

# Cancer: the changing trajectory of the disease course

Assoc Prof Tit Albreht, MD, PhD, Scientific Co-ordinator of iPAAC, NIJZ,

e-mail: tit.albreht@nijz.si



### The cancer trajectory



- Traditional approaches focusing on diagnosis and treatment
- Gradual development of screening programmes
- More stress on early detection
- Introduction of health promotion programmes
- Increasing survival opening 'new issues':
  - Survivorship
  - Late effects of treatment
  - Living with extended disease
- Psycho-oncological and psychosocial care
- Palliative and end-of-life issues



### Consequences of the new trajectory

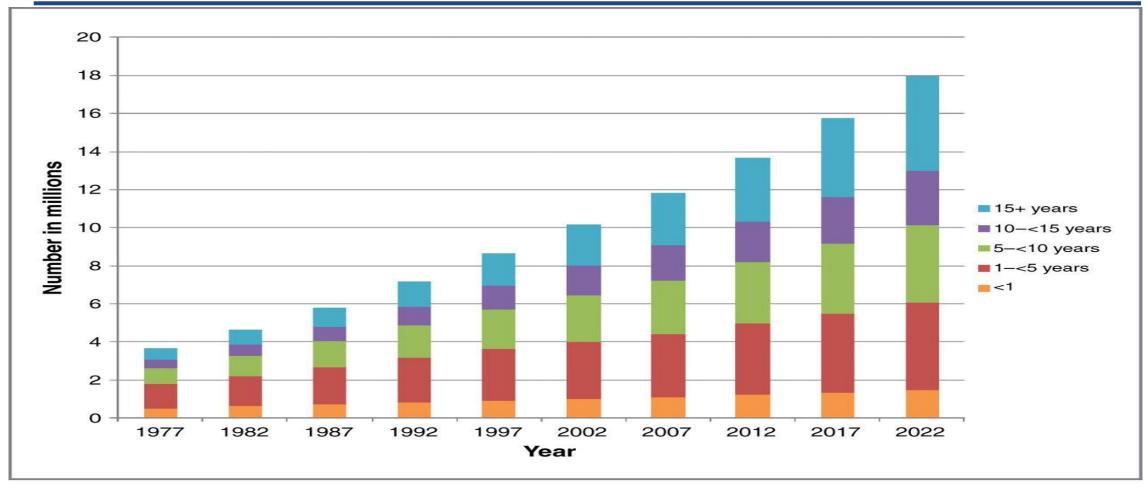


- Diversification of the inputs for cancer control
- Rising importance of primary care
- After-care for an extended period of time a resource and guideline challenge
- Rehabilitation becoming one of the crucial issues given the improvements in survival
- Living with extended disease
- Palliative and end-of-life care



# Estimated and projected number of cancer survivors in the United States from 1977 to 2022 by years since diagnosis



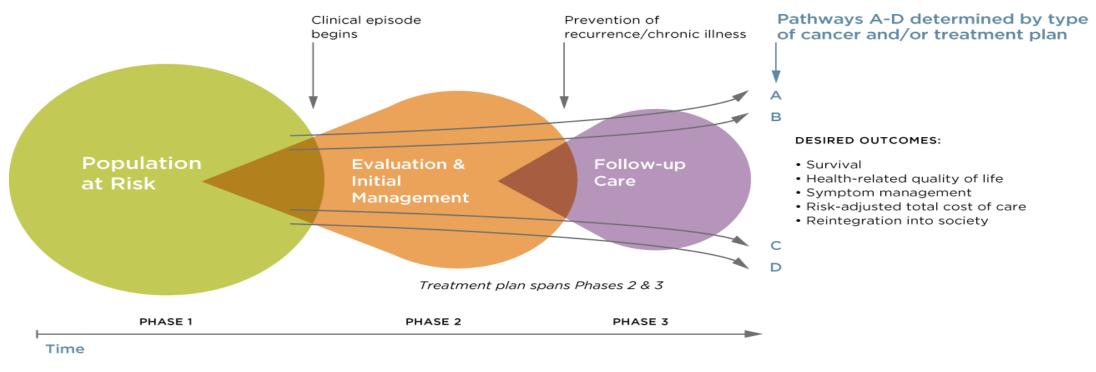


Source: De Moor JS, Mariotto AB, Parry C, Alfano CM et al. Cancer Survivors in the United States: Prevalence across the Survivorship Trajectory and Implications for Care. Cancer Epidemiol Biomarkers Prev; 22(4); 561–70. doi: 10.1158/1055-9965.EPI-12-1356



# Patient Focused Episode of Care Model for Cancer Care





#### ISSUES TO BE CONSIDERED THROUGHOUT THE EPISODE:

- · Access to care
- Pyschosocial needs
- Treatment preferences
- · Informed decision-making
- Palliative care

