LONG TERM CARE FOR CANCER SURVIVORS

HEALTH SUMMIT : CARE FOR CANCER
UPPSALA HEALTH SUMMIT
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Decreased Cancer mortality in Europe

Childhood Cancer Mortality

[Graph showing the decrease in childhood cancer mortality per million from 1950 to 2000 for Europe and the USA.]
EORTC Survivorship achievements

- Hodgkin’s Lymphoma (2037 survivors)
- children/adult leukemia (10,000 survivors)
- Methodology innovation: data merging with registries
- early breast cancer (10,747 survivors)

EORTC Survivorship taskforce

- 1st Survivorship Summit
- 2nd Survivorship Summit
- 3rd Survivorship Summit

Launch Special Issue Survivorship Journal of Cancer Policy

The future of cancer therapy
EORTC Cancer Survivorship research program

- Fellowship on legal issues
- Fellowship on epidemiology research
- The YOU infrastructure
- Publications:
  - Reports from summits
  - Special issues:
    - (Journal of Cancer Policy)
  - “cancer Survivorship: an innovative era for research and the need for cross-border collaboration”.

The future of cancer therapy
Long-term data collection

Cancer Free ≠ Problem Free
..who is a cancer survivor?

- someone who has been **cured** from cancer
- Also someone who lives in a **long** remission (without evidence of remaining disease) (how long is long??)
- Also someone with remaining but stable and **quiescent** cancer (without treatment)
- Also someone under **maintenance treatment** (even though going on for years….
- …

ALL OF THE ABOVE

*S. Rauh, EORTC Cancer Survivorship Summit, 2018*
Survivorship issues

Physical/Medical
- e.g., pain, fatigue, memory problems, lymphedema, infertility, sexual impairment, amputations, secondary malignancies, cardiovascular, pulmonary, renal disease, neuro/muscular impairments etc

Psychological
- e.g., depression, anxiety, uncertainty, isolation, altered body image

Societal
- e.g., changes in interpersonal relationships, concerns regarding health or life insurance, job lock/loss, mortgage, return to school, financial burden
What's needed to support work access among survivors?

Survivor

Employer

Health professional

communication & engagement

policies, procedures, strategies, interventions, incentives? penalties? Law?

L. Sharp, EORTC Cancer Survivorship Summit, 2018
Long Term Survival Study: fertility among survivors of ALL (EORTC trials)

- Most survivors who tried to have children, succeeded (75% of females, 72% of males)
- However, the average number of children per female seemed to be lower than in the general population
- Incidence of birth defects and medical abortions was low, both among female survivors and the partners of the male survivors

C. Piette & al
A long-term clinical research infrastructure within EORTC

The YOU (Your Outcome Updates)
Aim

• To build the capacity to answer long-term questions, cross-tumor, cross country
• To provide the platform and legal framework to collect high quality long-term follow-up data for patients in EORTC or EORTC supported clinical trials
The RIGHT to be forgotten!

The right to be forgotten: a change in access to insurance and loans after childhood cancer?

30 years after cancer

1/3 experienced difficulties buying a home...

1/10 for small amount of personal loan...


New French Law Feb 2016
Belgian Partyka Law

• In Belgium the law "Partyka – Lalieux" come into force on 1st January 2015.
• The objective is to facilitate access to credit life insurance policy in relation to mortgages for those who have a history of disability and serious or chronic illness.
• The law opens also the possibility to appeal the insurer’s decision to a committee called "Bureau de suivi de la tarification".
• The committee consists of representatives of insurance companies, patients and consumer organisations. Through this law, it would also be possible to appeal a refusal or a premium that is 75% above the cost of the basic premium.
Conclusions

• Survivorship is a rapidly growing issue - and this is great !!!

• Awareness of physical issues in survivorship care has still to rise, more evidence to be gained – and shared with our patients

• Interventions should follow an established common track, then individualized « made-to-fit»

• I (the oncologist) can’t do it all myself ... : need for multi-disciplinarity and organizing workflows

• Patient empowerment : facilitator and catalyst!

S.Rauh, EORTC Cancer Survivorship summit, 2018
European cooperation

Dream – Reality – Necessity

- Radium
- DNA
- Helsinki
- EU CTD
- EU CTR
- Nitrogen
- Mustard
- Nuremberg
- EU Data Protection Directive
- Human Genome
- NGS
- GDPR

From the Channel to the Moon

1909

Bleriot

1969

JULY 20, 1969

The future of cancer therapy
Thank you