Optimizing data collection at a BMT unit

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Copenhagen

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No disclosureure
Overview:

• Presentation of center
• What was our problem
• What did we do
• How is it going so far
• Local experiences from implementing Med-A day 0
• How we keep track on forms due
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Transplant history in Copenhagen

• First transplant performed April 1971
• Second transplant performed December 1972
• 110-120 first transplants each year

• Myeloablative and non-myeloablative transplants
• Children and adults
• Using BM, PBSC, single and double CBU

• 2000 first transplants
• 1430 myeloablative
• 533 non-myeloablative
Our center provides data for:

- EBMT - day 0, day +100 and annual
- CIBMTR - day 0, day+100, day+180 and annual
- Different CBB - various
- Local database - day 0, day +100 and annual
- Research center under CIBMTR
- 1000 patients are due to follow up each year.
What was the problem

- Accurate data collection is essential
- No tradition for systematically performing audits
- Most data available - but lack of evaluation
- Physicians not familiar with data collection according to EBMT/CIBMTR
- Preparing for a JACIE accreditation
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What did we do
Information required for the patient file by day +100, +180 and Annual.
The aim of this tool is to collected correct information on HSCT patients.
Our center collects information for the local database, CIBMTR, EBMT, Donor Registers and Cord Blood Banks.
A number of patients are enrolled in protocols and studies which often requires similar information.

The consulting physician evaluates and documents the following in the patient file:
Status of remission; requires the physicians assessment by blood samples, biopsies, scans (etc.)
GvHD; requires the physicians assessment and diagnosis.
Liver-, lung-, and other complications; requires the physicians assessment and diagnosis.
Karnofsky score and occupational status; informed by the patient at the consultation.

The Data Manager looks up information about:
Take; according to the applicable definitions by reviewing the blood tests and transfusion records in the patients file.
Infections; the clinical microbiology tests are reviewed.
Secondary malignancy; are found in the national pathology database in Denmark.
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### Information required for the patient file by day +100, +180 and Annual.

The aim of this tool is to collect correct information on HSCT patients. Our center collects information for the local database. CIBMTR, EBMT, Donor Registers and Cord Blood Banks. A number of patients are enrolled in protocols and studies which often requires similar information.

The consulting physicians evaluate and document the following in the patient file:
- Status of infections; requires the physician’s assessment by blood samples, biopsies, scans (etc.)
- GrHD; requires the physician’s assessment and diagnosis.
- Liver, lung, and other complications; requires the physician’s assessment and diagnosis.
- Karnofsky score and occupational status; informed by the patient at the consultation.

The Data Manager looks up information about:
- Tans; according to the applicable definitions by reviewing the blood test and transfusion records in the patient file.
- Infections; the clinical microbiology tests are reviewed.
- Secondary malignancy; are found in the national pathology database in Denmark.

#### Data noted by the consulting physician

<table>
<thead>
<tr>
<th></th>
<th>Day +100</th>
<th>Day +180</th>
<th>Annual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Karnofsky score</td>
<td>⬠</td>
<td>⬠</td>
<td>⬠</td>
</tr>
<tr>
<td>Status of infections</td>
<td>⬠</td>
<td>⬠</td>
<td>⬠</td>
</tr>
<tr>
<td>Start of GrHD, organ involvement, stage and grade</td>
<td>⬠</td>
<td>⬠</td>
<td>⬠</td>
</tr>
<tr>
<td>Start of GrHD organ involvement, grade and overall severity</td>
<td>⬠</td>
<td>⬠</td>
<td>⬠</td>
</tr>
<tr>
<td>New complications</td>
<td>⬠</td>
<td>⬠</td>
<td>⬠</td>
</tr>
<tr>
<td>Pulmonary complications</td>
<td>⬠</td>
<td>⬠</td>
<td>⬠</td>
</tr>
<tr>
<td>Other complications (TAM, renal failure requiring dialysis, hemorrhage, cardiovascular events, heart failure, diabetes, genetic deficiencies)</td>
<td>⬠</td>
<td>⬠</td>
<td>⬠</td>
</tr>
<tr>
<td>Occupational status</td>
<td>⬠</td>
<td>⬠</td>
<td>⬠</td>
</tr>
<tr>
<td>Date of withdrawal of immunosuppressive agents</td>
<td>⬠</td>
<td>⬠</td>
<td></td>
</tr>
</tbody>
</table>

