The use of adhesive tags as a facilitating tool in the data report of chronic GVHD in a HSCT Center lacking electronic medical records

Hospital Amaral Carvalho (HAC)
Jau-SP - Brazil
The 1st Bone Marrow Transplant was performed in our center in August, 1996.

2,924 Transplants were performed from August, 1996 until November, 2017.

We started the data reporting to the CIBMTR as a Comprehensive Report Forms (CRF) Center in January, 2009.
Transplants Reported to the CIBMTR

January, 2009 until November, 2017
1,830 Transplants were reported

Servicio de Transplante de Medula Óssea
Currently the data collection team is composed by 3 professionals:

- 2 Data Managers
- 1 Nurse
HAC – Hematopoietic Stem Cell Transplant Center

Brazilian public hospital

Electronic medical records are not used

The medical records are performed manually in the patients charts
Routine of the data collection team

The forms are updated according to the CIBMTR

Through medical and multidisciplinary records we look for descriptions of intercurrences that have to be reported

If there are any questions in the cases, the medical staff is verified

Weekly meetings with the medical staff are scheduled to clarify the cases
Chronic GVHD

The subject with the most questions

Mainly after the forms update in 2017
(revision 4)
Form 2100 – chronic GVHD

Update Revision 4
Chronic GVHD

The updated forms request more detailed data about each organ involved by cGVHD

Growth of number of cases to check with the medical staff
What could we do...

To improve data reliability, reduce errors, and streamline reporting?
So...

We developed an adhesive tag to classify cGVHD

One tag for the most common organs affected by cGVHD
### DECH-c Boca

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Sem sintomas</td>
</tr>
<tr>
<td>1</td>
<td>Leve com sinal de doença mais não limitando a alimentação</td>
</tr>
<tr>
<td>2</td>
<td>Moderada com sinal de doença, com limitação parcial da alimentação</td>
</tr>
<tr>
<td>3</td>
<td>Severa com sinal de doença ao exame com maior limitação alimentar</td>
</tr>
</tbody>
</table>

**Características de líquen plano:**
- [ ] Sim
- [ ] Não

### DECH-c Pele

**Score DECH-c Pele**

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Sem sintomas</td>
</tr>
<tr>
<td>1</td>
<td>≤18% da SC</td>
</tr>
<tr>
<td>2</td>
<td>19-50% da SC, ou alterações de esclerose superficial com possibilidade de pinchamento</td>
</tr>
<tr>
<td>3</td>
<td>&gt;50% da SC, ou com alterações de esclerose profunda sem possibilidade de pinchamento ou mobilização; úlcera ou prurido</td>
</tr>
</tbody>
</table>

**Características:**
- [ ] Liqueen plano
- [ ] Lesões maculo-papulosoas
- [ ] Esclerose cutânea
- [ ] Ceratose follicular
- [ ] Ichthyose
- [ ] Hipopigmentação
- [ ] Prurido
- [ ] Eritema
- [ ] Hiperpigmentação

### DECH-c Pulmão

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Sem sintomas</td>
</tr>
<tr>
<td>1</td>
<td>Sintomas leves (falta de ar após subir um lance de escadas)</td>
</tr>
<tr>
<td>2</td>
<td>Sintomas moderados (falta de ar após andar em terreno plano)</td>
</tr>
<tr>
<td>3</td>
<td>Sintomas graves (falta de ar em repouso; requer uso de O₂)</td>
</tr>
</tbody>
</table>

**Teste Função Pulmonar:**
- [ ] Não
- [ ] Sim: FEV1 ________%

### DECH-c Trato genital

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Sem sintomas</td>
</tr>
<tr>
<td>1</td>
<td>Sinais leves e mulheres com ou sem desconforto no exame</td>
</tr>
<tr>
<td>2</td>
<td>Sinais moderados e podem ter sintomas com desconforto no exame</td>
</tr>
<tr>
<td>3</td>
<td>Sinais severos com ou sem sintomas</td>
</tr>
</tbody>
</table>

Atualmente é ativo sexualmente:
- [ ] Sim
- [ ] Não
Implementation

The adhesive tags were distributed in the HSCT departments

Facilitating the access to the new tool

After the diagnosis, reevaluation or new progression of cGVHD, the physician glues the tag in the medical charts and fills the tag
Censuradas as informações pessoais.

**DECH - Pulmão**
- Score 0: Sem sintomas
- Score 1: Sintomas leves (falta de ar após subir um lance de escadas)
- Score 2: Sintomas moderados (falta de ar após andar em terreno plano)
- Score 3: Sintomas graves (falta de ar em repouso; requer uso de O2)

**Teste Função Pulmonar:**
- Não ( ) Sim: FEV1 55%

**DECH - Oído**
- Score 0: Sem sintomas
- Score 1: Leve, sintomas de ouvido seco que não afetam as AO
- Score 2: Modesto, sintomas de ouvido seco que afetam
- Score 3: Severo, sintomas de ouvido seco que afetam significativamente as atividades diárias (dúvida nos banhos, necessidade de evitar a água)

**DECH - Boca**
- Score 0: Sem sintomas
- Score 1: Leve com sinal de doença mais não limitando a alimentação
- Score 2: Moderado com sinal de doença, com limitação parcial da alimentação
- Score 3: Severo com sinal de doença ao exame com maior limitação alimentar

**Características de líquen plano:**
- Não
Lungs
287. Lungs

Yes →
No

Lung score

- Score 0 – No symptoms
- Score 1 – Mild symptoms (shortness of breath after climbing one flight of steps)
- Score 2 – Moderate symptoms (shortness of breath after walking on flat ground)
- Score 3 – Severe symptoms (shortness of breath at rest; requiring oxygen)

Were pulmonary function tests performed?

Yes →
No

Specify if any lung abnormalities were present, but explained entirely by non-GVHD causes:

Abnormality present but explained entirely by non-GVHD documented cause

Yes →
No

Specify cause:

Eyes
266. Eyes

Yes →
No

Eyes score

- Score 0 – No symptoms
- Score 1 – Mild dry eye symptoms not affecting ADL (requirement of lubricant eye drops ≤ 3x per day)
- Score 2 – Moderate dry eye symptoms partially affecting ADL (requiring lubricant eye drops >3x per day or punctal plugs), without new vision impairment due to keratoconjunctivitis sicca (KCS)
- Score 3 – Severe dry eye symptoms significantly affecting ADL (special eyewear to relieve pain) OR unable to work because of ocular symptoms OR loss of vision due to keratoconjunctivitis sicca (KCS)

Keratoconjunctivitis sicca (KCS) confirmed by ophthalmologist?

Yes →
No
- Not done

Specify if any eye abnormalities were present, but explained entirely by non-GVHD causes:

Abnormality present but explained entirely by non-GVHD documented cause

Yes →
No

Specify cause:
Results

The report has been improved, but it is still far from ideal

The presence of this tool has been stimulating the medical staff to make a more detailed evolution

The number of cases to be checked with the medical staff has decreased

Contributing to greater agility in completing the report and sending data
Conclusion and comments

- Low cost solution and easy reproducibility
- More detailed information
- Greater data reliability assurance
- Standardization of information
- Allowing the data manager to report data with greater security, even without having an advanced medical knowledge
Data collection team - HAC

THANKS!