

Healthcare professionals' views of young people transitioning from curative to palliative care

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“I don't see the point in measuring life in terms of time anymore. I'd rather measure life in terms of making a difference”
- Stephen Sutton



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Initial work

**Death, dying and emotional labour :
problematic dimensions of the bone marrow
transplant nursing role?**

Kelly D, Ross S, Gray B and Smith P (2000).

Journal of Advanced Nursing

Volume 32: 952–960.

‘They shouldn't say it's fine when it's not...’



Issues in transition to palliative care

- TYA patients often have to experience concurrent transitions which are accompanied by unmet needs (Kelly and Gibson 2008).
- Parents have reported experiences of perceived system failure, lack of communication, uncertainty and anxiety when young people requiring palliative/supportive care (Kirk and Fraser 2014).
- Research on patient experiences of transition has shown that more research is required to understand the dynamics of this process (Kralik, Visentin and van Loon 2006, Doug et al 2011)
- 2015 systematic review – ‘little is known about the potentially complex transition to palliative care’ (Gardiner et al. BMJ).

Feelings

The continued experience of awareness



Challenges in transition

A scoping review of transition to palliative care identified three challenges in the transition process to palliative care:

- 1) The nature of transition and what it means to patients varies.
- 2) There is often lack of time to prepare patients and their families.
- 3) There is lack of information regarding the goals of palliative care.

(Marsella 2009)

Existing research

Edwards et al (2014) JBI Review 30 studies.

Most involved medical case review or interviews with bereaved parents. Few trials, some cohort studies.

Lack of focus on staff perceptions

Culture of EOL care for young adults uncharted territory

Research questions

1. How do HCPs experience the transition process?
2. How do HCPs communicate within and between professional and lay groupings to effectively manage this process?
3. What are the particular needs to teenagers and young adults that HCPs need to meet?
4. How do HCPs manage the physical and emotional labour that TYA cancer care requires?
5. Are there particular areas of TYA cancer EOL care that require additional support?

Methods

- Semi-structured interviews with professionals involved in curative and palliative paediatric and adult oncology care
- 20 professionals recruited through professional networks: medical consultants, clinical nurse specialists, health psychologists, social workers, dietitians.
- Questions on experiences of transition, challenges and identification of training needs
- Interviews transcribed and analysed thematically
- Ethical approval provided by School of Healthcare Sciences, Cardiff University

1. How do HCPs experience the transition process?

- Acknowledged as ‘part of the parcel’
- Particularly distressing due to individual dynamics / associations are being made between patients and HCPs own children or young relatives (triggers include age, name, physical appearance)
- Managers commented on over-involvement by staff
- Difficult relationships with families can be an issue
- Strong focus on promotion of TYA autonomy

Issues with staff

'The most difficult part of the transition process is handling the distress of the professionals. Professionals find this extremely distressing, particularly inexperienced professionals. They cannot handle the relatives' expressions of anger, of feeling let down so they cannot provide consistent information anymore.' (Consultant in TYA oncology)

Issues with relatives

'Bad transition is a mess to solve. Patients are handed over to my service and they don't know that they are palliative. So first I explore what they know. Then I focus on easy things: pain relief and symptom control. Then end of life care.' (Consultant in Paediatric Palliative Care)

Letting go

- I think sometimes with our young people they find it, our team, our medical team in particular find it very difficult to discuss ending treatment, or limiting most other treatment options and this is particularly complicated because we have a phase one trial on inpatient service at the (hospital) so we get some young adults who are coming to us for phase one trials who are very, very sick but want still want to pursue, which is understandable. You understand why they want to pursue full active treatment for as long as possible and so sometimes the transition perhaps isn't as easy for people to completely solidly discuss because there's still this prospect of treatment.

