Collaborating with Cancer Registries to Conduct Survivorship Research Studies

Sharon Campbell | June 24, 2010
North American Association of Cancer Registries
Goal
Provide evidence to guide health care decisions, resource allocation for increasing number of survivors

Study Purpose:
Develop and Validate Unmet Needs Survey
Identify Prevalence and Predictors of High Unmet Needs
WHAT ARE UNMET NEEDS?

Definition

• Problem or concern for which a person is unable to get the help they need to resolve the problem.

• Distinguish between:
  • problems which a person experiences and
  • problems they wish help in managing.

• Informs action to be taken or resources to be provided, in order to attain optimal well-being.
COLLABORATED WITH THREE PROVINCIAL CANCER REGISTRIES

Alberta
Simple Random Sample

PILOT
Manitoba
Stratified Random Sample

Research Team

Nova Scotia
Simple Random Sample
Random sample of survivors 12 to 60 months post diagnosis

Mailed, self-administrated survey with follow-up
  Unmet Needs, Cancer History, Health Care Utilization, Support, Demographics, *Quality of Life (NS, AB)*
ELIGIBILITY CRITERIA

- 12 to 60 months since first diagnosis
- Currently alive
- Age 19 plus at diagnosis
  - NS: < 84 at dx
- Histologically confirmed
  - Exclude NMSC, in-situ, (MB – neurologic)
- Not declined research participation before
DATA COLLECTION PROCEDURES

**Registry**
- Create File
- Link to Study ID
- Mail all Surveys & FU
- Answer Participant Calls

**Research Team**
- Prepare Surveys
- Send to Registry
- Track Responses by ID
- Inform Registry

**OSTS**

**Survivor**
- Call Registry *(Questions or Decline)*
- Complete & Return Survey or Follow-up
- Not Respond
## Recruitment Protocol & Completion Rate

<table>
<thead>
<tr>
<th>STEPS</th>
<th>MB</th>
<th>NS</th>
<th>AB</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-notification letter</td>
<td>NO</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>Info Letter &amp; Survey</td>
<td>First Contact</td>
<td>Quest</td>
<td>Quest</td>
</tr>
<tr>
<td>1(^{st}) Follow-up</td>
<td>Quest</td>
<td>Quest</td>
<td>Post-Card</td>
</tr>
<tr>
<td>2(^{nd}) Follow-up</td>
<td>Letter</td>
<td>Letter</td>
<td>Quest</td>
</tr>
<tr>
<td>Non-Respondent</td>
<td>NO</td>
<td>YES</td>
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The diagram on the right illustrates the progression over time (PreNotice, QQ, 1st FU, 2nd FU, Final) with different colors representing MB, NS, and AB.
RECRUITMENT PROTOCOL
Varied by province to test best RR

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| % Eligible | 70.5 | 84.5 | 82.8 |
| % Return   | 49.0% | 64.6 | 63.0 |
| % Complete | 48.8 | 56.4 | 57.8 |
CUMULATIVE COMPLETION RATES

No Difference by Time Since Diagnosis
REASON FOR INELIGIBILITY

- Undeliverable
- Deceased
- Decline

Alberta
Nova Scotia
Manitoba
DECLINED PARTICIPATION:

- ask be removed: 4.6% (Alberta) vs 4.6% (Nova Scotia)
- not have cancer: 1.5% (Alberta) vs 0.8% (Nova Scotia)
- no needs: 0.9% (Alberta) vs 0.5% (Nova Scotia)
**Selection Criteria**

<table>
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<td>% Female</td>
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<tr>
<td>Age 60 + at Diagnosis</td>
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<tr>
<td>% Urban</td>
<td></td>
</tr>
<tr>
<td>Type of Cancer</td>
<td></td>
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<tr>
<td>Time since Diagnosis</td>
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No Differences Between Universe of Eligible Cases, Random Sample or Completed surveys
• Small % reported a recurrence or spread of their cancer (5.9%) or a new primary cancer (6.5%), or both (8.2%).

• Interestingly, 10.4% of survivors felt they were cancer free.
NO UNMET NEEDS (*Manitoba*)

• 148 (26.9%) of 550 survivors did not have any unmet needs at all in the last month (n=138) or had only one low unmet need (n=10).

• % of survivors with no unmet needs may be higher because many non-respondents called registry to say they were not participating because they had no unmet needs.
RESULTS – Top 10 Unmet Needs

Top 10 Unmet Needs (Manitoba)

- Worry if treatment worked: 11.8
- Dealing with anxiety: 12
- Finding info about complementary/alternative...: 12.1
- Coping with bad memory, lack of focus: 12.1
- Feeling stressed: 12.3
- Finding financial assistance: 12.4
- Fatigue: 13.7
- Not feeling sure cancer has gone: 13.8
- Being told I had cancer: 14.9
- Fears about cancer spreading: 16.3
## WORKING TOGETHER: Priorities

<table>
<thead>
<tr>
<th>Researchers</th>
<th>Cancer Registry</th>
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<tbody>
<tr>
<td>• Representative sample</td>
<td>• Patient Confidentiality*</td>
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<tr>
<td>• High Response and Completion Rates</td>
<td>• Patient Reactions</td>
</tr>
<tr>
<td>• Data Quality</td>
<td>• Physician Reactions</td>
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<tr>
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<td></td>
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* NAACCR Workshop 2002
Researchers:
Population based cancer registries provide almost complete sampling frame of survivors
Higher external validity

Registries:
Extend use of surveillance data to improve survivors’ health, quality of life
Potential to increase registry resources
## Provincial Cancer Registries

**Manitoba**  
Donna Turner  
Cheryl Clague  
Huminara Khair  

**Nova Scotia**  
Maureen McIntyre  
Rosalee Walker  
Ron Dewar  

**Alberta**  
Carol Russel  
Lorraine Cormier  
Jhichang Jiang  

## University of Waterloo

**Sharon Campbell**  
Principal Investigator  

**Stephanie Filsinger**  
Research Coordinator  

**Laura Holtby**  
Research Manager  

**Matt van De Meer**  
Database Developer  

**Matt Grey**  
Database Manager
The Propel Centre for Population Health Impact™ is a partnership between the Canadian Cancer Society and the University of Waterloo (UW).

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