

Follow-up for Cancer Survivors in Danish Health Care

– the patients perspective



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Follow-up and Danish Health Care

- Public based system. < 3% private providers
- GP: gatekeeper to specialized care
- Follow-up generally carried out by specialist at hospitals



Rutinebased practice through many years

Evidence is weak

Big variations in practice !



More patients with a greater complexity will need follow-up



- Cancer incidence is rising
- More patients will survive with cancer
- An increasing number will suffer from long term sequales and co-morbidity

***Follow-up has to manage
a plurality of cancer diagnosis***



- **Physical problems**

- ✓ Recurrence and spread of the cancer disease
- ✓ Adverse reactions to the treatment
- ✓ Long term sequale
- ✓ Co –morbidity

- **Psychological needs**

- ✓ Depression
- ✓ Anxiety etc.

- **Social problems**

- **Self –management needs**



***Health care has to manage a plurality of
needs and empower patients !***



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 Reipurt. 2009. Danish cancer patient

Follow-up is regarded as the "life line"



“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 statements – Danish Cancer Society, 2008



PatientSurvey 2009. Danish Cancer Society

Questionnaires distributed through disease specific cancer associations

- 924 patients responded: 65% women/35% men
- 25 different cancer diagnosis:
breast cancer 32%, myelomatosis 18 % prostatacancer 17%

The results were not influenced by diagnosis



Questionnaire focus

- ✓ Priorities, experiences and actions to symptoms
- ✓ Quality and continuity in medical care
- ✓ Information received,
- ✓ Waiting for visits and results
- ✓ Handling of worries
- ✓ Actions to symptoms between visits

- ✓ Involving GP



Results:

Patients Priorities and experiences

	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



Continuity and Confidence in Medical care

Patient experience of receiving the appropriate medical care having the same doctor

91% find it important to meet the same doctor

Receiving appropriate care ?	High degree	Some degree	Minor degree	Not at all
Same doctor each time (24%)	69	23	7	1
Same doctor most times (27%)	59	33	7	1
Different doctors (49%)	31	45	15	9



53 % of men and 78 % of women had experienced worrying symptoms between visits.

30 % experienced to be informed about what to do.

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



The Importance of Involving own GP

How important ?	Very important	Important	Less important	Not important	Not relevant
That your GP is informed about your follow-up pathway ?	46	37	13	3	1
That your GP become responsible of part of the care- program ?	20	24	24	17	16



Main Conclusions

Substantial incongruence between patient's needs and the content of follow-up - differences in accordance to gender

Quality has to be improved in nearly all aspects of care

An individual care plan – coherent across different setting - has to be developed in agreement with the patient



The Patient Perspective

Feel confident

- to receive the best possible care

To experience

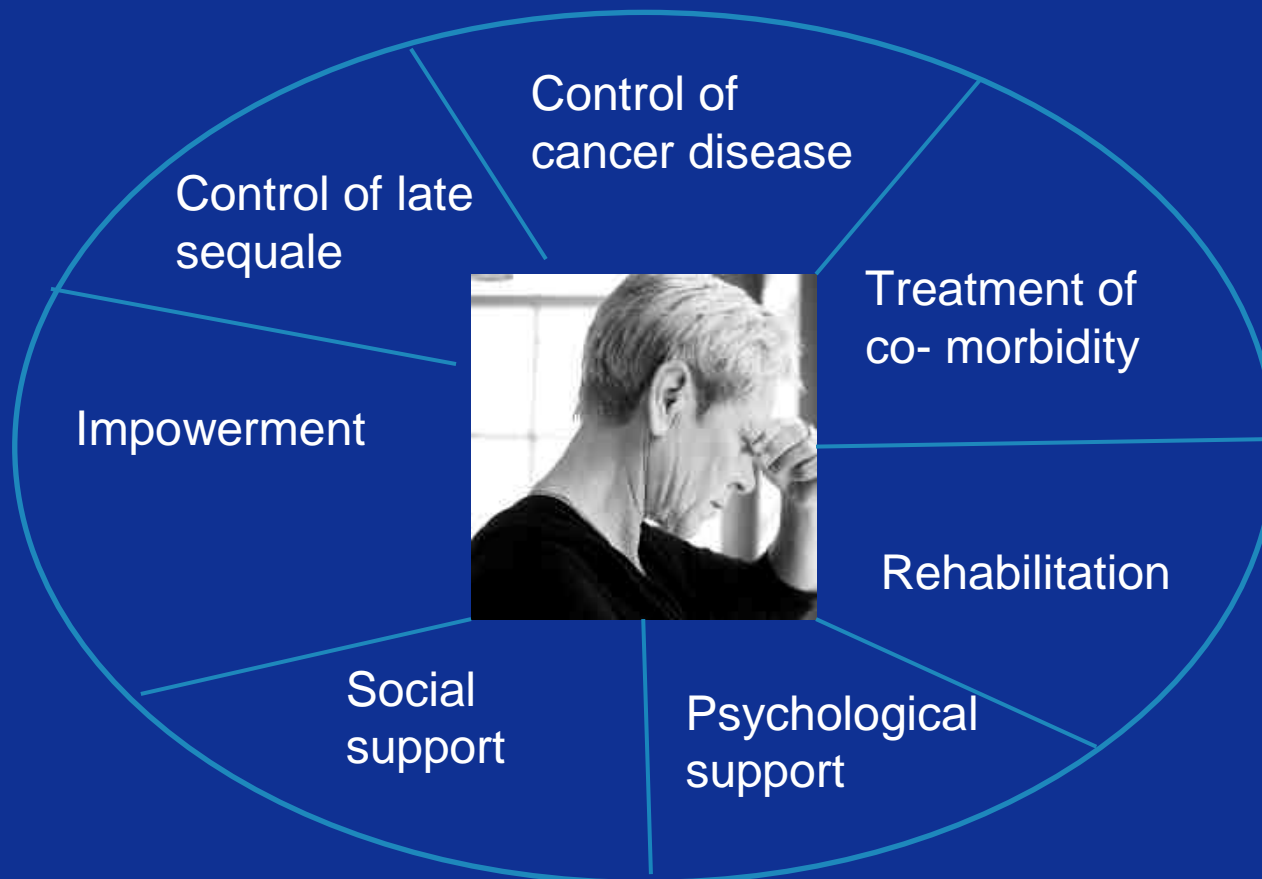
- to be listened to – their needs and problems
- to be informed about plan, care and how to act on symptoms
- to be advised on life-style etc
- A prepared, competent doctor
- that care are consistent and timely

From symptom- control to treatment of the patient



Patient- Centeret Follow-up

A multidisciplinary and cross sectional care program
not leaving the patient in a limbo



Focus

Improve care from the patient perspective and ensure evidence

Agreement that radical changes are needed

