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How can we promote the quality of life of children who have survived cancer?

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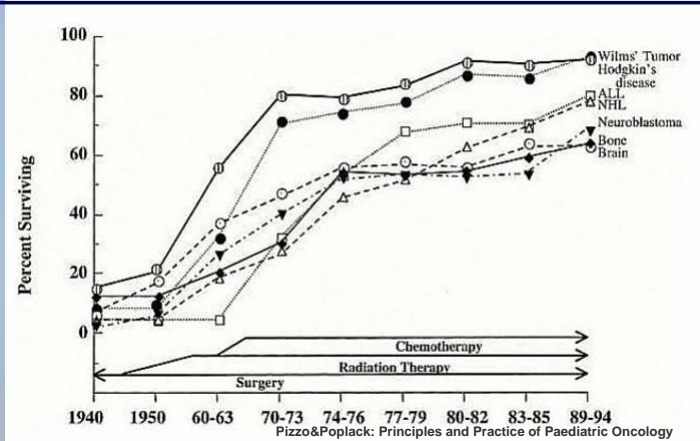
Childhood cancer survivors

- The likelihood of a 5-year survival has increased from less than 30% in 1960 to more than 75% today.
- **The paradigm in paediatric oncology has changed: towards current expectation of "cure" and survival into adulthood → cancer in children is now perceived to be a chronic disease.**
- **Thus, childhood cancer survivors represent a growing, at-risk population with a need of specialized health-care and psychosocial support.**



Cure rates of childhood cancer

In the near future (estimated 2010) 1 in 250-500 AYA will be a childhood cancer survivor!



Quality of Life

- Along with the increasing cure rates **the QUALITY of SURVIVAL** instead of the **survival itself** has become the marker of cancer treatment success.

BECAUSE . . .

PRICE for CURE → survivors' well-being

Survivors experience a spectrum of cancer-related morbidity that affects both physical and mental health.

2/3 of childhood cancer survivors suffer from at least one of serious late sequelae of the cancer treatment!



PRIZE for CURE → survivors' well-being

- **Physical problems**
 - Growth
 - Fertility
 - Organ function impairments /heart, lungs, kidneys etc./
 - Physical restrictions
 - Risk of early death
 - "adult" diseases in children (like strokes)
- **Psychosocial and Educational problems**
 - PTSD
 - Learning, memory
 - Educational achievement
 - Lack of self-confidence
 - Compromised opportunities
 - Social isolation
 - Social competence
 - Lower self-image
 - Lower marital rates
 - Underemployment
 - Independent living etc.



Child Psycho-Oncology

- There is a continuing international cooperation in Paediatric Oncology (SIOP, COG, UKCCSG, BFM, SFOP ..), focusing on late effects and QoL issues.
- QoL is currently being implemented to the clinical trials as the important end-point of new clinical trials (Hodgkins, sarcomas etc.).
- A new research area "Psycho-oncology" has been established.

HOWEVER



QoL research limitations

- Still the paucity of research on QoL in children cancer survivors
 - Prospective longitudinal studies are vital!
 - Complex study design in terms of health, social and educational issues, parental-child relationship etc.
- Much of the current research with sufficient sample size, appropriate age- and gender-matched controls is prevalently retrospective and focused on particular determinants

(Barrera M. et al, Cancer 2005, De Clercq, J Ped Psych, 2004, Oeffinger K., NEJM 2006, Upton&Eiser, Child Care Health Dev, 2006...)





The **Q**uality **o**f **L**ife Longitudinal Study
in **O**nco**l**ogy **P**ae**d**iatric **P**atients

<http://qolop.eu>



Research on child cancer survivors

- current research on the quality of life in children with cancer is facing methodological problems

Eiser, Hill, Vance, 2000, Wallace et al., 2001, Patenaude, Kupst, 2005, Last, Grootenhuis, Eiser, 2005

- „qolop“ project designed to meet contemporary requirements on research methodology



Methodological requirements

1. methodology reflecting the multiple-sources & multidimensional nature of 'quality of life'
2. longitudinal research design
3. implementation of developmental approach (changes in the criteria of the quality of life over time)
4. multi-informant perspective
5. systems approach (family, siblings!)
6. comparison with healthy population & other chronic ill children



„qolop“ design...

1. multidimensional nature of 'quality of life'
 - MMQL (Bhatia et al., 2002, Bhatia et al., 2004)
 - Objective indicators: mobility, sensory functions
 - Subjective indicators: moods and feelings, life satisfaction
 - Methods measuring other determinants of QoL besides health:
 - child personality (temperament)
 - parent/child relationships
 - friends



...„qolop“ design...

2. longitudinal design & developmental approach

- Original method controlling sources of QoL: children assess not only satisfaction, but also importance (value) of life domains – 30 domains

How important is for you...

...to be healthy, to have good relationships with people, etc.

How are you satisfied with your...

...health, relationships with people etc.



...„qolop“ design

3. multi-informant perspective

- Information from physicians, children, parent(s)

4. systems approach (family, siblings!)

5. comparison with healthy population & other chronic ill children

- Expected sample size = 300 children
(criteria: 2 – 5 years in remission, 8 – 18 years old)
- Will be compared with 300 healthy children and 300 chronic ill children (e.g. asthma)



The „qolop“ outcomes

- Therapeutic modifications to reduce cancer-related morbidity
- Survivor education based on individual specific treatment risk
- Fact sheets and educational materials for patients and their parents
- Interventions to enhance resilience following cancer experience
- Educational programmes and materials for caregivers - physicians, nurses, psychologists



Thank you for your attention!
Muchas Gracias por su atención!
Moltes gràcies per la seva atenció!



qolop - the Czech Republic

<http://qolop.eu>

