Danish Cancer Society; PRO - Projects

PRO Cancer Patient Reports

PROM – projects (ongoing)
• Population-based: Lung cancer
• Clinical-based:
  o Lung cancer: Model 1
  o Prostate cancer: Model 2
• Adverse events: Oncology

PREM – surveys
• Surveys incl. all cancer patients diagnosed at a specific time (2011 and 2013).
• Survey among adolescents diagnosed (ongoing)
• Overall aim: Focusing on patients preferences, needs, experiences with cancer care through their trajectory

Today
• The survey – method and focus
• The use of data
• Illustration of how the patient perspective provides useful information

Upcoming Project: PROM and PREM combined
A cohort – study; Adolescents with cancer

Overall aim: Focusing on patients preferences, needs, experiences with cancer care through their trajectory
The study – Objective and Focus

To measure cancer patients’ experiences with the quality of care they have received

The Patient’s Perspective

GP  Specialist  Hospital  GP  Social care

Part 1


Part 2

= the patients’ needs, experiences, preferences and behaviour
Designing and Developing the Survey Instrument

1. Background
   Aim
   Themes
   Target population

2. Conceptualization
   Literature
   Focus group interviews
   Reference group/Key persons

3. Developing the questionnaire
   Generating items
   Structure

4. Validation
   Cognitive interviews
   Reference group/Key persons

5. Final questionnaire
Study Population

Inclusion Criteria:
- Patients registered with a first time cancer in the national patient register
- Resident in Denmark
- 18 years or older

Part 1 - Population
6720 patients registered with a first-time cancer diagnosis in the period 1st May to 31st August 2010

Part 2 - Population
6914 patients registered with a first-time cancer diagnosis in the period 16th April to 15th September 2010

Participants
Newly diagnosed cancer patients
4363 (65 %) answered a questionnaire in the summer 2010

Participants
Cancer patients approx 2-2½ years from the time of diagnosis
4,401 (64 %) answered a questionnaire in the summer 2012
Centrale Results across the two parts of the study

- Patient- and system barriers for being **quickly diagnosed**
- **Complications**, and lack of information about the risk
- Lack of **continuity** and problems related to **transitions**
- Patients wish to be **involved**, but this wish is not always accommodated
- **Relatives** are not sufficiently involved and do not receive the help/support, they need
- Lack of support for handling **emotional reactions** and **sexual problems**
How We Use the Data
National Strategy for Redesigning the Follow-up Care

- The number of people living beyond a cancer increasing (DK: 245,000)
- The effect of routine follow-up on survival is questionable
- The patient profile is changing

- how can the patient perspective adds value this work?


### Compliance of Care to Patients’ Needs

#### Needs

<table>
<thead>
<tr>
<th>In need of help, in relation to:</th>
<th>Physical problems</th>
<th>Emotional reactions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need</td>
<td>63.2%</td>
<td>58.6%</td>
</tr>
<tr>
<td>No need</td>
<td>36.8%</td>
<td>41.4%</td>
</tr>
</tbody>
</table>

#### Unmet Needs

Did the patients receive the help they had a need for?

<table>
<thead>
<tr>
<th>Physical problems</th>
<th>48.4%</th>
<th>34.0%</th>
<th>17.7%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, to a great extent</td>
<td>Yes, to some extent</td>
<td>To a lesser extent/not at all</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Emotional reactions</th>
<th>38.9%</th>
<th>30.8%</th>
<th>30.3%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, to a great extent</td>
<td>Yes, to some extent</td>
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<td></td>
</tr>
</tbody>
</table>

Variation in Cancer Patients’ Needs

Objective of paper: Understanding the variation in the patients’ needs and experiences of the services.

Needs and unmet need adjusted for age, cancer disease, sex, comorbidity, marital status, type of treatment, treatment complexity and setting of follow-up

Results

• Large group of patients reported no need for support to physical or emotional problems
• Some specific groups more likely to have need and report unmet needs
  Younger cancer patients
  Patients with comorbidity
• Setting of follow-up did not have any impact of the level of unmet needs

Sperling et al., Current organisation of follow-up does not meet cancer patients’ needs. Dan Med J: 61(6);2014
**Every 4th Patient Does Not React on Symptoms**

For the patients reassurance is the most important benefit of follow-up consultations even after several years of follow-up.  
*(Danish Health and Medicines Authority, 2009)*

<table>
<thead>
<tr>
<th>Have you experienced symptoms between follow-ups that worried you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>34.9%</td>
</tr>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>

**If so, what did you do?**

<table>
<thead>
<tr>
<th>Action</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Waited till the next follow-up</td>
<td>24%</td>
</tr>
<tr>
<td>Got in touch with the ward/department at the hospital</td>
<td>37%</td>
</tr>
<tr>
<td>Got in touch with my GP</td>
<td>33%</td>
</tr>
<tr>
<td>Got in touch with a specialist outside the hospital</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
</tr>
</tbody>
</table>
Reorganization – what do the Patients Prefer?

How would you prefer your follow-up pathway to be organized?

- 92.9% of respondents prefer a series of regular, planned examinations at regular intervals.
- 7.1% prefer without planned appointments, but with the option of having an examination done quickly if needed.

Reorganization of follow-up care is not just a cultural change for the professional but for the patients too.

If there was the same examination programme (i.e. that same scans and tests), would you prefer the consultations to be done by a:

- 84.5% of respondents prefer a medical professional at the hospital.
- 8.2% would prefer a specialist outside the hospital.
- 5.1% would choose a doctor at the hospital.
- 2.2% would opt for a nurse at the hospital.
A prospective cohort study among young adult and adolescent with Cancer

To investigate the patients’ needs, experiences, quality of life and recovery after treatment.
Thank you for listening!

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