Developing a Cancer Survivorship Monitoring System for South Australia

Date: 07/2/15

Presentation Overview

- National Age Profile
- Cancer Statistics Nationally and for the State
- Variations in Health Outcomes
- Cancer Survivorship Monitoring
- Establishing a survivorship monitoring system for SA

Research Team

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National Age Profile Predictions

Between 1982-2013: number of people > 60 years of age has doubled from 2 million to 4.5 million
Estimated to be: 5.5 million in 2020.

More people surviving cancer

More People Living with Cancer
Variations in outcomes

- About 1/3 of people affected by cancer live in non-metropolitan areas. Mortality rates are higher for those in remote areas.
- Cancer incidence and mortality rates are higher for those living in lower socioeconomic status area than those in higher.
- Aboriginal and Torres Strait Islander (ATSI) peoples are 6% more likely to be diagnosed with cancer and 50% more likely to die from cancer than non-ATSI Australians.

We know the statistics but don’t monitor psychosocial needs at a population level.

How many does this impact in SA?

1 in 2 Australians will be diagnosed with cancer by the age of 85. 28% of all deaths in South Australia are due to Cancer. In 2013 there was a total of 51,000 people with Cancer in SA.

How does Cancer Council SA currently support survivors?

Activities in cancer support across domains of unmet needs

- Quality of life
- Co-morbidities before and after Cancer diagnosis
- Psychological distress
- Utilisation of health care services
- Treatment satisfaction
- Understanding the patients experience

Cancer Registry Data in SA

Gap in Monitoring Cancer Survival

There is NO Patient Reported Outcome (PRO) monitoring tool that measures a comprehensive range of physical and psychosocial outcomes with no agreed minimum dataset for survivorship in Australia at a population level.

- Quality of life
- Co-morbidities before and after Cancer diagnosis
- Psychological distress
- Utilisation of health care services
- Treatment satisfaction
- Understanding the patients experience
NHMRC Partnership Grant: Cancer Data and Aboriginal Disparities (CanDAD)

Background:
Plan to develop an advanced data system for describing cancer stage, co-morbidity, clinical management and outcomes of Aboriginal People with cancer in SA and then monitor progress and serve as an exemplar.

Next stage:
Develop and pilot test a methodology for gathering qualitative data around access cultural safety and patients perspectives of their care. Plan is to link the narratives to health outcome data.

Why is Monitor important?
- There is no mechanisms for collecting survivorship data in SA at a population level
- Identify gaps in services
- Identify high risk groups
- Challenge Assumptions
- Inform support services
- Inform clinicians
- Inform Policy makers
- Monitor impact of changes of health service or support service delivery on the consumer
- Drive research into improving psychosocial outcomes
- Inform Advocacy strategy
- Targeted communication planning

FCIC Pilot Study

Study aim
- To determine acceptability and feasibility of collecting information from people about their experiences following cancer treatment.

Method
- Survivors recruited via Survivorship Clinic (over 6 months)
- Completed treatment with curative intent
- Initial survey + survey at 12 months

Review of international models

Existing registries Set up, processes and governance Minimum datasets Data linkage

Project Plan: Phase I

Stakeholder engagement

Key stakeholders
- Clinicians
- Policy makers
- Cancer Registry
- Researchers
- Consumers

Existing relationships with key stakeholders
**Data Analyses**

- What % of eligible patients take part initially?
- What % are retained at follow-up?
- Feedback on the survey (questions, online vs paper preferences, how often willing to complete surveys?)
- Quality of the data collected (e.g., missing responses, reliability)

**Project Plan: Long-term strategy**

- **Phase I**
  - Feasibility study
  - Multi-site infrastructure
  - Managing risk
  - Consult with other Cancer Councils regarding tool for adoption nationally
- Implement an integrated survivorship monitoring tool through the CCR Registry
- Stakeholder engagement
- Seek funding

**Draft Survey**

<table>
<thead>
<tr>
<th>Category</th>
<th>Measure</th>
<th>Number of items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health-related Quality of Life</td>
<td>Functional Assessment of Cancer Therapy – General (FACT-G) + Cancer Specific Symptom Subscales</td>
<td>27 items + 7-24 depending on cancer type.</td>
</tr>
<tr>
<td>Co-morbidity before and after cancer</td>
<td>The Self-administered Co-morbidity Questionnaire</td>
<td>14 items (includes open-ended responses).</td>
</tr>
<tr>
<td>Cognitive functioning</td>
<td>The FACT-Cognitive function (version 3) – measured co-morbidities and health-related quality of life subscales</td>
<td>50 items.</td>
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<tr>
<td>Psychological distress</td>
<td>K10</td>
<td>K10 = 10 items + checklist of possible concerns.</td>
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<tr>
<td>Post-traumatic growth</td>
<td>Post-traumatic Growth Inventory – short form (PTGI)</td>
<td>10 items.</td>
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<tr>
<td>Utilisation of health care and support services</td>
<td>Questions from SA Health Monitor Survey</td>
<td>5</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>Questions from the SA Health Monitor Survey</td>
<td>5</td>
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<tr>
<td>Unmet needs</td>
<td>Cancer Survivors Unmet Needs Survey</td>
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<tr>
<td>Employment status</td>
<td>Questions from UK Dept Health Longitudinal Study of Cancer Survivors</td>
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<tr>
<td>Problems with insurance and loans</td>
<td>Questions from PROFILES</td>
<td>3</td>
</tr>
<tr>
<td>Treatment satisfaction</td>
<td>Questions from UK Dept Health Longitudinal Study of Cancer Survivors</td>
<td>4</td>
</tr>
</tbody>
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**Summary**

- More people surviving cancer but there are many adverse affects
- Quality data is needed to build a greater understanding to inform service delivery and advocacy
- Develop good systems, not just good luck.
- A dedicated registry is the best model to meet this need
- Cancer Council SA is undertaking a program of research and stakeholder engagement to establish a survivorship registry

Thank you