The gap between theory and practice: quantity and quality of care plans and treatment summaries across survivorship care pilot sites in South Australia


February 2nd 2017
Background

> Survivorship care plans and treatment summaries are considered the key component of survivorship care
  • Even though there is conflicting evidence of their utility in clinical trial setting
> South Australia is taking a state-wide approach to health transformation
> South Australian Cancer Service has been asked by the National Cancer Experts Reference Group to develop and pilot a state-wide survivorship framework that may help informing survivorship care initiatives nationally

SA Health
Aims

> To design, pilot and evaluate a state-wide strategy to deliver survivorship care to adults and children treated for cancer with curative intent in South Australia.
Strategy for translating evidence into practice.

1. Summarise the evidence
   Identify interventions associated with improved outcomes
   Select interventions with the largest benefit and lowest barriers to use
   Convert interventions to behaviours

2. Identify local barriers to implementation
   Observe staff performing the interventions
   "Walk the process" to identify defects in each step of implementation
   Enlist all stakeholders to share concerns and identify potential gains
   and losses associated with implementation

3. Measure performance
   Select measures (process or outcome)
   Develop and pilot test measures
   Measure baseline performance

4. Ensure all patients receive the interventions
   Implement the "four Es" targeting key stakeholders from frontline
   staff to executives
   Engage
   Explain why the interventions are important
   Evaluate
   Regularly assess for performance measures and unintended consequences
   Execute
   Design an intervention "toolkit" targeted at barriers, standardisation,
   Independent checks, reminders, and learning from mistakes
   Educate
   Share the evidence supporting the interventions

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1. **Magnitude of the problem**
   - Survivors perceptions and needs
   - Providers perceptions and needs
   - Data on incidence, prevalence, patterns of care

2. **Solutions**
   - Existing models of care
Strategy for translating evidence into practice.

3. Strategy development
   Stakeholder feedback
   Process/system mapping
   Consensus meeting re solutions
   Work on tools strategies
   Ongoing stakeholder feedback

Peter J Pronovost et al. BMJ 2008;337:bmj.a1714
Strategy for translating evidence into practice.

4. Measures development
Process and outcome
HE measures
Framework of measures

Peter J Pronovost et al. BMJ 2008;337:bmj.a1714
Strategy for translating evidence into practice.

5. Intervention pilot
EOI
Communication strategy
Toolkit
Regular feedback

Peter J Pronovost et al. BMJ 2008;337:bmj.a1714

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Cancer Treatment summary

Minimum information for inclusion

Needs assessment
Distress thermometer and problem checklist

Cancer surveillance
(reurrence and detection)

Side-effect management
(treatment toxicities; physical, psychosocial and economic impact)

Other health problems
(co-morbidities)

Wellness and health promotion
(prevention and screening)

Other
(eg. return to work or school, financial support)

CONTEXT SPECIFIC eg. Aboriginal, CALD, people with special needs

Implementation Principles
- Multi-disciplinary, multi-sectoral and comprehensive (survivor, family and community)
- Evidence-based
- Data driven
- Technology enabled

Overarching Principles
1. Holistic and patient-centred
2. Safe
3. Accessible
4. Effective
5. Efficient
6. Equitable

Survivor
Care plan

Workforce
Tools
Data

KPIs
Health economic measures
Methodology

> 4 champion teams recruited after EOI
  • Nurse/med onc
  • Inner metro (2), outer metro (1), rural (1)
  • 1 well established survivorship service

> 3 month recruitment of patients
  • Established templates and procedures
  • Regular debrief, action and outcome logs

> Ethics approval for evaluation
  • TS and CP content, demographics
  • Feedback from champions
  • Patient/survivor survey
Cancer Treatment Summary for Patients Name

Type of Cancer:
Date and details of diagnosis:
Stage:
Pathology findings and pathology service:

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Type/findings</th>
<th>Doctor/Hospital/Dates</th>
<th>Complications/changes to treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hormonal treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiation therapy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supportive and other services</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*This is a brief record of the major aspects of your cancer treatment. This document is not intended to be a detailed or comprehensive record of your care. If however, you would like a more detailed account of your treatment please contact your cancer specialist.*

Summary completed by:  

Date:

South Australian Survivorship Framework – Treatment Summary
**Distress Thermometer and Checklist**

Distress is often unpleasant feelings or emotions that can impact on the way you think, feel and act. It can include feelings like sadness, worry, anger, helplessness and guilt. It's common for someone who has been diagnosed with cancer to experience some level of distress at some point in time (anywhere from diagnosis and beyond). Your level of distress may only be minor or could be more serious where you find that you're not able to do the things you used to do. It's important for your Treatment/Medical Team to know how you're feeling. By completing the following tool your team will work with you and help link you with other supportive services (for example counsellors, social workers, dietitians) when you need or want to.

**Instructions:**

1) Please circle the number 0 – 10 that best describes how much distress you have been experiencing in the past week including today.

