Survivorship Connections: A Model of Youth Friendly Survivorship Care
Kate Thompson & Lucy Holland
Acknowledgements
Background

• In Victoria > 280 AYAs/year (15-25) are diagnosed with cancer
• A cancer diagnosis in the AYA years can impact the achievement of major developmental life milestones:
  – Identity, autonomy & independence, intimate & mature relationships, education, employment & financial independence
• AYA survivors report poor health outcomes
  – Obesity & physical morbidity\textsuperscript{1,2}, body image and sexual problems\textsuperscript{3}, lower educational achievement\textsuperscript{4}, social isolation\textsuperscript{5}, less likely to partner & have children\textsuperscript{4}, anxiety & depression\textsuperscript{3}, PTSD\textsuperscript{6,7}, low self esteem\textsuperscript{3} & existential distress\textsuperscript{8}, FCR\textsuperscript{8}
Objective

- This pilot project aimed to develop, implement and evaluate a pilot model of survivorship care for young people aged 15-25 years at diagnosis:
  - End of treatment coordination
  - Youth friendly screening/assessment & goal setting
  - Treatment summary and care planning
  - Facilitating GP engagement and supporting shared care arrangements
  - Information provision for both young people and GPs
  - Emphasis on self management through skill development
Method

• Patients
  – Young people aged 15-25 years at diagnosis for any cancer type
  – Treated in the adult healthcare setting
  – Life expectancy at least 12 months
  – Transitioning to post-treatment care

• Sites
  – Peter MacCallum Cancer Centre
  – The Royal Melbourne Hospital
  – Bendigo Healthcare

• Community partner
  – CanTeen Australia
Recruitment

End of Treatment Consultation
Overview of Survivorship
Identification of GP
AYA Oncology Survivorship Screen

Post Treatment Consultation
Survivorship Care Plan & Health & Wellbeing Plan
Referrals - Specialist AYA/Community Based

GP Case Conferences
Clinician
Patient

Reviews (3, 6, 9, 12 months)
AYA Oncology Survivorship Screen
Survivorship Care Plan/Health & Wellbeing Plan Updated
Communication with Team & Primary Care

Final Evaluation
Evaluation

• Patient reported measures
  – Distress (distress thermometer)
  – Unmet need (AYA S/Ship Screening Tool)
  – Health and wellbeing (SF-12)
  – Quality of Life (AQoL-6D)
  – Experience of each interaction (PEQ)

• Experience of carers

• Experience of healthcare professionals and GPs

• Health economic evaluation (cost of the project)
Results

46 young people & carers

Characteristics

Age (ave) 20.4 years
Age (range diagnosis) 15-25 years
Age (range consent) 15-26 years
Male # (%) 23 (50%)
Female # (%) 23 (50%)
Distress (>4) baseline 39.53%
Distress (>4)3 months 31.82%

Diagnoses

Most common reported needs at Baseline

<table>
<thead>
<tr>
<th>Need</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of recurrence</td>
<td>67</td>
</tr>
<tr>
<td>Boredom</td>
<td>67</td>
</tr>
<tr>
<td>Not knowing fertility status</td>
<td>61</td>
</tr>
<tr>
<td>Less energy than before</td>
<td>56</td>
</tr>
<tr>
<td>Being unable to exercise</td>
<td>56</td>
</tr>
</tbody>
</table>

Treating Hospital

<table>
<thead>
<tr>
<th>Hospital</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>PMCC</td>
<td>59</td>
</tr>
<tr>
<td>RMH</td>
<td>18</td>
</tr>
<tr>
<td>Austin Health</td>
<td>2</td>
</tr>
<tr>
<td>LaTrobe Regional Hospital</td>
<td>2</td>
</tr>
<tr>
<td>Western Health</td>
<td>2</td>
</tr>
<tr>
<td>Monash Medical Centre</td>
<td>2</td>
</tr>
<tr>
<td>St Vincent's</td>
<td>2</td>
</tr>
<tr>
<td>Maroondah</td>
<td>2</td>
</tr>
<tr>
<td>Ballarat</td>
<td>4</td>
</tr>
<tr>
<td>Box Hill Hospital</td>
<td>4</td>
</tr>
</tbody>
</table>
Results

• Demographics
  – Representative of the AYA population (age, gender & carer identity)
  – Broad range of diagnoses, treatment types, locations & durations
  – High rate of relapse & withdrawal

• Distress, Need, Quality of Life & Burden of Disease
  – Clinically significant distress ~40% at baseline (no change at 3 months)
  – # of reported needs reduced between baseline & 3 months
  – Clinically significant reduction in QoL at baseline.
  – Improvement in QoL over time at 3 months.

