Maria Cable,
Course Director,
Teenage/Young Adult Cancer Care
Coventry, UK
Defining and describing this emergent speciality- 25 years in the making

Advocates for development of specialist age appropriate services amongst other things

Together we provide accredited education for professionals in this field this past 8 years
WHAT?

Competency, Competencies, Competence and Competences

....and Competence Frameworks

In Teenage/Young Adult (TYA) Cancer Care

Or Adolescent (AYA) Cancer Care
Since 2004

Launched 2012

www.tyac.org.uk

Launched 2014
Developing Nursing Competence

Led by Sam Smith
Built on work by Gibson et al 2003, 2012
3 stage Delphi Process
   1- TCT Funded nurses (n=12)
   2- Wider Nursing Survey (n=132)
   3- Consensus event (n=32)
Mapped against views of Young People and national nursing agenda issues
EXPERT STAFF

Expert staff who have time and will listen, support, provide information and communicate effectively and appropriately for my age. Some comments from young people were:

- People that are there for you who can help and listen to you.
- Treating patients as individuals, understanding that they all have different needs and don’t necessarily understand what is happening in medical terms.
- Nurses have got to be nice and have a positive attitude to help the patient and give the patient confidence.
- A happy, helpful environment with people & staff who are easy to talk to.
- Support to suit the individual needs of each patient, as well as medical treatment.

INTERNET ACCESS

Other young people

TEENAGERS’ ENVIRONMENT

SPECIALISTS

An age appropriate environment, shared with other young people (not adults or children). Some comments from young people were:

- Access to the internet and flexible visiting hours.
- I think it is really important that young people are treated like teenagers and not like children or adults.
- Teenage Cancer Trust is great, it’s a lot better than an adult ward.
- Being cared for in the right environment by specialist people.

SOCIALISE

Being able to meet other young people to socialise and for support. Some comments from young people were:

- Gives people who have suffered a chance to get their lives back by letting them meet new people and go to social events and activities in their local area.
- Young people on separate wards, together they can support each other, mind over matter - it really helps!
- Make sure they have a way to stay in touch with friends.

MEET OTHERS’ SOCIAL EVENTS

ACTIVITIES’ SUPPORT

STAY IN TOUCH

METAPHRASE

SUPPORT

SAFETY

COMFORT

LISTENING

INDEPENDENCE

SENSE OF IDENTITY

DIGNITY

Feeling safe, comfortable, cared for and respected. Some comments from young people were:

- Trying to be interested and understand the patient’s situation - care about them, take them seriously.
- People listening to you. Not treating you as invisible, but a person matters – NOT another Cancer Patient.
- Quality care is being supportive in a happy and jolly way, making everything as fun as possible and respecting everyone’s needs.
- Quality care is when a person has opportunities to be independent, respected and able to keep their sense of identity.
- Having my dignity, thoughts, feeling and decisions respected.

WWW.TEENAGECANCERTRUST.ORG
• Multi-professional
• Age appropriate – life changing
• Seeing the young person first; then cancer
• Equal access- trials, services, resources, drugs
• Policy
• Specific education for professionals
• Built Environment

The role of the nurse here?
## Core roles/themes in nursing competency framework

<table>
<thead>
<tr>
<th>Level</th>
<th>Competent</th>
<th>Experienced/Proficient</th>
<th>Expert</th>
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<tbody>
<tr>
<td>Definition</td>
<td>The competent nurse, plans and implements care based on conscious knowledge acquisition on a given issue.</td>
<td>The experienced/proficient nurse sees things as a whole rather than component parts, bases care on knowledge acquisition and experience and can set long term goals.</td>
<td>The expert nurse has highly developed analytical evaluation and decision-making skills based on experience, academic achievement and dissemination.</td>
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<tr>
<td>Examples</td>
<td>Staff Nurse in various setting eg community, designated centre, specialist centre</td>
<td>Clinical Nurse Specialist in TYA Cancer or Site Specific</td>
<td>Lead Nurse Nurse Consultant in TYA Cancer</td>
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<td>Ward Manager TYA Cancer Unit</td>
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<td>Nurse Practitioner in Chemotherapy</td>
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6 broad Competences
Independent and not hierarchical in order

<table>
<thead>
<tr>
<th>Competence 1</th>
<th>Competence 5</th>
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<tr>
<td>Demonstrates and applies teenage and young adult (TYA) nursing specific knowledge and skills in order to support the complex needs of TYA patients with cancer; through individualised care planning to address physical, psychosocial and spiritual/cultural throughout the cancer trajectory.</td>
<td>Contributes to nursing leadership in Teenage and Young Adult Cancer Care.</td>
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<th>Competence 2</th>
<th>Competence 6</th>
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<td>Demonstrates and applies the patient advocate role; working with and alongside Teenage and Young Adult patients, promoting patient empowerment to ensure patient views are central to all aspects of care, choice and decision making.</td>
<td>Demonstrates the need for professional development of self and others within teenage and young adult cancer care.</td>
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<td>The competent nurse, plans and implements care based on conscious knowledge acquisition or given issue.</td>
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<td>The expert nurse has highly developed analytical evaluation and decision-making skills based on experience, academic achievement and dissemination.</td>
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Mapped against
Using the Framework

- For use in a variety of settings
  - TYA Cancer specific – no other roles/functions

- Serves multiple purposes
  - Identify gaps in individual or teams competence/knowledge
  - Assist with developing new roles

- Multi method approach to assessment- direct observation, self assessment, feedback from others

- Evidence collation forms part of RN professional portfolio

- Support Teenage Cancer Trusts Nurse Education Framework
Teenage Cancer Trust Nurse Education Framework

**TYAC SPECIFIC-SPECIALIST**
- Eg TYAC CNS, Nurse Manager
- Specialist
- AHP or other role

**TYAC NON SPECIALIST**
- Eg Staff nurse on TYAC, Adult or Children's Ward, Hospice staff

**Occasional TYAC Contact**
- Eg POONS, Hospice staff, newly qualified staff, Non registered professionals

**Advanced education**
- Eg Post Grad Cert, MSc, PhD

**Specialist module**

**Training/Study Days/App**

**Staff groups in Number**

**Level of education and delivery**
Our Competencies........Now what?

• We believe they are transferable across the professional groups
• Pilot implementation in three UK sites all offering variation in service provision
• The wider oncology (adult and children's services), adolescent health, national and international communities are looking for guidance
• Connect with other alliances such as ENCCA looking at wider professional and medical competence
Lastly

Coming together is a beginning. Keeping together is progress. Working together is success.

Henry Ford

Learning with, from and about each other

Barr 2000,

Thank you to Sam Smith, Dr Dan Stark, colleagues and CanTeen

m.cable@coventry.ac.uk
A scoping exercise of favourable characteristics of professionals working in teenage and young adult cancer care: ‘thinking outside of the box.’


Box 1. Top key competencies for health professionals working in TYA cancer care

1. Expertise in treating paediatric and adult cancers.
2. Understanding cancer.
3. [Delivery of] appropriate information about the disease.
4. Bridge between TYA need for information and parental reaction to withholding information.
5. Giving mutual respect.
6. Good knowledge and skills about diagnosis.
7. Using team skills.
8. Having time to sit and talk/spend time with young people.
9. Helping young people express their emotions.
10. Involvement of siblings.
11. Not patronising.
12. Respect privacy.
13. Take the young person seriously.