

Follow-up programs for Cancer Survivors



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More patients will need follow-up

- Around every 3th in the developed countries will suffer from cancer
- Cancer incidence is rising
- More patients will survive and live longer with cancer
- An increasing number of survivors will have long term sequele

Cancer includes many diseases with different treatment and prognosis



Follow-up: - when treatment ends and a new life begins!

"The treatment phase is by many experienced as a remarkably safe period and simultaneously you eagerly count down for chemo and radiation to be in the past. And then the down period suddenly arrives. Now you must handle all on your own. The safe white world is suddenly history."

Per Reipurth. 2009. Danish cancer patient

Follow-up is regarded as the "life line"



Which needs?

- Physical problems
 - ✓ Recurrence and spread of the cancer disease
 - ✓ Adverse reactions to the treatment
 - ✓ Late sequele
 - ✓ Other chronic disease(es)
- Psychological problems as
 - ✓ Depression
 - ✓ Anxiety
- Help to increase empowerment
- Existentialistic problems



Future challenge

- **Evidence for effect of control is sparse:**
 - ✓ Improved surviving
 - ✓ Time to recurrence
 - ✓ Quality of life
 - ✓ Organizational model
- **We need to:**
 - ✓ Learn from each other
 - ✓ Monitor outcome and evaluate the quality of care
 - ✓ Ensure research



Program

- Introduction and results from a Danish survey among patients
Janne Lehmann Knudsen, Danish Cancer Society
- Canada's approach to survivorship: what do patients need?
Carol Sawka, Cancer Care Ontario, Canada
- Follow up: Is current practice fit for purpose
Gilmour Frew and Alastair Smith, NHS Improvement, UK
- Cancer patient survivorship program
Mary Mc Cabe, Memorial Sloan-Kettering Cancer Center, USA
- Discussion



Follow-up and Danish Health Care

- Big variation in practice
- Public financed; < 3 % private
- GP: gatekeeper to secondary care, where cancer treatment are carried out
- Diagnostic process follows national guidelines (cancer care management programs)
- Follow-up generally carried out at specialized departments in hospitals



Follow-up at the national agenda

- A national conference was held in September 2009 arranged by Danish Regions and National Board of Health, Multidisciplinary Cancer Groups and Danish Cancer Society
- Danish Cancer Society presented results from the patient survey
- Agreement that radical changes and more knowledge are needed
- Pathway programs should be extended with specific "care management program for cancer patients after treatment"



Patient cases

"How many lives would be saved or prolonged by better follow-up?"

"I want a follow-up system which is equal for all, and also those who do not "shout loud" should be met by a system, that invites to the best possible treatment and involvement of the patient..."

Patient citations – Danish Cancer Society, 2008



Survey

- Questionnaires based on 924 cancer patients distributed through patient organisations:
- **Focus on:**
 - ✓ Content of follow-up in general. Details about the last visit
 - ✓ Information received, waiting time for visits and results
 - ✓ Handling of patient worries
 - ✓ Continuity in medical care
 - ✓ Investigation, information tc.
 - ✓ Patient's reaction to symptoms between control visits
 - ✓ Involving GP



Main results

- Differences according to gender in priorities, experiences and actions to symptoms
- There is substantial incongruence between patients' needs and the content of follow-up
- Quality needs to be improved in nearly all aspects of care to ensure patient's faith in health care

Individually organized follow-up is needed!



Issues evaluated as most important and patients experiences in follow-up

	Very important/ important - %	Experienced %
Examination for recurrence of cancer	93	83
Examination for spread of cancer	93	50
Information about symptoms to be aware of	97	30
Having the same doctor at each visit	91	24
Information about late sequales	92	36



Assessment of the clinical process

	Women %				Men %			
	High	Medium	Less	Not at all	High	Medium	Less	Not at all
Confidence in right clinical exam. and treatment	42	40	13	6	58	31	7	3
Doctor's listening to worries	44	37	16	3	61	33	5	2
	Very good	Good	Bad	Very bad	Very good	Good	Bad	Very bad
Doctor's knowledge of patient record	20	50	12	5	24	54	10	5



Continuity in medical care

Patient's priorities:

- 90 % find it important to meet the same doctor at each control visit

Patient's experiences:

- 24 % have had the same doctor at each control visit
- 27 % have had the same doctor at most of the control visits

"It is very ensuring to know that the person who have "verdict." also knows me as a person and have knowledge about my entire treatment"



53 % of men and 78 % of women had experienced symptoms, that worried between visits

Only 30 % had been informed about important symptoms and contact address if symptoms occur

Reaction to symptoms	Men %	Women %
Contact to GP	22	35
Contact to specialist	6	5
Contact to unit where control takes place	56	61
Wait till next control visit	38	23
Other actions	2	6



Patients want to have faith in health care - and ask for:

- Being heard about their worries and taken seriously
- Receiving the "correct examinations"
- A well prepared, competent doctor and the same each visit
- Information about side effects, late sequelae, symptoms to be aware of and where to go
- Counseling about healthy life style, psychological and social issues
- Equality in health care service throughout the country

From control of the disease to treatment of the whole person



Cancer is also a chronic disease

The health care system should provide service:

- In cooperation with the patient
- Multidisciplinary and across sectors
- A cross sectional program is needed as a supplement to the existing pathway program



Conclusion – 1

- Is planned medical follow-up necessary?

Yes! based on the risk of:

- Recurrence and spread of cancer
- Late sequelae of disease and treatment
- Development of new cancer or other chronic disease
- Depression and other psychic reactions

How, when and where must be based on the best existing knowledge



Conclusion – 2

- Is multidisciplinary follow-up necessary?

Yes! – because:

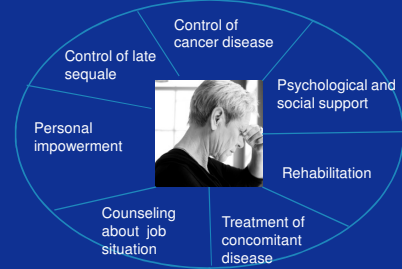
- Preventing the patient to be *"left in limbo"*
- Ensure that patients don't need to be their own coordinator
- Provide the patients with psychosocial support when needed
- Increasing patient empowerment

*One entrance to a coordinated pathway
ajusted to individual need*



Follow-up in the future:

*– a multidisciplinary and cross sectional program
after treatment of cancer*



**More evidence is needed
– but actions now are crucial!**

