Occupational outcomes in childhood cancer survivors

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Survivors in working age

Number of (childhood) cancer survivor employees is increasing

Better treatment

However: Adverse late effects
Decreased work ability
Employment is important

– Higher quality of life of working CCS

-- Self-esteem and emotional support

– Might be more important for CCS than for healthy people:
  – Work is main concern in life for 19% of CCS (bone marrow transplantation) vs for only 2% of their age-matched controls

– Income and (Health) Insurance

– Economic need in ageing society

– Entire working life could be lost

Prevalence Unemployment CCS

- Survivors of childhood cancer are almost twice as likely to be unemployed compared to healthy individuals\(^1\)
  - CCS of CNS and brain tumors almost five times more likely to be unemployed
  - Risks for survivors of blood or bone cancers were elevated but not statistically significant
  - No increased risk was found for survivors of other or mixed diagnoses
- Confirmed in later studies
- Long-term CCS > 20 years no effect\(^2\)
- Germany: higher employment rates of CCS\(^3\)

\(^1\)De Boer et al Cancer, 2006; \(\ldots\) \(^2\)Ottaviani, 2013. \(^3\)Dieluweit 2011.
Prevalence Unemployment ACS

- Adult cancer survivors “only” have a 37% higher chance of unemployment compared to controls \(^1\)
  - Already work experience
  - Have professional relationship with employer
  - Access to occupational physician, rehabilitation services
  - Early focus on return to work in treatment process
  - Fewer disabilities?

\(^1\) De Boer et al. JAMA 2009.
Risk factors for unemployment CCS

- Diagnosis
- Younger Age
  - On average, career starts at a later age than siblings
- Female
  - Young female CCS might more often choose not to start working compared to males and healthy females
- Treatment:
  - (Cranial) Radiotherapy
- Education
  - Lower IQ
Risk factors for unemployment CCS

- Physical late effects
  - Poor physical functioning
- Neurocognitive late effects
  - Task efficiency limitations
  - Memory problems
- Emotional problems
  - Depression
  - Anxiety
  - Emotional regulation
  - Coping with illness
- Discrimination (US, Japan)
- Pain and fatigue?
What CCS think

- Qualitative study, US
- Interviews, n=17
- 100% reported vocational guidance from their family
- 65% from school
- 30% from medical professionals
- 100% of employed CCS had informed employers
- 73% of subjects said cancer affected their goals/motivation for work
- 91% of those who did described the impact as positive

Karanth, 2012
Interventions: Adult CS

- Interventions to enhance return-to-work for cancer patients: a Cochrane review
- Effective in RCTs with:
  - Counseling and / or
  - Return to work module and / or
  - Physical activation

In hospitals

De Boer et al. Cochrane Database Syst Rev. 2011
Interventions: Adult CS in AMC

- Focus on early interventions
- Part of the usual psychooncological care
- Prevent problems
- Website development
- Physical training
- Support from specialised oncological occupational physician
Interventions in CCS: the past
Information Leaflet

• Included information about employment
• 50 attendees of a long-term follow-up clinic
• 41% was interested in the information about jobs given in the leaflet
• Half of the patients thought the illness could have a negative effect on their future
• They were especially concerned about limited job opportunities

Interventions: the present
Support programs

Career and Vocational Counseling

You're preparing to graduate from high school and enter the workforce, or you may be looking at colleges to apply for — and then cancer strikes. That doesn't mean you have to give up on your goals.

MD Anderson Children's Cancer Hospital has trained vocational counselors to assist you with college and career preparations. There are many resources out there for childhood cancer survivors, and Children's Cancer Hospital specialists can help you discover what resources will benefit you.

High school juniors and seniors can receive help with:
State vocational services

- In the US, vocational services are offered to unemployed CCS
- N=368, 18-25 years
- 22 types of services, including:
  - Assessment of medical impairments (67% used)
  - Counseling and guidance (64% used)
  - College or university training (42% used)
  - Vocational rehabilitation (19% used)
- After intervention: 52% employed
- Provision of vocational training, on-the-job training and job search assistance are related to employment

Strauser et al. 2010.
Emma at work

- Emma’s Children’s Hospital of the Academic Medical Center (AMC) in
- Special agency for temporary jobs for chronically ill youths 15-25 years.
- Aim: to get work experience to improve chances of an independent life.
- 2012: over 100 young adults were placed
Interventions: the future
Future perspectives

- More knowledge on (longitudinal) employment status and risk factors
- Focus on amendable risk factors
- Implementation of guideline (SKION)
- E-health and E-work
- Early (clinical) interventions
- Inclusion of stakeholders: CCS, parents, physicians, employers, GPs.
Cancer and Work Network: CANWON

- **Goal**: to form a highly integrative Europe-wide team of researchers, experts and stakeholders
- **Aim**: to integrate and disseminate knowledge on:
  - Work participation and prognostic factors
  - Work-related costs of cancer survivorship
  - Role of employers
  - Development and evaluation of innovative, interdisciplinary interventions

- [http://www.cost.eu/domains_actions/isch/Actions/IS1211](http://www.cost.eu/domains_actions/isch/Actions/IS1211)
- **CCS?** (Italy, Austria, Switzerland, Hungary, Czech, Bulgaria, Latvia, Estonia, Lithuania, Croatia, Serbia, Malta, Iceland, Luxembourg, Yugoslavia, Cyprus: still missing)
Conclusions

– Increasing attention
– Employment is important for patients
– Employment is important for psychosocial oncological care
– Early interventions
– Quality of life
Questions?

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