The stage for childhood cancers: the JARC pilot study

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- WP of epidemiology, task on data quality in population based cancer registries
- Stage in childhood cancers (Toronto guidelines)
Childhood cancers (0-14 years of age)

Background

• Rare ( < 1 % all malignant cancers)
• Classified differently to adult cancers (ICCC-3)
• Uses different staging systems to adult cancer

Aims

• Can Toronto guidelines be adopted by the European registries?
Paediatric cancer stage in population-based cancer control: the Toronto consensus principles and guidelines

Toronto stage guidelines
Pilot study for neuroblastoma and Wilms tumours
Registries, countries, period, cases

REGISTRIES
Belgium
Denmark
France
Greece
Hungary
Italy (7)
Malta
Norway
Portugal (1)
Slovakia
Slovenia
Spain (5)
Switzerland

CASES
Neuroblastoma = 499
Nephroblastoma = 387
complete incidence, at least 10 consecutive cases per tumour

PERIOD OF DIAGNOSIS
2002-2015
Sample, age (% distribution)

**NEUROBLASTOMA**

**WILMS**

red = pilot study
blue = from EUROCARE-5
Toronto stage, collected : 97%
<table>
<thead>
<tr>
<th>age</th>
<th>&lt;1</th>
<th>1-4</th>
<th>5-14</th>
</tr>
</thead>
<tbody>
<tr>
<td>% 5-yr surv</td>
<td>91</td>
<td>59</td>
<td>53</td>
</tr>
</tbody>
</table>

EUROCARE-5 survival [Lancet Oncology, 2013]
EUROCARE 5-year survival: from 89% in Norway to 55% in Estonia
Toronto stage, by country
Nephroblastoma

EUROCARE 5-year survival: from 100% in Switzerland and Slovenia to 66% in Estonia
### Sources

Administrative, pathological reports, clinical records, other

<table>
<thead>
<tr>
<th>Source</th>
<th>Neuroblastoma</th>
<th>Wilms</th>
</tr>
</thead>
<tbody>
<tr>
<td>clinical record *</td>
<td>93</td>
<td>70</td>
</tr>
<tr>
<td>pathological report.*</td>
<td>94</td>
<td>87</td>
</tr>
</tbody>
</table>

*alone or together with the other sources
Examinations to define T and M by registrars

<table>
<thead>
<tr>
<th></th>
<th>T</th>
<th>M</th>
</tr>
</thead>
<tbody>
<tr>
<td>neuroblastoma</td>
<td></td>
<td></td>
</tr>
<tr>
<td>one</td>
<td>11</td>
<td>32</td>
</tr>
<tr>
<td>two</td>
<td>54</td>
<td>36</td>
</tr>
<tr>
<td>three</td>
<td>27</td>
<td>26</td>
</tr>
<tr>
<td>Wilms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>one</td>
<td>7</td>
<td>48</td>
</tr>
<tr>
<td>two</td>
<td>58</td>
<td>6</td>
</tr>
<tr>
<td>three</td>
<td>25</td>
<td>4</td>
</tr>
</tbody>
</table>

*T*: CT scan, MRI, abdominal ultrasound  
*M*: Scintigraphy, marrow agobiopsy, x-ray thorax
survival, neuroblastoma (n=499)
survival, Wilms (n=387)

Kaplan-Meier survival estimates

Missing
II
I
III
IV

28 deaths
Comparison with other studies
Stage, comparison with other studies
MISSING

Population registries from Argentina, SEER, Denmark, UK.

missing 35% - 21%
Australian study on Toronto staging
Assessing the feasibility and validity of the Toronto Childhood Cancer Stage Guidelines: a population-based registry study

Joanne F Aitken, Danny R Youlden, Andrew S Moore, Peter D Baade, Leisa J Ward, Vicky J Thursfield, Patricia C Valery, Adèle C Green, Sumit Gupta, A Lindsay Frazier

Summary

Background Cancer stage at diagnosis is crucial for assessing global efforts to increase awareness of childhood cancer and improve outcomes. However, consistent information on childhood cancer stage is absent from population cancer registries.
Could a registry simply collect stage recorded in the chart by the physician?

Not in Australia:

- Stage was present in the record in only 39\% of cases (93\% could be staged using the Toronto Guidelines).

- The staging system used was not recorded.

- Staging data were inconsistent – different stages were recorded (different times, different opinions?..)
Cost of collecting data elements and assigning Toronto stage, Australian study

average 18 minutes per case

<table>
<thead>
<tr>
<th>Personnel</th>
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<tr>
<td>Average cost per case</td>
<td>€ 20.80</td>
</tr>
</tbody>
</table>
Discussion

- Toronto guidelines are applicable and should be implemented also for the other childhood cancers.
- Training course with test for validation are welcome (ENCR?)
- We hope the Toronto stage could be included in the routine of the majority of European registries.
- Involvement of the paediatric oncology community (for example, stage must be reported in the clinical record).
- Further efforts to standardise the stage coding among registries.
Proposal: can the next EUROCARE include stage according to the Toronto guidelines?
Belgium: National (Liesbet Van Eycken, Nancy Van Damme);
Denmark: National Childhood (Filippa Nyboe Norsker, Jeanette Falck Winther)
Estonia: National CR (Keiu Paapsi, Kaire Innos)
France: National Childhood Solid Tumours (BLacour, EDesandes);
Greece: National (Eleni Petridou,);
Hungary: National childhood CR (Jakab Zsuzsanna);
Italy: Agrigento and Trapani (Pina Candela, Tiziana Scuderi),
Barletta Andria Trani (Enzo Coviello),
Campania childhood (Francesco Vetrano, Fabio Savoia),
Catania Siracusa Enna (Marine Castaing),
Palermo (Francesco Vitale, Rosalba Amodio),
Pavia (Lorenza Boschetti),
Varese (Giovanna Tagliabue, Sabrina Fabiano);
Malta: National CR (Dominic Agius);
Norway: National CR (Bernward Zeller, Aina Helen Dahlen);
Portugal: South Portugal (Ana Miranda);
Spain: Basque Country (Arantza Lopez de Munain Marques),
Girona childhood (Rafael Marcos-Gragera),
Granada (Maria Jose Sanchez),
Murcia (Maria Dolores Chirlaque),
Navarra (Eva Ardanaz, Marcela del Pilar);
Slovakia: National CR (Chakameh Safaei Diba);
Slovenia: National CR (Zadnik Vesna, Žagar Tina);
Switzerland: Swiss national childhood (Claudia Kühni, Shelah Redmond)