Young People with Cancer and Hospital Care

how can hospital care promote wellbeing?

...from practice to research to practice...

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‘Young people with cancer – a small but in many ways a uniquely vulnerable group of cancer patients’

(Mike Richards, National Cancer Director, 2008)
Adolescence, young adulthood & cancer ...a ‘dual crisis’

- Identity
- Self esteem
- Peers
- Family
- Self image
- Self agency
- Purpose
The clash: interrupting transition

- The ongoing demands of illness fundamentally clash with the young person and family’s developmental trajectory of separation/individuation.

- From emerging independence to ‘infantile’ dependence: Young person and parents may retreat to the safety of the more known relationships associated with younger life stage.
Good outcomes are more than survival

**Life in the future…**

‘the ability to *mature successfully into adulthood*’ &
‘with increasing survival, the physical, emotional and social sequelae, which may impair the **quality of life** in the long term become more important’

(NICE CYP Improving Outcomes Guidance, 2005)

**Life in the present… a life worth living**

‘*You matter because you are you… you matter to the last minute of your life,* and we will do all we can **not only to help you die peacefully, but to live until you die**’

(Dame Ceciley Saunders)
Salutogenesis and Sense of Coherence

‘the total story of the human being in their social context, inclusive of their illness and psychosocial supports’ (Antonovsky, 1987:12)

**bio-psycho-social wellbeing**

*How to maintain wellbeing in face of adversity?*
SOC & wellbeing

SOC
Capacity for wellbeing & coping

Meaningfulness

Comprehensibility

Manageability
SOC & young people with cancer

- Comprehensibility
  - Manage uncertainty

- Meaningfulness
  - Maintain motivation

- Manageability
  - Access resources

TYAs
### Background to PhD Study

#### Teenagers & Young Adults with Cancer

- ‘young people with cancer are a small but uniquely vulnerable group of cancer patients’ *(Mike Richards, National Cancer Director, 2008)*

- ‘Dual crisis’: adolescence, young adulthood & cancer

- Quality of life, future life chances and successful developmental life stage transition compromised

#### Hospital Care

- ‘Age-appropriate care’ *(NICE, 2005)*

- Specialist units?? Philosophy of care??Multi-disciplinary practice??

- Patient-centred care? Family-centred care? Collaborative partnership care?

- Age-appropriate communication??

- Age-appropriate family involvement??

- Split between paediatric & adult provision
**Research Aim:**
to investigate the experiences of teenagers and young adults living with cancer, primary carers and multi-disciplinary professionals and examine how hospital care can meet young people’s changing needs promoting wellbeing in everyday life

**Research Objectives:**
- to examine the evolving experiences of young people living with cancer and the impact on their everyday lives
- to explore perspectives of hospital care which enhance wellbeing and promote resilience

**3 stakeholder groups:**
1. teenagers and young adults with cancer
2. primary carers
3. multi-disciplinary professionals

How can hospital care enhance young people’s wellbeing?
### A Qualitative Narrative Research Design

**Purposive Sample of Teenagers & Young Adults [TYAs](n=16):**

<table>
<thead>
<tr>
<th>Diagnosis:</th>
<th>Cancers necessitating significant hospital care</th>
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<tbody>
<tr>
<td>Excluded:</td>
<td>TYA with advanced cancer</td>
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<tr>
<td>Age:</td>
<td>8 young people (16-20 yrs), 8 (21-24 yrs)</td>
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<tr>
<td>Hospital Care Contexts:</td>
<td>Belfast City Hospital (adult)</td>
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<td></td>
<td>Royal Belfast Hospital for Sick Children</td>
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<td>Fieldwork:</td>
<td>6-9 months with each young person and carer</td>
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<td>Multiple Methods:</td>
<td>Semi-structured interviews (x3) (illness narrative; identity narrative; relationships narrative; care narrative)</td>
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<td>Written/Audio/video diaries (self directed)</td>
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<td>TYA Research Reference Group</td>
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**Carers (n=16):**
- Identified by & recruited with young participant
- Semi-structured interviews (x2)
- Carers’ Research Reference Group

**Multi-Disciplinary Professionals (n=15):**
- Professionals identified with experience of caring for young people
- Single interview with option of follow-up
- Professional Research Reference Group
Nuala (23 years)

A conveyor belt of old sick people

... (it) was like a conveyor belt – just people coming and going, and coming and going – and most of them were really old.......... yeah and they were sick, so they were, and I was just sitting there looking....
Nuala (23 years)

Assuming

- when you see people coming in who have near the same thing you have and then they’re fine one minute and they’re really sick the next minute, you just assume that it’s going to happen to you.... ...... in your head, I put 2 and 2 together and got 5, so I did....... you can’t figure it out in your head......
Nuala (23 years)

Wanting to ask but not wanting to ask

- no, I didn’t ask the nurse - I was going to ask the nurse but I didn’t want to ask at the same time because to be honest I thought she was dead

Being nosy

- ...... maybe the nurses would think maybe I was being nosy or something by asking so..
Nuala (23 years)

Comparing yourself –
you shouldn’t but you can’t help it

- you just assume that you’re the same as everyone else -
  I was comparing myself to everyone that came in.... you can’t help it, you just compare yourself to everybody – but at the same time, you shouldn’t be but you can’t help it
Nothing else to do

but you’ve got nothing else to do with your time, all you’ve got to do is sit there and think about things...........it was just me sitting on my own all day, basically, waiting until someone came to visit me....
Nuala (23 years)

I know I’m sick but I don’t feel sick

- aye well I know I’m sick like but... (pause)... not, no... sometimes, no you don’t see yourself as sick and then someone would say oh you’re not allowed to do that cause you’re sick, and then...Oh yeah, I forgot...not forget that you’re sick but almost like... – I know I’m sick, but I don’t feel sick
Nuala (23 years)

I know I’m sick but I don’t feel sick

- aye well I know I’m sick like but... (pause)... not, no... sometimes, no you don’t see yourself as sick and then someone would say oh you’re not allowed to do that cause you’re sick, and then...Oh yeah, I forgot...not forget that you’re sick but almost like......I know I’m sick, but I don’t feel sick

I’m lying half dead

- oh aye, yeah, probably —....... people think I’m just lying in here for months on end real sick, but I’m not ....... I think that they think I’m lying half dead, you know, can’t do nothing for myself
SOC

Managing uncertainty
Working it out on her own

Maintaining motivation
Doing nothing
But not ‘really’ sick

Accessing resources
On her own

Nuala
Elizabeth (21 years)

- ... when I first went into hospital .. its very shocking and you try to take everything in and your attitude is that you just lie here and do everything the doctor tell you because you don’t know what else you are meant to be doing.
Elizabeth (21 years)

- Yes that was the first. Because before that when I first went into hospital I think you sort of go in its very shocking and you try to take everything in and your attitude is that you just lie here and do everything the doctor tell you because you don’t know what else you are meant to be doing.

- And then after what happened to me in ICU, I just thought no, this is...Medically you know what is best for me, but in every other way I know what I need to keep going and from that day, any other time I have been in hospital, it has been my way whether they like it or not.
Partnership

- Integrate the patient and carers as partners and essential members of the healthcare team (NICE Supportive & Palliative Care, 2004)
- Supporting agency and participation

‘when others decide everything for us – when they set the task, formulate the rules, and manage the outcome – and we have no say in the matter, we are reduced to being objects. A world thus experienced as being indifferent to what we do, comes to be seen as a world devoid of meaning’

(Antonovsky, 1987)