- Family engagement
- Health education/Behavior change
- Genetic testing/Counseling
- Symptom assessment/Management
- Rehabilitation

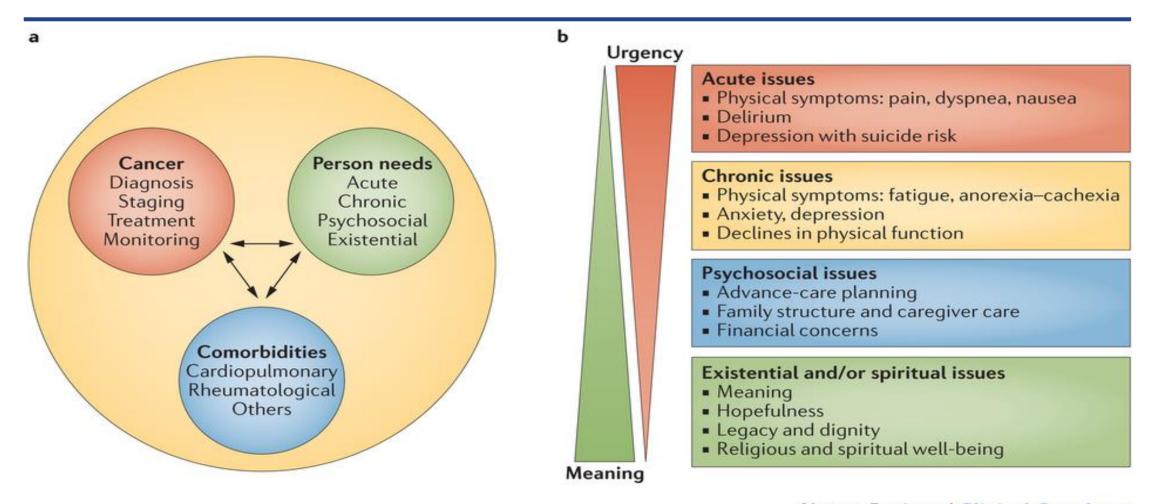
- · Care coordination
- Advanced care planning
- Comorbidities
- Risk of therapy

Performance Measurement Coordination Strategy for PPS-Exempt Cancer Hospitals - June 2012



# Care needs of patients with advanced-stage cancer





Nature Reviews | Clinical Oncology

Source: Hui D, Bruera E. Integrating palliative care into the trajectory of cancer care. Nature Reviews/Clinical Oncology. March 2016;13: 159-171.



# Indicators of successful integration of palliative care into oncology practice



#### Education

- Palliative-care competence in oncologists
- Undergraduate palliative-care curriculum
- Lectures and curriculums on palliative-care for oncologists/fellows\*
- Palliative-care rotations for oncology fellows\*
- Oncology rotations for palliative-care fellows
- Conference on palliative care for oncology professionals
- Continuing medical education for oncologists\*
- Formal testing of palliative-care skills in examinations

#### Clinical structure

- Outpatient clinics\*
- Inpatient consultation teams\*
- Palliative-care units
- Community-based teams

#### e units based teams

#### Research

- Research activity and/or publications on palliative care
- Funding to support palliative-care research
- Palliative-care research involving patients with early stage disease
- Presence of a chair in palliative care

#### Clinical processes

- Interdisciplinary palliative-care teams\*
- Simultaneous care
- Availability of palliative-care services
- Routine symptom screening in oncology clinic\*
- Supportive-care guidelines
- Specified timing of palliative-care referral
- Referral criteria for palliative care
- Clinical care pathways
- Embedded clinics
- Palliative-care nurse practitioner
- Communication and coordination
- Combined multidisciplinary tumour boards
- Early palliative-care involvement\*

#### Administration

- Centres of excellence or models of integration
- Palliative care recognised as a specialty
- Reimbursement or programme funding
- National standards or policy
- Regional organization
- Opioid availability
- Palliative care and oncology within the same department
- Support of cancer-centre leadership
- Public awareness and advocacy

#### Nature Reviews | Clinical Oncology

Source: Hui D, Bruera E. Integrating palliative care into the Itrajectory of cancer care. Nature Reviews/Clinical Oncology. March 2016;13: 159-171.

Integrated

oncological

and palliative



## Challenges – current and future



- Health promotion and various lifestyle interventions
- Screening and early detection developments underway
- Diagnostics more sophisticated and leading to more stratification of patients
- Therapies: developments in all main branches
- Genomics: important in risk assessments, stratification of screening, classification of tumours
- Long-term therapies: prevention and treatment
- Survivorship challenges
- Palliative care as an inseparable part of the process of cancer care



## "External" elements of cancer control



- Governance and financing
- Cancer resources
- Cancer data and information
- Research



### Health promotion and lifestyle interventions



- Constant developments
- Implementation of the European Code Against Cancer (ECAC) and its continued development
- Addressing ALL harmful substances, which can be impacted through legal actions – e.g. bans, requirements, environmental standards, food chain control, additives, housing, traffic, etc.
- Working with the different sectors involved



# Screening programmes and early detection



- Updating and reviewing existing established screening programmes
- Stringent assessment of new programmes level of evidence, ratio between harms and benefits, methodological issues
- Stratification of populations
- Early detection focusing on cancers, which have limited options for screening, but may be accessible through markers
- Role of genomics overexpectations?, aid in stratification?

