Recording Stage of Disease in Cancer Registries: Problems and Solutions for Low and Middle Income Countries

Dr D. Maxwell Parkin
PREMISE:

Recording STAGE at diagnosis is important for:

- Prognosis
- Decisions on treatment
- Judging public knowledge of cancer/availability of diagnosis
- Evaluation of early diagnosis/screening
- Comparisons of cancer survival
DO cancer registries record STAGE (or extent of disease) for at least SOME types of cancer?

According to Cancer Incidence in Five Continents, Volume IX of the registries included in the volume:

- 3/5 from Africa
- 3/11 from South America
- 21/28 from Asia (excl Japan & Korea)

record “Stage of the disease”
### 24 registries (2014)

<table>
<thead>
<tr>
<th>Name of Cancer Registry (25 registries)</th>
<th>Stage recorded (Y/N)</th>
<th>TNM (Y/N)</th>
<th>Treatment (Y/N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Botswana National Cancer Registry</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Registre des cancers de Brazzaville</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Registre des Cancers d’Abidjan</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Addis Ababa Cancer Registry</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Gambia Cancer Registry</td>
<td>Y (EOD)</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Kumasi Cancer Registry</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Registre de Cancer de Guinee</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Eldoret Cancer Registry</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Nairobi Cancer Registry</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Malawi Cancer Registry</td>
<td>Y (EOD)</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Mauritius Cancer Registry</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Registro de Cancro de Beira</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Namibian National Cancer Registry</td>
<td>Y (EOD)</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Registre des cancers du Niger</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Abuja Cancer Registry</td>
<td>N</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Calabar Cancer Registry</td>
<td>N</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Ibadan Cancer Registry</td>
<td>Y (EOD)</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Seychelles National Cancer Registry</td>
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<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Eastern Cape Province Cancer Registry</td>
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<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>S. African Children's Cancer Group (SACCSG) Tumour Reg.</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>South African National Cancer Registry</td>
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<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Tanzania Cancer Registry</td>
<td>N</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Kampala Cancer Registry</td>
<td>Breast and cervix</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Zimbabwe National Cancer Registry</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
</tbody>
</table>

16/24, 10/24, 15/24
NOT BAD! BUT...... HOW COMPLETE ARE THESE DATA?

Studies of size and stage of breast cancer in Africa & their influence on survival

Eight cancer registries
1143 cases of breast cancer

<table>
<thead>
<tr>
<th>Status</th>
<th>No. of cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage</td>
<td>401</td>
</tr>
<tr>
<td>T or N or M</td>
<td>394</td>
</tr>
<tr>
<td>cT or cN or cM</td>
<td>211</td>
</tr>
<tr>
<td>pT or pN</td>
<td>57</td>
</tr>
<tr>
<td>No data on any fields above</td>
<td>364</td>
</tr>
</tbody>
</table>
When the stage/extent of the cancer is recorded in the clinical/pathological records according to the TNM system, these codes should be registered.

The registry should record the best available data - that is pT (rather than cT) and pN (rather than cN), if they are available.

Normally, if there is any evidence (clinical or pathological) of metastatic disease, M will be recorded as 1.
What if it is not there?

DO-IT-YOURSELF
Breast Cancer Staging

Regional lymph nodes (N)

Clinical

N0 No regional lymph node metastases

N1 Metastasis to ipsilateral level I axillary lymph node(s)

N1a Metastasis in level I axillary lymph nodes that are clinically fixed or involved or in clinically detected ipsilateral internal mammary nodes in the absence of clinically involved axillary lymph node metastases

N1b Metastasis in level I axillary lymph nodes fixed to one another (cohesive) or to other structures

N2 Metastasis in level II axillary lymph nodes fixed to one another (cohesive) or to other structures

N2a Metastasis in level III axillary lymph nodes fixed to one another (cohesive) or to other structures

N2b Metastasis in level II axillary lymph nodes

N3 Metastasis is in level II axillary lymph nodes(s), with or without level I axillary node involvement, or in clinically detected ipsilateral internal mammary lymph nodes, in the presence of clinically involved (II) axillary lymph node metastases, or metastasis in ipsilateral supraclavicular lymph nodes, with or without axillary or internal mammary lymph node involvement

N3a Metastasis in level II axillary lymph nodes(s), with or without level I axillary node involvement

