

Cancer survivorship plan in the Netherlands: a guideline for professionals in oncology

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Comprehensive Cancer Centres

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association
comprehensive
cancer centres

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Introduction

- Increase in cancer incidence
 - Increase of cancer survivors
 - 4% dutch population
 - Limitations in the availability of care professionals and finances
- ↓
- Lack of evidence for the present follow-up strategies and inadequacy in dealing with side effects
- ↓
- Fundamental changes in oncology and its organization
- ↓
- Evidence based guideline to improve cancer survivorship care

Methods

- In 2007 report of the Ministry's Health Council regarding cancer aftercare
 - Advised development tumor specific survivorship programs and individual survivorship care plan for each patient
- The Comprehensive Cancer Centres (CCC's) developed an evidence-based guideline 'Cancer Survivorship Care' for professionals (2008-2009)
 - CCC's are expertise centres for oncological and palliative care
- The guideline is a translation into practice of the Health Council's advice regarding cancer aftercare

Methods II

- The general method for evidence-based guideline development is followed
Handbook guideline development of the CCC's
- Evidence for adequate cancer survivorship is systematically investigated for 20 key questions
- Multidisciplinary working groups formulated the recommendations
- Patients' perspectives regarding aftercare are systematically investigated by a review and a working conference for cancer survivors and care professionals (Open Space Method)

Patients' perspectives

Open Space method

“I can't believe that after all these meetings, workshops and conference sessions, the most valuable time for me was still during the coffee breaks, when I met with people I wanted to meet with and talk about the issues I wanted to talk about.”

Harrison Owen, author of Open Space Technology:
A Users Guide



Results

- **Cancer aftercare is aimed at**
 - the detection of new cancer manifestations
 - the detection and treatment of side effects of cancer (treatments)
 - the evaluation of medical care
- **The guideline**
 - covers these aims of cancer aftercare and provides recommendations at the level of the care provider, the care institutions and national parties

Results II

- A guideline for professionals

The guideline provides guidance to professionals on aftercare for survivors diagnosed with a solid tumour, in the first year after cancer treatment had been completed, which is when most side effects occur

- The guideline includes

a card for decision making in tumour specific guidelines
a format for a survivorship care plan

- Guideline available in English

on www.oncoline.nl in Q4 2010

- Web-based TV broadcast and an e-learning tool available on internet (in Dutch, professionals received accreditation points)

Recommendations for the care provider

- **Early side effects require a systematic approach**
 - Regular detection through validated instruments
 - Informing patient about side effects, treatment and selfmanagement
 - Treatment of early side effects and referral on indication
- **Late side effects require information**
 - detection should end after 1 year if no clear health benefit, inform well!
- **Review after one year**
 - End aftercare process when possible
- **A cancer survivorship care plan supports the systematic approach of aftercare**
- **Detect new manifestations only in case of improved survival**
- **Most aftercare is self-care**
 - Inform patients about disease, consequences and aftercare
- **Coordination of care is necessary**
 - Transparent division of tasks between medical specialists, nurses, gp's.
- **Evaluation of medical procedure requires systematic approach**

Recommendations for care institutions

- Cancer survivorship requires specific skills
- Care institutions must ensure that care providers are equipped for the task
- ICT provides great opportunities
record patients survivorship care plans in electronic databases and dossiers
- Care innovation provides opportunities for restructuring/innovation of care process

Recommendations for national parties

- Cancer survivorship care plans need to be specified
Tumor-specific integration
- Early detection of new manifestations only if there is evidence for improved duration of quality of life
- Evaluation of quality of care is needed using indicators
- Structural quality improvement requires adequate financing

Discussion

- It is a general guideline that needs to be further elaborated
- The guideline is the first step to a larger process of innovation in cancer survivorship care
- This includes a cultural and paradigm shift in cancer after care: from medical orientated to improvement of patients' quality of life
- These major changes take a long time
- The implementation of the guideline includes national policy making and care system improvements

Responsible party

Guideline working group Cancer survivorship care,
Comprehensive Cancer Centres

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