## Diagnostics



- Rapidly advancing area
- Helping in refining staging and also the characteristics of tumours and their invasiveness
- Its refinement may sometimes lead to upstaging (!)
- Essential today in the proper stratification of patients
- Diversity of techniques as another requirement for MDTs

# Therapy



- Important advancements in various fields
- Technology needs to be seen in the broadest sense IT, equipment, surgical techniques, immunotherapies
- The need to advance and adapt health technology assessment (HTA)
- Reorganisation of services -> more role to networks and links between levels (secondary/clinical -> primary)
- Special attention that needs to be given to studies of organisational and system's approaches

#### Genomics



- Great potential in various aspects of cancer care:
  - Screening and its potential stratification
  - Use for diagnostic purposes
  - Extended uses as to be determined through additional research
- The need for health systems to steer, monitor and evaluate its use
- But, also to further stimulate research with a view to improving precision and outcomes

# Long-term therapies for extended/advanced cancer



- A rising group of patients previously either without serious options for treatment or treated with relatively inefficient therapies
- The main challenges are in:
  - Proper follow-up and continued research
  - Ensuring that these patients are not discriminated against
  - Importance of the measurement of the QoL and in general developing tools to measure process quality and not only final outcomes
- Importance of secondary and tertiary prevention as well as prevention of late effects and their management



# Survivorship issues



- Increasing survival rates are opening more questions:
  - Viability of employment and societal attitudes towards cancer patients
  - Rational monitoring of patients in remission
  - Ensuring continuity of care and also of dealing with social issues
  - Defining clearly health and social system's responsibilities for bringing solutions
- "Droit à l'oublie" a single action or a potential model to follow?
- Detailed monitoring of late effects and secondary cancers
- The need to monitor longitudinally either/or through clinical as well as through population registries



# Survivorship issues



- Psycho-oncological and psychosocial care as necessary and indispensable elements of the cancer care continuum
- The need to ensure full rehabilitation and return to work or to premorbid life

### Palliative care and end-of-life care



- The need to plan palliative care from early on
- Palliative interventions that serve also patients with limited disease, but having side effects and/or symptoms to treat
- Assistance to be organised and secured as a part of a single disease trajectory, not as a separate basket!

# Governance and financing



- Cancer resources
- Cancer data and information
- Research

# Governance and financing 2.



- European health systems recognise that cancer care can represent a catastrophic cost and needs to be financed predominantly from public finance
- Having said that, there are challenges ahead:
  - Increasing need for screening and early detection programmes
  - Diagnostics is becoming increasingly complex as it steers the actual care of oncological patients
  - Therapies are diversified and are often not adequately assessed through HTA
  - Securing sufficient funding and financing of cancer care and cancer control
- International collaboration and networking of cancer institutions is becoming a necessity, in particular for smaller countries, e.g. ERNs, CCCs



# Governance and financing 3.



- In cancer care, we need to appreciate both outcomes as well as process results, since isolated focus on outcomes alone, especially final, excludes for example patients with disseminated disease
- It is important to develop governance instruments at all levels:
  - Regularly updated guidelines and protocols
  - Patient pathways
  - Quality indicators
  - Policy documents, such as NCCPs last but not least

### Cancer resources



Governance and financing

- Cancer data and information
- Research

#### Cancer resources 2.



- In cancer care, there is very intense activity around patients in the initial phases of their treatment
- Cancer care is one of the most resource-intense activities in health care
- Development of skills and of formed professionals is complex and takes a significant amount of time
- Jointly shared resources in big centres to include smaller hospitals and even patients and institutions from other countries may become inevitable

### Cancer data and information



- Governance and financing
- Cancer resources

Research



### Cancer data and information 2.



- Cancer is one of the best studied health problems globally
- Registries have had a long-standing tradition of their development and different uses
- Today, population registries need to be further strengthened with additional sets of data, e.g.: on treatment, after-care, outcomes, clinical trials, social determinants, etc.
- Putting more stress on the outcomes, such as PROMs



### Research



- Governance and financing
- Cancer resources
- Cancer data and information

### Research 2.



- Research is an inseparable part of the continuum of cancer care and care development
- Supporting research also through its public funding seems to be important
- Combination of national and international funding and collaboration
- Overcoming barriers with involvement of own patients in international clinical trials

## iPAAC – Implementing for the future



#### THANK YOU!