2) Please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

### Extreme Distress

- [ ] 10
- [ ] 9
- [ ] 8
- [ ] 7
- [ ] 6
- [ ] 5
- [ ] 4
- [ ] 3
- [ ] 2
- [ ] 1
- [ ] 0

### No Distress

- [ ]

**YES**

- Child care
- Housing
- Insurance / financial
- Transportation
- Work / school
- Treatment decisions

**NO**

- Family Problems
  - Dealing with children
  - Dealing with partner
  - Ability to have children
  - Family health issues

**YES**

- Emotional Problems
  - Depression
  - Fears
  - Nervousness
  - Sadness
  - Worry
  - Loss of interest in usual activities

**NO**

- Spiritual / religious / cultural concerns

**Other Problems:**

Adapted from the National Comprehensive Cancer Network (NCCN) Clinical Practice Guidelines and Distress Thermometer for Patients
# Care Plan for Patient's Name

This care plan aims to assist in identifying and developing your health goals as a cancer survivor and steps you can take to reach these. You’re encouraged to discuss and share your care plan with your GP, family or others you feel can support you and continue to build as you achieve your goals or have other needs arise in the future.

<table>
<thead>
<tr>
<th>Current issues, problems or concerns</th>
<th>Level of importance to you</th>
<th>Goal moving forward</th>
<th>Strategy</th>
<th>Who should assist you in achieving it</th>
<th>GP Involvement</th>
<th>Other providers involved (ie: specialist)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Surveillance</td>
<td>1-very</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2- somewhat</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3- not important</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Side effect management</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other health problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wellness &amp; health promotion</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Data collected

> Demographics
> Process measures
> Content: completeness and quality
> Providers and survivors’ feedback
## Results

<table>
<thead>
<tr>
<th>Demographic Data</th>
<th>Total</th>
<th>Site A</th>
<th>Site B</th>
<th>Site C</th>
<th>Site D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cohort (#)</td>
<td>43</td>
<td>34</td>
<td>6</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Age range (years)</td>
<td>32 - 80</td>
<td>39 - 80</td>
<td>32 - 75</td>
<td>53 - 71</td>
<td>0</td>
</tr>
<tr>
<td>Median age (years)</td>
<td>59</td>
<td>59</td>
<td>58.5</td>
<td>59</td>
<td>0</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Male</td>
<td>7 (16%)</td>
<td>6 (18%)</td>
<td>1 (17%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>- Female</td>
<td>36 (84%)</td>
<td>28 (82%)</td>
<td>5 (83%)</td>
<td>3 (100%)</td>
<td>0</td>
</tr>
<tr>
<td>Tumour type</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Breast</td>
<td>32 (74%)</td>
<td>23 (67%)</td>
<td>6 (100%)</td>
<td>3 (100%)</td>
<td>0</td>
</tr>
<tr>
<td>- Colorectal</td>
<td>7 (16%)</td>
<td>7 (21%)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>- Ovarian</td>
<td>1 (2%)</td>
<td>1 (3%)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>- Tonsil SCC</td>
<td>1 (2%)</td>
<td>1 (3%)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>- Testicular</td>
<td>1 (2%)</td>
<td>1 (3%)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>- Cholangiocarcinoma</td>
<td>1 (2%)</td>
<td>1 (3%)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Results

<table>
<thead>
<tr>
<th>Preparation</th>
<th>Appointment</th>
<th>Follow-up/Finalising</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 – 90 mins (avg 51 mins)</td>
<td>45 – 90 mins (avg 57 mins)</td>
<td>30 – 75 mins (avg 46 mins)</td>
</tr>
</tbody>
</table>

Total: average of 154 minutes per person

Challenges identified:

1. Location of medical records and files (in some instances across multiple sites)
2. Accessing original documentation (eg. pathology reports)
3. Compiling information of treatment, particularly if survivors received services in both the public and private sectors
Results – Treatment Summary

TS complete with regards to:

> Date of diagnosis (98% included)
> Diagnosis (100% included)
> Stage (90% included)
> Pathology findings (98% included) and service providers (95% included)
> Treatment received (100% included)

Details relating to complications were more likely to be missing:
• Time of when complications developed
• Level of severity of complications
• Actions taken
• When or if the complications were resolved
### Results

