PALLIATIVE CARE FOR YOUNG PEOPLE WITH LIFE-LIMITING ILLNESS: WHAT SHOULD WE BE TEACHING SPECIALIST PALLIATIVE CARE TRAINEES?

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BACKGROUND: ME

- Me
- Palliative care work and adolescents
- Adult palliative medicine
- Lurking
- H&D House

BACKGROUND: THE PROJECT

- Patient with epilepsy
- We don’t know what we don’t know

THE HIGHER SPECIALIST TRAINING CURRICULUM FOR PALLIATIVE MEDICINE 2010

- Recognise the principles of transition of care for teenagers and young adults between paediatric and adult palliative care services including knowledge of the differences between adult and children's hospices and the conditions they usually care for
- Know about the presentation, usual course and current management of common, life limiting, progressive illnesses in teenagers and young adults treated within paediatric palliative care who are likely to need adult palliative care services, such as Duchenne Muscular Dystrophy, Cystic Fibrosis

WHAT THE LITERATURE TELLS US

- HCPs avoid or withdraw from clinical situations for which they feel uncomfortable or inadequately prepared

PURPOSE OF MY STUDY

Objectives

a) identify the knowledge skills and attitudes necessary to provide good palliative and end-of-life care for young people

b) to make recommendations about curriculum change, if necessary

Aims

- to propose a curriculum that best prepares adult palliative care physicians to have the knowledge, skills and attitudes to provide excellent palliative and end-of-life care for young people
- to promote the development of a workforce that is willing and able to provide high quality care for young people in the future

METHODOLOGY

- Interviewed current ‘star performers’
- Semi-structured interviews using a topic guide
- Audio-recorded and transcribed
- Purposeful sampling for interviewees
  - convenience sampling
  - snowballing or chain-referral technique
- Transcriptions analysed iteratively using the grounded theory approach

RESULTS

- 2015
- 15 interviews
- 4 GPs, 4 paediatricians, 7 adult physicians (5 consultants in adult palliative medicine)

THEMES

1. Context
2. Challenges
3. Clinical care
4. Communication
5. Decision making
6. Planning Ahead

1. CONTEXT

Background

-Relatively new and unfamiliar population of patients

-Low volume high intensity work

Remember what we have is low volume high intensity work. Whereas the adult world is very used to high volume, to put it bluntly very straightforward and simple stuff…

1. CONTEXT cont.

Adolescence/young adulthood : impact of illness on the tasks of adolescence, development & maturation

…so they're losing physical skills at times when they should be acquiring independence

…they want some sex please, thank you very much

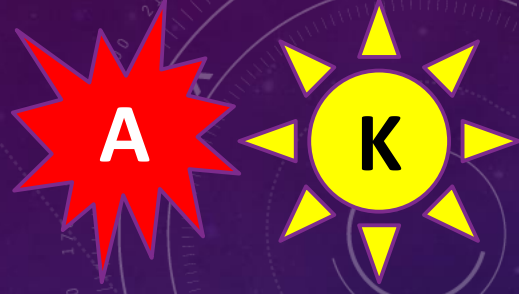
How do you identify your peer group when actually you can't go anywhere without your mum taking you? …

1. CONTEXT cont.

The whole person: employment, education, relationships, housing

…we need to start to look at them as adults and say, “Actually you have got a disability. Yes, it is life threatening but you should be at school. Why haven’t you done GCSEs? Why are you not doing A-levels?”…

2. CHALLENGES



What's gone before

- Contrast between the adult & children's sector
- Leaving children's services behind

…anxiety, fear and loss that both the children and families experience through the transition phase

"Oh they are not very nice in adult services, you won't know anyone, it is a bit tacky in outpatients, the paint is peeling off the wall, they haven't got all these nice colourful things."

2. CHALLENGES cont.

Healthcare: coordination of healthcare, emergency healthcare, role of the GP

..We are lovey-dovey, we are really soft and gentle and we are really nice people. So you go from an acute admission into a paediatric unit where the children will be known to the ward staff, might have been known for 10 or 15 years …Now you go onto an acute *(adult)* medical take. You get clerked in by the lowest common denominator, the basic houseman who takes one look at you with your all your disabilities, all your list of drugs and goes, “Bloody hell, I don’t know what to do.”