• Acceptability (high), primary care engagement mixed

• Carers identified several unique needs
  – Relationships, emotional coping, work, finances, identity & hope...
### Outcomes

- **Supporting documents**
  - AYA Screening Tool
  - Health & Wellbeing Plans
  - Templates (letters etc)

- **Supporting resources**
  - Finding & Visiting a GP
  - Information & resources for young people
  - Information & resources for GPs
  - Survivorship Resource
  - Directories (GP’s, AYA, Carers)
Outcomes

Information and Resources for Young People

Here are a few places to start in terms of information and resources on a range of topics that may be of interest. Please call us on 03 9656 1744 or talk to your GP if you have any questions.

Cancer information and Support

ONTrac at Peter Mac provides a broad range of services for young people aged 15-25 years living with cancer across Victoria and Tasmania. Services include adolescent medicine and oncology, clinical trials information, psychology, social work, family counseling, exercise physiology, occupational therapy, education and employment support. They also offer information and support to siblings, parents, partners and peers.

Cancer Council Victoria (CCV)
The CCV website provides a range of information and resources about cancer and survivors of childhood, adolescent and young adult cancer. The website includes a range of resources and information for young people, parents, partners, and health professionals.

CarTeen
CarTeen is an Australian support organisation for people living with cancer. The organisation provides a range of resources and support for young people, including a helpline, online forum, and a range of events and programs.

WEB-BASED RESOURCES UTILISED:
http://www.cancer.org.au
http://www.youngcancer.org.au

Cancer care for adolescents and young adults

Resources for GPs

Working with young people

Tips for a youth-friendly general practice

Adolescent health: a GP resource guide
Comprehensive information on all aspects of working with young people (divided into chapters)

Cancer in young people

Challenges facing survivors of childhood and adolescent cancer
Summary of the physical, psychological and social impacts of cancer for an AYA survivor

Young adult oncology: the patients and their survival challenges (journal access required)
Summary of the major issues and points of difference for AYAs versus other age groups

Psychosocial issues in adolescents with cancer (journal access required)

Summary of the key psychosocial issues for young people diagnosed with cancer

Psychosocial management of AYAs diagnosed with cancer
Advice and good practice points to assist in recognising and meeting psychosocial needs

Long-term follow-up guidelines for survivors of childhood, adolescent and young adult cancer (FREE ACCESS)

Good general resource - a well-established set of follow-up guidelines developed by the Children's Oncology Group in the USA

Fertility preservation for AYAs diagnosed with cancer
Discussing fertility; information on preservation options, follow up and potential late effects

Cancer Learning: Adolescents and Young Adults
Online hub containing regularly updated information on and links to all things AYA cancer (e.g. guidelines and reports, professional groups, journals, patient support)

ONTrac at Peter Mac

Victorian Adolescent & Young Adult Cancer Service
Recommendations

Post-treatment, flexible & holistic survivorship care for AYA patients

• Continuation of study  n=100
• AYA survivorship care pathway incorporating:
  – Screening, AYA Survivorship Care Plan (Treatment Summary/Health & Well Being Plan), Reviews
• Resources:
  – Tools & Templates, Information Fact Sheets (AYA & GP), Youth Friendly GP Directory, Service Provider Directory, Carer Resources Directory, Survivorship Resources for AYA
• Education & Training, Secondary Consultation Service
• Further research into physical function, fitness and wellbeing, self management interventions, and carer interventions
Steering Committee

- Dr Kate Drummond, Neurosurgeon, RMH
- Prof Lena Sanci, Deputy Head Department of General Practice, The University of Melbourne
- Kate Thompson, Project Lead
- Dr Lisa Orme, Paediatric, Adolescent & Young Adult Oncologist
- Professor John Zalcberg, Director, Cancer Medicine, PMCC
- Lucy Holland, Project Coordinator
- Sam Van Staalduinen, Project Coordinator
- Dr Claire Treadgold, CanTeen Australia
- A/Prof Lynette Joubert, Director of Research School of Health Sciences, The University of Melbourne
- Priscilla Gates, ACSC
- Dr Cathy Andronis, GP, IECHS
- Meredith Layton, GPV
- Xenia Alexander, AYA Consumer
- Liz Huglin, AYA Consumer
- Liz Walker, AYA Consumer
References