N3b Metastasis in ipsilateral internal mammary lymph nodes and axillary lymph nodes

N3c Metastasis in ipsilateral supraclavicular lymph node(s)

Pathologic (pN)

pN0 Regional lymph node metastases histologically, negative IHC

pN1 Regional lymph node metastases histologically, positive IHC, involving ITO

pN1< Regional lymph node metastases histologically, negative IHC

pN2 Regional lymph node metastases histologically, positive IHC, negative IHC

pN3 Regional lymph node metastases histologically, positive IHC, involving ITO

pN3< Regional lymph node metastases histologically, positive IHC, negative IHC

Pathologic (pN)

pN0 Positive molecular findings (RT-PCR) but no regional lymph node metastases detected by histology or IHC

pN1 Micro metastases; or metastases in 1-3 axillary lymph nodes (positive lymph nodes in internal mammary nodes, with metastases detected by sentinel lymph node biopsy but not clinically detected)

pN1a Axillary lymph nodes with metastases < 0.2 mm

pN1b Axillary lymph nodes with metastases < 1 mm

pN1c Axillary lymph nodes with metastases > 1 mm

pN2 Axillary lymph nodes with metastases in internal mammary nodes, with metastases detected by sentinel lymph node biopsy but not clinically detected

pN2a Axillary lymph nodes with metastases in internal mammary nodes, with metastases detected by sentinel lymph node biopsy but not clinically detected

pN2b Axillary lymph nodes with metastases in internal mammary nodes, with metastases detected by sentinel lymph node biopsy but not clinically detected

pN3 Axillary lymph nodes with metastases in internal mammary nodes, with metastases detected by sentinel lymph node biopsy but not clinically detected

pN3a Axillary lymph nodes with metastases in internal mammary nodes, with metastases detected by sentinel lymph node biopsy but not clinically detected

pN3b Axillary lymph nodes with metastases in internal mammary nodes, with metastases detected by sentinel lymph node biopsy but not clinically detected

pN3c Axillary lymph nodes with metastases in internal mammary nodes, with metastases detected by sentinel lymph node biopsy but not clinically detected

1. Superficial axillary nodes
2. Brachial axillary lymph nodes
3. Interpectoral axillary lymph nodes
4. Deep axillary lymph nodes
5. Infraclavicular lymph nodes
6. Supraclavicular lymph nodes
7. Internal mammary nodes
8. Paramammary or intramammary lymph nodes
The Cancer Staging Tool
By Morten Ervik (IARC/CIN), Giulio Napolitano (NICR), and Lisa Ranaghan (NICR)

Welcome to the Cancer Staging Tool, provided to you thanks to a NICR, IARC, and UICC collaboration. The tool will help maximise the availability, standardisation and comparability of cancer staging internationally.

**Sites**

<table>
<thead>
<tr>
<th>Site</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
</tr>
<tr>
<td>Cervix</td>
</tr>
<tr>
<td>Colorectal</td>
</tr>
<tr>
<td>Lung</td>
</tr>
<tr>
<td>Prostate</td>
</tr>
</tbody>
</table>

Endorsed by:
- International Agency for Research on Cancer
- World Health Organization
- International Association of Cancer Registries

Used with the permission of the Union for International Cancer Control (UICC), Geneva, Switzerland. The original source for this material is Leslie H. Sabin (Editor), Mary K. Gospodarowics (Editor), Christian Wittekind (Editor), *TNM Classification of Malignant Tumours, 7th Edition*, published in November 2009 by Wiley-Blackwell

This tool has been reproduced with due care. Any inconsistencies with the UICC TNM classification 7th edition and published errata are unintentional. Neither NICR nor UICC carry any liability should unforeseen errors emerge.
ENCR RECOMMENDATIONS
Condensed TNM for Coding the Extent of Disease

Members of the Working Group:
Dr F. Berizzo, Varese Cancer Registry, Milan, Italy (Chairman)
Dr C. Brown, East Anglian Cancer Registry, Cambridge, UK
Dr T. Möller, Southern Swedish Cancer Registry, Lund, Sweden
Dr L. Sobin, Armed Forces Institute of Pathology, Washington, USA

With additional contribution from:
Dr J. Fafre, Digestive Cancer Registry, Dijon, France

April 2002
Condensed TNM

When T, and/or N, and/or M have not been explicitly recorded in the clinical/pathological records, the cancer registry should attempt to score extent of disease according to the Condensed TNM scheme:

\[
\begin{align*}
T &: \quad L \ (\text{Localised}) \quad A \ (\text{Advanced}) \quad X \ (\text{cannot be assessed}) \\
N &: \quad 0 \quad + \quad X \ (\text{cannot be assessed}) \\
M &: \quad 0 \quad + \quad X \ (\text{cannot be assessed})
\end{align*}
\]

Where T and N are abstracted, if possible, from the pathology report, or, in its absence, from the clinical record (X-Ray, endoscopy, etc).