2. CHALLENGES cont.

Environment and staffing in the hospice setting

- Developmentally, age- and physically- appropriate environments
- Staffing ratios

…flexible about how we match our team to the needs of the individual patients …..we have a broad brushstroke one to one care, sometimes you need more than one to one…

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General approach

-Already have many of the symptom control skills

-Unfamiliar diagnoses

...not being terrified of the unknown...Okay, you don't know the name of the illness because only one in six people in the country have got this particular metabolic illness, but it's someone with a PEG (you have MND patients)... It's someone with BiPAP (you have COPD patients)…. It's someone who can't communicate very well (you have Parkinson's Plus patients). You can do all the skills. It doesn't matter what the label is…

3. CLINICAL CARE cont.

Symptom control: seizures, dystonia, spasms, reflux, constipation, secretions, psychological issues

Medical technology: gastrostomies, ventilation, tracheostomies, cough assist, feeding

Pharmacology: LBW, dosing, routes, side effects

When I give my talks I show up two slides. One is I say, "Symptom management in paediatrics is dead easy. I can teach anybody about symptom management in one day and it will fix 95% of problems." Then we have a second slide that says, "Children's palliative care is really difficult and requires expert multidisciplinary knowledge."

4. COMMUNICATION

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Parents/carers alongside the YP: family dynamics, involving parents/carers (parents as experts)

Still encouraging independence but still keeping them (the parents) on side is a key skill, I think…

…having an understanding of family dynamics or of understanding the importance of parents' views…

…the parents are experts and I'm very happy to listen to what they've got to say

4. COMMUNICATION cont.

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Adolescence

… an adult will generally be polite and go through the social mores and will tell you, “Thank you very much.” …A teenager will tell you to, “F*** off.” Or will just non-verbally tell you exactly whether they like you or not…

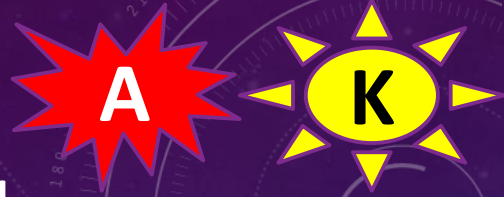
Young people less or unable to communicate: learning disability, non-verbal patients

…about feeling comfortable with communicating with all levels of communicators

Of course we can communicate with people. Of course we can do that, but actually, if you’ve not done it a lot with people with learning disabilities, you can’t necessarily do it well…

5. DECISION MAKING

- Supporting young person to be involved
- Change in parental responsibility
- Legislation: MCA, DOLS, best interests, LPA, deputyship



…when the young person becomes 18 and he goes into adult services the parents aren't parents any longer, they're just another important person to be consulted…warn the parents that…time and again, people will be checking out that the person has capacity or not…

6. PLANNING AHEAD

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Prognostication:

sudden death, Category 4 patients

…these young people, they'll collapse and die suddenly. They're so frail, they're maintaining a balance, but then they just tip off the edge

6. PLANNING AHEAD cont.

Advance Care Planning: DNACPR, Admissions Passports, Emergency Healthcare Plans

"How can you be a *(children's or young adult)* hospice and not have a DNR in place?" I said, "You don't understand these things then."

6. PLANNING AHEAD cont.

Quality of life judgements

…what judgement are you making on that young adult's quality of life? Are you the right person to make that judgement?

CONCLUSIONS

- Current learning objectives are unlikely to facilitate a workforce competent to provide excellent holistic palliative care to this relatively unfamiliar group.
- An understanding of the unique contexts of these YP and families as they graduate from children's services is required.
- Challenges and clinical skills were identified that should be considered for delivery of services and good clinical care.
- Distinct set of communication skills.
- A common framework for prognosticating, identifying palliative care need and supporting advance care planning in this group of YP is yet to evolve.

THANK YOU

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