Assessing late effects in young cancer survivors

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Overview

- What is late effects care?
- Is this the same as survivorship?
- What does a young person need to be adequately prepared?
- Delivering late effects care: what is the right environment?
- Does existing care meet patient need?
- What happens when a patient reaches 25y?
Late effects - medical

Functional
- e.g. stomas
- amputation

Physical

Malignant

Non Malignant

Endocrine

Psychological
- e.g. anxiety
- depression

Organs specific
Late effects: young cancer survivor

Functional
e.g. college, social, financial, family

Physical

Psychological
e.g. anxiety, body image, memory

Impaired Health Status

Quality of Life

Resilience

Post-traumatic growth
Providing services for patients with established disease

What is late effects care?

- a multidisciplinary approach which supports clinical efficiency and promotes coordinated patient-centered care both for those with:
  - identified late effects
  - both moderate and high risk for problems because of intense treatment exposures
- comprehensive management of complex, chronic medical issues by multiple sub-specialists

Are late effects and survivorship care synonymous?

- Traditionally late effects care had a medical focus
- Survivorship care encompasses more holistic and psychosocial needs of patients
- Late effects care *part* of survivorship care
Principles of late effects management

• Informed consent prior to treatment
• Adequate information and sufficient explanation to recognise symptoms at end of treatment
• Assessment and investigation – guided by risk and dependent on cancer treatment
• Triage approaches
• Specialist MDT referral for managing severe effects
• Systematic management
Function of Late Effects Clinic

- Monitoring for complications:
  - Thyroid nodules / cancer
- Management of chronic complications:
  - Hypopituitarism
- Manage expectations – reduce anxiety:
  - Advice about fertility
- Disseminate new information:
  - Breast cancer after mantle radiotherapy
- Co-ordinate other specialties – advocate
  - Cardiomyopathy after anthracyclines
- Health promotion:
  - Skin cancer after radiotherapy
Concerns

- Anxiety over recurrence
- Identity: relationships with peers and family
- Isolation
- Impact on mortality
- Poor body image
- Low self-esteem
- Returning to school, college, work
- Returning to “normal”
- Fertility, now or in the future and other late effects

Jones et al. Adolescent Cancer Survivors: Identity Paradox and the Need to Belong
Qual Health Res. 2011 Mar 29
Delivering late effects care: what is the right environment?

Location:

- Away from acute oncology clinics
What does a young person need to be adequately prepared?

- Manage fear of recurrence
- Gradual sharing of information - age-appropriate
- Sensitively and informed handling of recalls
- A supportive and reassuring relationship
- Continuity
- Accessible fertility advice
- Consistent access to reproductive services
- Acknowledgement of isolation post follow-up

Grinyer A Life after Cancer in Adolescence and Young Adulthood: the experience of survivorship
Routledge 2009
A risk stratified approach

- Empower patients for self-management
- Empower patients and transfer of knowledge and information between share care partners
- Patient centred care - liaison between subspecialists and delivery of complex care
Adaptable services to meet need

Case study - Mark ALL survivor

- Age 16 - attends transition LEC with his mum
- Age 18 - attends LEC, mum in waiting room
- Age 20 - DNA
- Age 24 - attends on his own
- Age 26 - attends with his partner seeking fertility advice
- Age 30 - pro-actively engaged in consultation, concerned about risks to off-spring and how to communicate medical history to children
Team work

- Multiple medical specialties
- Nursing
- Psychology
- AHPs
- Social work
- Liaison with primary care critical

Adequately prepared workforce
Do we know enough to provide an informed late effects/after care service?

- Consensus guidance
  - Evidence where it exists
  - Doesn’t include 16+ TYA

- Ever changing horizon

- Novel therapies
# Potential late adverse effects of chemotherapy

<table>
<thead>
<tr>
<th>Drug received</th>
<th>Potential late adverse effect</th>
<th>Protocol</th>
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</thead>
<tbody>
<tr>
<td>All chemotherapy</td>
<td>Impaired quality of life</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Secondary malignancy</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Transfusion-associated complications</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Dental caries</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Pigmented skin lesions</td>
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<tr>
<td></td>
<td>Impaired immunity against vaccine-preventable infections</td>
<td>E</td>
</tr>
<tr>
<td>Actinomycin D</td>
<td>Hepatic dysfunction</td>
<td>18</td>
</tr>
<tr>
<td>Amsacrine</td>
<td>Cardiac dysfunction</td>
<td>14</td>
</tr>
<tr>
<td>Asparaginase</td>
<td>No specific late adverse effect known</td>
<td></td>
</tr>
<tr>
<td>BCNU (carmustine)</td>
<td>Secondary leukaemia</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Gonadal dysfunction</td>
<td>11, 12</td>
</tr>
<tr>
<td></td>
<td>Respiratory dysfunction</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Renal dysfunction</td>
<td>20</td>
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<tr>
<td>Bleomycin</td>
<td>Respiratory dysfunction</td>
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</tr>
<tr>
<td>Busulphan</td>
<td>Secondary leukaemia</td>
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<td></td>
<td>Hepatic dysfunction</td>
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<tr>
<td>Carboplatin</td>
<td>Auditory dysfunction</td>
<td>7</td>
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<tr>
<td></td>
<td>Renal dysfunction</td>
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<tr>
<td>CCNU (lomustine)</td>
<td>Secondary leukaemia</td>
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<td>Auditory dysfunction</td>
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</tbody>
</table>
15. Respiratory

ALL PATIENTS
At Long Term Follow Up clinic:
1) History — exercise tolerance, smoking
2) Examination — respiratory system
NB Late respiratory effects appear to be restrictive rather than obstructive (although the latter can be seen after BMT)

PATIENTS WITH RISK FACTORS
1) Perform baseline pulmonary function tests (PFTs) at end of treatment — restrictive abnormality likely
2) If symptomatic or if abnormal PFTs (<2 SD below normal), repeat PFTs after 1 year and / or consider referral to Respiratory specialist
3) Advise against smoking

SPECIFIC ADVICE TO PATIENTS
1) Advise patients and **warn anaesthetists** about previous bleomycin treatment — high inspired oxygen concentration is associated with risk of worsening pulmonary fibrosis
2) Consider pneumococcal immunisation and annual influenza immunisation in patients with established lung disease

RISK FACTORS
- Chemotherapy
  - BCNU — greater risk with younger age (<5 years) and higher cumulative dose
  - CCNU
  - Busulphan
  - ?Bleomycin — little evidence of late toxicity in children
- Radiotherapy — greater risk with younger age, higher dose and larger treatment volume
  - Whole lung
  - Mediastinal
  - Mantle
  - Craniospinal
  - TBI
- Thoracic surgery
- BMT especially after conditioning with busulphan or TBI
What happens when a patient reaches 25y?

- Services patchy
Role of the Nurse

**Headline competences**

- Assess, plan, implement, review and document individualised care plans
- Support self-care
- Liaise with community
- Multi-professional working
- Transition of care
- Educational programmes
- Evidence based practice
Summary

- Listen, acknowledge, empathise and reassure
- Work with patients to encourage self-management
- Work in partnership with patients and primary care
Planning for the future: conclusion

- Much broader than dealing with physical treatment consequences
- Team work approach

Patient should remain Captain of the boat
Acknowledgements