#### Data collected by the data manager

<table>
<thead>
<tr>
<th></th>
<th>Day +100</th>
<th>Day +180</th>
<th>Annual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tans</td>
<td>⬠</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infection</td>
<td>⬠</td>
<td>⬠</td>
<td>⬠</td>
</tr>
<tr>
<td>Secondary malignancy</td>
<td>⬠</td>
<td>⬠</td>
<td>⬠</td>
</tr>
</tbody>
</table>
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Standard note day +100

19.11.2015 09:40 B Notat

Læge 4041 L9 Hæmatologisk ambulatorium 4041 1301

Ambulant kontrol dag +100
Siden sidst: ( ro i akut hud GVH )
Karnofsky score:100
Remissionsstatus:CR

gGVHD: har haft akut hud GVH
Cav oris: 0
Hud: yes
Tarm: 0
Lever: 0
Lunger: 0
cGVHD: 0

Infektion: 0
Komplikationer: 0

Ses igen: ca hver 14. dag

Aftrapper prednisolon

dim predn 20 mg dgl
sep noxa
sep valcyte
rp selitrex

Lidt højt BT

RM senere idag. Får svaret tlf cm 14 dage og ses igen om 4 uger. Henv

v behov.
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Standard note annual

Ambulant kontrol (1) år efter HSCT
Siden sidst: (Har det glimrende.)
Karnofsky score: 100
Erhvervsstatus: (let nedsat pga angst. Men karnofsky 100%)
Remissionsstatus: CR

aGVHD: 0
Cav oris: 0
Hud: 0
Tarm: 0
Lever: 0
Lunger: 0

cGVHD: 0
Infektion: 0
Komplikationer: 0
Immunosuppressiv behandling er seponeret d.: (ca feb 15),
Immunosuppressiv behandling er ikke seponeret ( )

Ses igen: 3 mdr
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How are we doing so far
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The results from the first day +100 audit:

- 44% had all requested data available
- 44% had KF available
- 56% had status of remission available
- 89% had GvHD status available
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The results from the first day +180 audit:

- 27% had all requested data available
- 64% had KF available
- 36% had status of remission available
- 55% had GvHD status available
- 45% had status of current or most recent work status available
The results from the second day +100 audit:

- 31% had all requested data available
- 50% had KF available
- 63% had status of remission available
- 63% had GvHD status available
The results from the second day +180 audit:

- 50% had all requested data available
- 50% had KF available
- 75% had status of remission available
- 75% had GvHD status available
- 75% had status of current or most recent work status available
The results from the first annually visit:

- 42% had all requested data available
- 46% had KF available
- 58% had status of remission available
- 62% had GvHD status available
- 54% had status of current or most recent work status available
Comparing audit results:

Day 100, 1. audit
Day 100, 2. audit

Day 180, 1. audit
Day 180, 2. audit
Local experiences from implementing Med-A day 0

How we prepare for data collection

- Create a folder containing information with name, date of birth, diagnose, date of diagnose, date and type of transplant, donor information
- Paper copy of Med-A or Med-B and disease specific form

Collecting data starts when conditioning regime has started

- Using patient file for informations on pre transplant condition, donor and graft information and conditioning regime.
- Using referring file for information on primary disease and treatment.
How do we keep track on what to do when

Data are requested:

- EBMT – day 0, day +100 and annual
- CIBMTR – day 0, day+100, day+180 and annual
- Different CBB - various
- Local database – day 0, day +100 and annual
- Various guidelines for follow up
In order to keep track on what to do and when to do it - we created our own folder system, that is fairly straightforward and easy to use

- Three different sheets; +100, +180 and annual follow up
- Prefilled with UPN, CRID, name, date of birth, diagnose, date of transplant, data and which form due

- One folder containing the sheets; +100 and +180 follow up
- One folder containing the sheet; annual follow up

- Stored in order of month and due date

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THANK YOU FOR LISTENING

Questions?

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