aplastic anemia, and a number of rare anemias,1,2 and can lead to significant cardiotoxicity, hepatotoxicity, and endocrine toxicity, resulting in a reduced life span and diminished quality of life.2

• Effective prevention and treatment of IO requires the ability to identify patients at risk, diagnose IO in affected patients, and apply an understanding of the differences between iron chelators and their appropriateness for use in specific patient populations in choosing treatment with the greatest probability of success.

• Determining the competence and practice performance of clinicians in the management of a complex condition such as IO is difficult. Nevertheless, self-assessments, while subjective, may illuminate important gaps in knowledge and competence that affect performance.

• To determine the current knowledge level, competence, and clinical practices in diagnosing and managing IO, an international survey was conducted among clinicians participating in the European School of Haematology (ESH) Curriculum in Iron Metabolism & Related Disorders on the ESH website.

METHODS

• Projects In Knowledge designed an online international survey to determine whether clinicians are knowledgeable and competent in the area of IO and its management or whether they need new educational interventions that improve practice performance.

• Beginning on November 11, 2009, the survey was emailed to a proprietary database of 1197 participants in the ESH Curriculum in Iron Metabolism & Related Disorders who are involved in the care of patients at risk for or with IO; responses were received through May 24, 2010.

• Participants self-assessed their level of competence and clinical practices in IO and its treatment in patients with thalassemia, myelodysplastic syndromes, sickle cell disease, hereditary hemochromatosis, and rare anemias.

• All responses were submitted anonymously.

• Responders chose the responses that best represented their current practice behavior and their level of competence (ability to perform tasks based on knowledge and skills) related to IO and its management.

• To determine the current knowledge level, competence, and clinical practices in diagnosing and managing IO, an international survey was conducted among clinicians participating in the European School of Haematology (ESH) Curriculum in Iron Metabolism & Related Disorders on the ESH website.

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The gaps between current level of competence and desired level of competence signal a need for and a strong interest in continuing education in these areas. Respondents’ interest in continuing education was also evident in their requests for further information on the following topics (in rank order):  

**Topic**  
Methods for monitoring iron load  
Clinical guidelines for the treatment of IO  
Effect of IO on cardiac function/toxicity  
Early identification of patients at risk for IO  
Efficacy/safety of oral ICT  
Safety issues as they relate to IO treatment  
Combination therapy with deferasirox  
IO in thalassemia patients: cause, effects, treatment  
When to treat patients for IO  
IO in MDS patients: cause, effects, treatment  
Determining the correct dose of ICT  
Appropriate patient selection for ICT  
Mechanisms of iron uptake  
Strategies to improve patient adherence to ICT  
How long do you treat with ICT?  
IO in SCID patients: cause, effects, treatment  
IO in HHT or rare anemia patients: cause, effects, treatment

**STUDY LIMITATIONS**  
- Respondents were self-selected and self-assessed.  
- Responses to questions of competence (very high, high, medium, low, and very low) are subjective.

**CONCLUSIONS**  
- The survey points out significant gaps between clinicians’ self-assessed levels of competence in diagnosing and managing IO, and translation and implementation of this knowledge into practice performance.  
- This was particularly evident in the gap between clinicians’ desired level of competence in differentiating between various indications and their current level of competence in this area.  
- The response rate to the survey among clinicians currently participating in an iron metabolism curriculum demonstrates their strong interest in these programs and their desire for continuing education in the areas identified.  
- Lack of clinical competence may be a barrier to identifying at-risk patients, as well as treating and counseling patients with IO.  
- Although self-selected, many of the respondents described themselves as less than highly/highly competent.  
- The gaps uncovered in this survey highlight the need for continued education in areas that are critical to practice improvement among clinicians and improved patient outcomes.

**REFERENCES**  

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**RESULTS**  
Seventy-three of the 1197 participants in the ESH Curriculum responded to the survey. Sixty-three (85.1%) were physicians, the majority of whom were hematologists or pediatric hematologic oncologists/pediatric oncologists. Breakdown of specialties is shown below:

<table>
<thead>
<tr>
<th>Specialty</th>
<th>% Survey Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hematology</td>
<td>30.0%</td>
</tr>
<tr>
<td>Pediatric Hematology/Oncology</td>
<td>11.0%</td>
</tr>
<tr>
<td>Hematology</td>
<td>10.0%</td>
</tr>
<tr>
<td>Pediatrics</td>
<td>7.0%</td>
</tr>
<tr>
<td>Gastroenterology/ Internal Medicine</td>
<td>5.5%</td>
</tr>
<tr>
<td>Oncology</td>
<td>5.5%</td>
</tr>
<tr>
<td>Pediatrics</td>
<td>5.0%</td>
</tr>
<tr>
<td>Other</td>
<td>49.3%</td>
</tr>
</tbody>
</table>

On a weekly basis, 84.8% of the respondents stated they treated patients with thalassemia major (81.9%) treated those with thalassemia intermedia, 78.8% treated patients with myelodysplastic syndromes, 84.4% treated sickle cell disease patients, 71.2% treated patients with hereditary hemochromatosis, and 78.8% treated those with rare anemias.

**Competence and Practice Performance**  
Self-reported clinical practices in the survey revealed several important deficiencies in the identification and management of IO, as well as significant gaps between competence and practice performance in three critical areas:  

- Screening for IO and implementing early therapy, educating patients about adherence and monitoring patient adherence, and monitoring and maintaining optimal iron chelation therapy (ICT) dosing.  
- Although 62.5% of respondents stated they always screen patients at risk for IO, only 50.0% said they always institute early ICT in patients with IO.  
- Thus, one (33.3%) of respondents do not always screen patients at risk for IO. Despite the serious toxicities associated with IO, half of the respondents, including many who screen for the condition, do not always implement early ICT to prevent these negative effects.

