Role of the cancer registry in clinical cancer control

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Turkey

Cyprus

Malta

San Marino

Albania

Portugal

Spain

Gibraltar

Marinique

Reunion

Iceland
Figure 2  Incidence of all cancer sites (ESR) male plus female
Elements of a quality system for (oncological) care

- Audit
- Professionals
- Organization
- Patients
- Research
- Education
Professionals

- symposia
- conferences
- training programs
- information material for patients, health care givers
- guidelines: evidence-based
- revalidation program
- palliative care structure
- studies, trials

local

Oncology committees

Different Disciplines (departments)

visits ICT

Regional/national (CCC)

Consultancy (medical and supportive care)

Working Groups Mono & multidisciplinary

Consultancy

Different Disciplines (departments)
guidelines

Regional: www.ikn.nl
National: www.oncoline.nl
Or: www.ikc.nl
Organization

• Includes

• Structure f.e.
  – structured multidisciplinary consultation for selected cases of cancer patients
  – Structured transfer of information given to the patient between the professionals

• Proces f.e.
  – waiting time between professionals

• Organization f.e.
  – Management of oncological care
Measurement tools

CCC national  ↔  CCC regional

Advisory board
(Professionals, pat. ass.)

Working groups, consultants

Reg. guidelines

Nat. guidelines

Input and process
- Structure
- Process
- Information supply
- Available professionals
- Organization conditions

Output
- Number of patients
- Diagnosis % acc. GL
- Treatment % acc. GL
- Complications
- % recurrence
- Survival
- Pat. satisfaction

External audit

pop. based cancer registry +

Nat. guidelines

Reg. guidelines

Working groups

Advisory board

Advisory board
(Professionals, pat. ass.)

Working groups, consultants

Reg. guidelines

Nat. guidelines

CCC regional  ↔  CCC national

Norms

Tools
Measurement tools

**CCC national** ← **CCC regional**

- **Advisory board**
  - (Professionals, pat. ass.)

- **Working groups**

- **Nat. guidelines**

- **Working groups, consultants**

- **Reg. guidelines**

**Norms**
- Input and process
  - Structure
  - Process
  - Information
  - Available prof.
  - Organization conditions

**Output**
- Number of patients
- Diagnosis % acc. GL
- Treatment % acc. G
- Complications
- % recurrence
- Survival
- Pat. satisfaction

**Tools**
- External audit
- Pop. based cancer registry +
Population-based cancer registry

- **Organization:** (since 1986)
  - 9 regional registries → one national registry

Some data:

- **Population:**
  - 15.5 million inh. (49% males, 51% females)
  - 450 inh/km²
  - 65,000 new cancer patients/year

- **Life expectancy:**
  - Males: 74 years
  - Females: 80 years
Population-based cancer registry

• Data collection:
  – Sources:
    – pathological lab.
    – Hospital discharge diagnosis
    – Radiotherapy institutions
    – Hematological departments

Medical records

• Abstraction and recording by trained registrars

• Data entry into the PC

• Regional registry ↔ national registry
Cancer registry and multidisciplinary working groups

• Annually feed back during a meeting of regional data out of the general cancer registry:
  – regional adherence to the guidelines

• Feed back on specific data concerning additional data asked by the WG (documentation/pattern of care studies):
  – Insight information
Invasive breast cancer

- GL since 1970’s on CCC level
  - GL since 1994:
    - T1-2, N0-2 : BCT
    - No age limit
- Incidence in NL
  - 1989: 7,894
  - 1998: 10,317
- Screening programme:
  - Starts in 1990, implemented in 1996 on national level (50-69)
  - Since 1996 : 70-74 years included

- 1998
  - T1 N0-2: 50.6% of all diagnosed breast cancers
  - T2 N0-2: 40.3 %
  - T1= <2 cm
  - T2= 2-5 cm
% BCS + RT for T1 N0-2 breast cancer patients
Compliance to GL

- **Lip cancer** (CCC level)
  - GL: no revision since 1989
  - Incidence WSR: 2,06
  - N=248, 1989-1997
- **Adherence:**
  - Diagnosis: 41%
  - Staging:
    - Physical exam.: 70%
    - Chest X-ray: 26%
  - Treatment: 44%
    » Int.JQHC 2001

- **Soft tissue sarcoma** of head & neck, upper and lower limbs (CCC level)
  - GL identical 1989-1998
  - Incidence WSR: M:1,17  F 1,24
  - Adherence:
    - Diagnosis: 41%
    - Staging:
      - Physical exam.: 70%
      - Chest X-ray: 26%
    - Treatment: 44%

  » Cancer 2001
Cancer registry and hospitals (1)

- **Pattern of care studies** on regional level:
  - additional data to the registry are registered on request of the professionals by CCC registrars
  - Evaluation on regional and local (hospital) level: **benchmarking**
    - Examples: complications of treatment versus patients’ volume (rectal surgery, chemotherapy...
Cancer registry and hospitals (2)

- Cancer registry as source for special requests:
  - patient satisfaction: results on hospital and professional level versus the regional average

- Planning, development and control:
  - Radiotherapy instruments
  - Capacity of medical specialists
  - PET scans
### Number of projects in the CCC’s (1989-2000)

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<th>CR + and adherence to GL</th>
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Conclusions

• 1. A population-based cancer registry including items on staging and initial treatments is of great use with regard to evaluation of implementation of clinical guidelines and clinical cancer control
• 2. More research is needed to better understand the reasons of differences between hospitals in compliance to GL, and to show the relevance of adhere to the GL for the patients
Conclusions

• 3. Improvement of the quality in oncological care requires an additional organization in order to feed back the results to the professionals, on regular basis (guarantee for quality)

• 4. The cancer registry can be used for many purposes, but usually only few are taken into account.
Conclusions

• 5. However the registry must contain data of high quality which the researcher and the user should rely on

• This requires a.o.
  – Well trained personnel and staff
  – Well defined data and an up to date manual
  – a systematic datacontrol on quality and a quality manager