2. How do HCPs communicate within and between professional and lay groupings to effectively manage this process?

- Main issues discussed in MDT so that all staff involved are clear
- Important to have good communication with GPs and community outreach teams to ensure seamless transition from hospital to community
- Sometimes it is difficult to get approval for additional resources for specialist TYA care from adult oncology budgets
- Paediatric teams have too many expectations of what adults teams can offer (esp when there is no designated TCT unit)
- Issues when hospice care is tailored to either to young children or the elderly

Communicating needs and managing expectations

'It is difficult to communicate and justify the additional needs of TYA patients to adult teams who see this group as a minority patient group. They do not understand why these adjustments and associated costs are justified.' (TYA Lead Nurse)

'Communication with paediatric teams can some times be an issue. Patients are not always referred early to the adult team so that a meaningful relationship can be established. Sometimes we also have difficulty managing parents' and paediatric teams' expectations which are not often realistic based on the workload of an adult team.' (Consultant in Adult Palliative Medicine)

The importance of timing

'Communicating with relatives during the transition phase can be a challenge. They may not be at the same space as you're that, they might not believe what you say, they might not hear what you say. Sometimes it takes many days, many weeks to have these conversations. [...] There is often discord between the patient and the medical team or even their family. As a nurse or a HCP our role is to be an advocate for the young person and to ensure that their best interests are served. I have certainly been in situations where the voice of the young person has been lost. ' (TYA oncology lead nurse)

3. What are the particular needs of adolescents and young adults that HCPs need to meet?

1. A good **relationship** with patient and patient's family can be difficult to achieve
2. Disclosure of information should occur at a **pace** that is appropriate for each individual case and not forced upon them because it suits clinical schedules
3. Patient and relatives' **expectations** need to be managed
4. Treatment shouldn't be disruptive to patients' **belief systems**
5. Managing parents when there is **disagreement** between TYA and parents on course of treatment
6. Parents can be **in denial** of what palliative care means (ie. lack of curative options)

Challenges

*'The **age** is always a challenge. You get very mature 24 yr olds and very mature 16yr olds. They decide what to do with the life they've got left very differently. And it's important for healthcare professionals to be able to listen to them and let them lead.'* (TYA Social Worker)

*'The biggest challenge in the transition phase is the clarity about the young person's **autonomy** to decide whether there should be more active treatment or not'* (Consultant in Paediatric Oncology)

A long time to die...

I don't know if the teenagers develop a great (unclear) on the ward and therefore find it difficult to not be on the ward and they can't imagine being in another setting so it can be really sad and especially if some of our young people have taken a very long time to die, obviously their hearts are strong and their lungs are strong and they don't die very quickly and that seems to be my experience then and that's really draining I think for all of us on the ward, all of the team. They're with us for such a long time and they're obviously having such discomfort and they're not having a great quality of life and sometimes of course they're still having quite intensive treatment but they're not going to get better but they don't want to not have treatment any more. So that can be quite exhausting and quite draining and quite sad

4. How do HCPs manage the physical and emotional labour that TYA cancer care requires?

- All HCPs mentioned experiencing different levels and forms of emotional burnout
- Psychological support was usually offered to senior staff members
- Some HCPs do not expect their work environment to provide bereavement support
- Coping mechanisms: good work-life balance, support from friends and family members, exercise, faith
- Becoming more resilient with experience

Making sense of burnout

'I think all professionals experience emotional exhaustion. If I wasn't able to experience this, then I would be selling my patients short. But the challenge for me is to find the right balance between being involved on a meaningful level, which is helpful, without interposing myself into someone else's life so that they become dependent on me. I have emotional scars that are still quite raw but these are injuries that I chose to make myself vulnerable to in order to help other people but I not want these injuries to be incapacitating so that I cannot help other people'
(Consultant in Paediatric Palliative Care)

'There aren't always support structures in the working environment to support staff and prevent burning out. I don't know how staff can bear doing this for a long time. It's hard, hard, hard stuff. You end up thinking that it's normal that young people die from cancer when it's not.' (Clinical Nurse Specialist in Palliative Care)

Summary: key issues

1. Communication between **adult and paediatric teams** and managing parents' expectations of care
2. Staff and patient experiences vary according to treatment pathway for **different types of cancer, strong relational elements to the work**
3. Difficulty in communicating **resources** needed for specialist care for this small group of patients with other adult oncology professionals
4. The concept of **autonomy** is TYA decision-making is understood very differently by different professionals
5. Limited **psychological support** and frequent reporting of risk of burnout. Personal reports of guilt and failure.
6. The nature of dying in young people is different.