- Current and Desired Levels of Competence  
Participants were asked four questions concerning their current level of competence and their desired level of competence in managing IO, followed by the same questions as they related specifically to patients with thalassemia, myelodysplastic syndromes, sickle cell disease, hereditary hemochromatosis, and rare anemias.

The questions addressed the following areas:  

1. The diagnosis of IO, techniques for assessing IO, and interpretation of the results.  
2. Identification of patients at risk of IO, the organs affected, and the clinical sequelae/disease burden of IO.  
3. The rationale for using ICT and the mechanisms of action of various iron chelators.  
4. Differentiation across various ICTs regarding efficacy, safety, administration, and approved indications in specific populations.

- Adherence: Patient Education and Monitoring  
- Difficultly with patient adherence was cited by respondents as a major obstacle in managing patients; however, not all respondents regularly educate patients about compliance and/or monitor adherence. Although 73.4% of respondents stated they always instruct patients on the long-term therapy and the need for support in order to ensure adherence, and 41.5% do not always monitor patients’ adherence to treatment suggests a significant gap between competence and practice performance and an important area for improvement.

- The greatest gap between competence and practice was observed in participants’ response to the need to monitor/maintain an optimal dosage of ICT. Here, 60.9% of respondents stated that they always monitor patients for changes in status and treatment response to ensure optimal dosing, but only 35.7% always consider titration of ICT to reduce or maintain iron levels. Thus, even when it is apparent that response to treatment is inadequate, many respondents do not consider dose titration as a potential step in reducing IO.

- Current and Desired High/Very High Levels of Competence  
Various approved iron chelators in terms of efficacy/safety, frequency/ methods of administration, and approved indications for specific patient populations (62.3% indicating a high/very high level of competence in the ability to differentiate across ICTs regarding their efficacy and safety, administration, and approved indications in specific populations).  

- Monitoring for Treatment Response and Titrating Dose  
- Current and Desired High/Very High Levels of Competence in Treating Different Patient Populations  
- Although >70% of respondents stated they treat patients with thalassemia, myelodysplastic syndromes, sickle cell disease, hereditary hemochromatosis, and rare anemias on a weekly basis, their self-assessed levels of competence was anemia patients: cause, effects, treatment.
On a weekly basis, 84.8% of the respondents stated they treated patients with thalassemia major; 81.9% treated those with thalassemia intermedia, 78.8% treated patients with myelodysplastic syndromes, 84.4% treated sickle cell disease patients, 71.7% treated patients with hereditary hemochromatosis, and 78.8% treated those with rare anemias.

Competence and Practice Performance

Self-reported clinical practices in the survey revealed several important deficiencies in the identification and management of IO, as well as significant gaps between competence and practice performance in three critical areas – screening for IO and implementing early therapy, educating patients about adverse effects and monitoring patient adherence, and monitoring and maintaining optimal iron chelation therapy (ICT) dosing.

Although 74.7% of respondents stated they always screen patients at risk for IO, only 50.0% said they always initiate early ICT in patients with IO. Thus, one third (33.3%) of respondents do not always screen patients at risk for IO. Despite the serious toxicities associated with IO, half of the respondents, including many who screen for the condition, do not always implement early ICT to prevent these negative effects.

The gaps between current level of competence and desired level of competence signal a need for and a strong interest in continuing education in these areas. Respondents’ interest in continuing education was also evident in their requests for further information on the following topics (in order rank):

1. How long do you treat with ICT?
2. IO in SCD patients: cause, effects, treatment
3. IO in thalassemia patients: cause, effects, treatment
4. IO in HDF or rare anemia patients: cause, effects, treatment

The gaps between current level of competence and desired level of competence signal a need for and a strong interest in continuing education in these areas.

Current and Desired High/Very High Levels of Competence

Various approved iron chelators in terms of efficacy/safety, frequency/Methods of administration, and approved indications for specific patient populations. 62.5% indicated a high/very high desired level of competence in the ability to differentiate across IO regarding their efficacy and safety, administration, and approved indications in specific populations.

STUDY LIMITATIONS

- Respondents were self-selected and self-assessed.
- Responses to questions of competence (very high, high, medium, low, and very low) are subjective.

CONCLUSIONS

- The survey points out significant gaps between clinicians’ self-assessed levels of competence in diagnosing and managing IO, and translation and implementation of this knowledge into practice performance.
- This was particularly evident in the gap between clinicians’ desired level of competence in differentiating between various ICIs and their current level of competence in this area.
- The response rate to the survey among clinicians currently participating in an iron metabolism curriculum demonstrable a strong interest in these programs and their desire for continuing education in the areas identified.
- Lack of clinical experience may be a barrier to identifying at-risk patients, as well as treating and counseling patients with IO.
- Although self-selected, many of the respondents described themselves as less than highly/hyperlly competent.
- The gaps uncovered in this survey highlight the need for continuous education in areas that are critical to practice improvement among clinicians and improved patient outcomes.

REFERENCES


RESULTS

Seventy-three of the 1179 participants in the ESH-CLAIMS survey responded to the survey. Sixty-three (86.0%) were physicians, the majority of whom were hematologists or pediatric hematologic oncologists/pediatric oncologists. Breakdown of specialties is shown below:

- Hematology: 21.9%
- Hematologic/Oncology: 11.0%
- Pediatrics: 8.2%
- Internal Medicine: 49.3%
- Other: 5.5%
- Pediatrics/Hematology: 2.7%
- Other specialty: 1.4%

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