M is based on the best available information, whether clinical, instrumental, or pathological.

For M, clinical signs and findings are enough to justify M+ in the absence of pathological confirmation of metastatic deposits.
The **Condensed TNM** should be based on all available clinical and pathological information, or on sound reasoning based on the understanding of clinical practices.

The conventional values of T, which correspond to T (Localised) and T (Advanced) are shown in a Table:

<table>
<thead>
<tr>
<th>Site</th>
<th>Localised</th>
<th>Advanced</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lip &amp; oral cavity</td>
<td>T1 - T2</td>
<td>T3 - T4</td>
</tr>
<tr>
<td>Pharynx</td>
<td>T1 - T2</td>
<td>T3 - T4</td>
</tr>
<tr>
<td>Larynx</td>
<td>T1 - T2</td>
<td>T3 - T4</td>
</tr>
<tr>
<td>Colon &amp; rectum</td>
<td>T1 - T2</td>
<td>T3 - T4</td>
</tr>
<tr>
<td>Breast</td>
<td>T1 - T3</td>
<td>T4</td>
</tr>
<tr>
<td>Cervix</td>
<td>T1 - T2</td>
<td>T3 - T4</td>
</tr>
<tr>
<td>Corpus</td>
<td>T1 - T2</td>
<td>T3 - T4</td>
</tr>
</tbody>
</table>

And a summary of the corresponding definitions (from TNM Manual 6th Edition) in an Appendix:

**Appendix 1.**

**Definition of A(dvanced)**
(usually minimum criteria for T3, else specified in text)

- Colon and rectum
  - T3. Tumour invades extends beyond the muscle coat of the intestine

- Breast
  - T4. Tumour of any size with direct extension to chest wall or skin

- Cervix uterus
  - T3. Tumour extends beyond uterus to pelvic wall or lower third of vagina, or further, or causes hydronephrosis or non-functioning kidney

- Corpus Uteri
  - T3. Tumour involves serosa or extends beyond uterus
N+ refers to spread to **regional lymph nodes**. The definition of 'regional nodes' for each site is provided in the TNM manual and in summary form in an Appendix (2)

Appendix 2.

**Definitions of regional lymph nodes (N+)**

**Colon and rectum**
The regional lymph nodes are the pericolic and perirectal nodes and those located along the ileocolic, right colic, middle colic, left colic, inferior mesenteric, superior rectal (hemorrhoidal), internal iliac arteries, mesorectal, lateral sacral, presacral, and sacral promontory (Gerota).

**Breast**
The regional lymph nodes are:

**Cervix uteri**
Paracervical, parametrial, hypogastric (internal iliac, obturator), common and external iliac, presacral, and lateral sacral nodes
What is needed....

- A group with INTERNATIONAL remit to review and revise the ENCR “Condensed TNM”:
  - Update to 7th revision of TNM
  - Ensure categories L/A and +/- map to
    - UICC/AJCC stage
    - “Extent of disease” (in situ, localized, regional, distant)

- Prepare a simple USERS GUIDE (not only online)
There are 4 stages of tumour size in bowel cancer

\[ T: L \]
- T1 means the tumour is only in the inner layer of the bowel
- T2 means the tumour has grown into the muscle layer of the bowel wall

\[ T: A \]
- T3 means the tumour has grown into the outer lining of the bowel wall
- T4 means the tumour has grown through the outer lining of the bowel wall. It may have grown into another part of the bowel, or other nearby organs or structures. Or it may have broken through the membrane covering the outside of the bowel (the peritoneum)
CONCLUSIONS

NOT EASY!

But the best hope of getting reasonable quality results, in a large proportion of cases, from cancer registries in low/middle income settings