#### Care Plan

<table>
<thead>
<tr>
<th>Problem</th>
<th>Total # CP reported on</th>
<th>% CP</th>
<th>Avg level of importance</th>
<th>Avg Strategy Score</th>
<th>Average Provider Score</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cancer Surveillance</strong></td>
<td>43</td>
<td>100%</td>
<td>1.2</td>
<td>2/5</td>
<td>1.2/3</td>
</tr>
<tr>
<td><strong>Heart health</strong> (hypertension, cholesterol management, risk of cardiac toxicities, atrial fibrillation, heart failure)</td>
<td>23</td>
<td>53%</td>
<td>2.1</td>
<td>2/5</td>
<td>1.1/3</td>
</tr>
<tr>
<td>- Management of existing condition</td>
<td>10</td>
<td>44%</td>
<td>2.1</td>
<td>2/5</td>
<td></td>
</tr>
<tr>
<td>- Prevention</td>
<td>13</td>
<td>57%</td>
<td>2.1</td>
<td>2/5</td>
<td></td>
</tr>
<tr>
<td><strong>Lifestyle</strong> (weight management, PA, HE, alcohol intake, smoking)</td>
<td>20</td>
<td>47%</td>
<td>1.7</td>
<td>2/5</td>
<td>1.6/3</td>
</tr>
<tr>
<td><strong>Cancer Screening</strong> (bowel, cervical, breast where applicable)</td>
<td>18</td>
<td>42%</td>
<td>2.1</td>
<td>2.1/5</td>
<td>1.4/3</td>
</tr>
<tr>
<td><strong>Bone health</strong> (osteofrasis, osteopenia, bone health)</td>
<td>16</td>
<td>37%</td>
<td>1.7</td>
<td>2/5</td>
<td>1.8/3</td>
</tr>
<tr>
<td><strong>Anxiety &amp; Depression</strong> (include fear recurrence)</td>
<td>12</td>
<td>28%</td>
<td>1.3</td>
<td>2/5</td>
<td>1.8/3</td>
</tr>
<tr>
<td><strong>Peripheral Neuropathy</strong></td>
<td>12</td>
<td>28%</td>
<td>2.3</td>
<td>1.7/5</td>
<td>3/3 (only on 1/12)</td>
</tr>
<tr>
<td><strong>Fatigue</strong></td>
<td>10</td>
<td>23%</td>
<td>1.6</td>
<td>2.1/5</td>
<td>1.6/3</td>
</tr>
<tr>
<td><strong>Lymphoedema</strong></td>
<td>7</td>
<td>16%</td>
<td>2</td>
<td>2/5</td>
<td>1.8/3</td>
</tr>
<tr>
<td><strong>Bowel problems</strong> (diarrhoea, constipation; both; IBS)</td>
<td>7</td>
<td>16%</td>
<td>1.8</td>
<td>1.9/5</td>
<td>1.5/3</td>
</tr>
</tbody>
</table>
Results – champions’ feedback

> “Different model of care”
  • Templates useful
  • Delivery improved with confidence and skill
  • Team support valued
  • Specialist endorsement important
  • Patient preparation important
Results – survivor feedback

• Response rate 35% (15/43)
• 93% reported value in attending a survivorship appointment

Treatment Summary:
• 87% reported having a personalised copy as being useful

Care Plan:
• 73% found the CP useful, 20% unsure
• 67% had used their CP and shared with GP
• 47% reported acting on a goal

Time of appointment:
• 53% reported time SCP developed was “just right”, usually between 2 weeks to 6 months post-treatment

100% recommended all survivors in future receive individualised TS & CP
Strenghts and limitations

- Real life setting, real life resources
- Consumer engagement and feedback
- Small numbers
- Mostly breast cancer
- Self selected champions
- No measure of impact on outcomes
Conclusions

> The initial pilots of the state wide model indicate significant variability in uptake and quality of service

> Future work needed on

  • Strategies needed to insure quality of TS and CP
  • Engagement with providers that goes beyond initial champions
    ▪ Move from the illness to wellness model
    ▪ Preparation of provides and survivors
    ▪ Defining the demand and capacity for service
    ▪ Engagement of GPs
  • Long term impact and sustainability
Survivorship Steering Group

Professor Bogda Koczwara (Chair): Senior Staff Specialist in Medical Oncology FCIC
Ms Tracey Doherty (Co-chair): A/ Service Director, SA Cancer Service
Ms Chantelle Hislop: Senior Project Officer, SA Cancer Service
Dr Kate Cameron: Nursing Director, WCH
Professor Marion Eckert: Director Rosemary Bryant AO Research Centre, UniSA
Ms Julie Marker: Consumer & Chairperson, Cancer Voices SA
Ms Chris Christensen: Consumer & Deputy Chairperson, Cancer Voices SA
Ms Karen van Gorp: Consumer, Melanoma Patients SA Facilitator & Cancer Voices SA
Mr Michael Fitzgerald: Nurse Practitioner Candidate (Medical Oncology), SALHN
Ms Nicole Loft: Nurse Practitioner (Haematology), CALHN
Dr Dagmara Poprawski: Medical Oncologist, CHSA
Ms Kate Turpin: Nurse Practitioner (Haematology/Oncology), WCH
Dr Michael Osborn: Lead Clinician, Consultant Haematologist Oncologist, Youth Cancer Service SA/NT
Ms Janet Stajic: Senior Project Officer, SA Cancer Service
Clinical A/Professor Taryn Bessen: Senior Staff Radiologist, CALHN
Dr Nadia Corsini: Senior Research Officer, Cancer Council SA

Pilot Champion Teams

Mr Michael Fitzgerald & Professor Bogda Koczwara: SALHN
Ms Julie Campbell & Dr Dagmara Poprawski: CHSA
Ms Shirley Roberts & Dr Rohit Joshi: NALHN
Ms Janette Prouse & Dr Sid Selva: CALHN

Thank you to all stakeholders who have contributed to the development of the SA Survivorship Framework over the past 2 years