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Teenage and young adult palliative and end of life care service evaluation

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Executive Summary

Background

The end of life support and palliative care experiences of teenagers and young adults (TYAs) and their families are often poor and vary widely throughout the UK, because neither paediatric hospice and palliative care services nor their adult equivalent are equipped to meet the particular requirements of this group. It is, however, vital that TYAs receive a service that is tailored to meet their specific needs. This evaluation has set out to examine the issues that affect the palliative and end of life care for this age group and to document best practice so that it can subsequently be made available to all who are in need of it.

Aims

The evaluation had two main aims:

- The primary aim of the evaluation was to establish current provision of palliative and end of life care provision for teenagers and young adults with cancer in Teenage Cancer Trust Units and how this relates to the wider care setting.
- The secondary aim was to develop a guide for good practice based on the experience of those delivering/arranging palliative and end of life care in the Teenage Cancer Trust Units.

Methods

The evaluation was carried out using a combination of questionnaires, observation and interviews with staff in seven selected Teenage Cancer Trust Units across the UK. Additional meetings and discussion with key personnel contributed to setting the study in a wider context.

Evaluation Sample

Seven Units were visited: Birmingham, Cardiff, Clatterbridge, Glasgow, The Royal Marsden, Southampton and University College Hospital London. A total of 23 professionals working with TYAs with cancer were interviewed and 23 questionnaires were completed.

Key Findings

Practice across the Units

- The policies currently in operation vary widely from Unit to Unit
- A TYA End of Life Care Pathway could act as the basis for more consistent policy and practice
- Such a document would need to be adaptable to local conditions but would still provide a framework for good practice
- Links with the palliative care team are important and should be established at an early stage
- A young person should be able to choose the unit as the place to die

The challenges of supporting TYAs at the end of their lives

- Transition problems from hospital to community-based care
- Lack of specialist paediatric palliative care services
- Lack of agreement between staff about allowing TYAs to die on the Unit
- The need to establish better communications between PTC and community-based services
- Insufficient TYA-specific hospice care
- Gap in services for 16-18 year olds
- The range of services may result in lack of clarity about the 'best' option

Training and resource needs

- An age-specific end of life care pathway
- Training in pain management and control for TYAs
- A specialist in TYA palliative and end of life care accessible at all times
- Advanced age-appropriate communication skills
- Pre-bereavement and bereavement support training
- Counselling training for staff where appropriate
- Emotional support for staff

- Training on how to maintain appropriate boundaries
- Reciprocal training opportunities for hospital palliative care clinicians and hospice staff

Examples of best practice

- Listening to what TYAs and their families want and need at the end of their lives
- Being flexible and adaptive within a set of guiding principles
- Commitment to providing care for TYAs in the place where they want to die
- Building strong links with other services both inside and outside the hospital
- Bringing SPC services in at an early stage
- Recognising families' possible continuing need for contact and support after bereavement

Recommendations

- A dedicated TYA end of life care pathway is needed as a framework for use across all TCT Units though it must be flexible enough to accommodate local conditions.
- There is a need for consistency both within and between Units in terms of their policy on end of life care – again allowing for local conditions
- A specialist in TYA palliative and end of life care needs to be accessible at all times
- Strong communication needs to be established between the TCT Units and other care settings
- The problem of community based care for 16 -18 year olds needs to be addressed
- Additional training and resources are needed to support staff who are more used to the treatment of TYAs than to their end of life care
- The ongoing needs of bereaved families need to be considered and addressed
- Staff training for pre-bereavement and bereavement support, communications etc.
- Records of preferred place of death and actual place of death for each patient who dies should be collected from Units annually

Abbreviations

ACT – Association for Children with Life-threatening and Life-limiting Disease

CP – Care Pathway

CYPOSST - Children and Young People's Outreach and Symptom Specialist Team

DGH – District General Hospital

EOL - End of Life

MDT – Multi Disciplinary Team

PATCH - Paediatric Palliative Advice for Care at Home, Hospice or Hospital

PCT – Primary Care Trust

POON – Paediatric Oncology Outreach Nurse

PTC – Primary Treatment Centre

SHO – Senior House Officer

SPC – Specialist Palliative Care

TCT – Teenage Cancer Trust

TYA – Teenage and Young Adult

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Teenage and young adult palliative and end of life care service evaluation

1. Background and context

Teenage Cancer Trust has been developing specialist services for teenagers and young adults (TYAs) with cancer in principal treatment centres throughout the UK for 20 years. For those young people who do not survive their illness, the end of life and palliative care experiences for them and their families are often poor and vary widely throughout the UK. This is because neither paediatric hospice and palliative care services nor their adult equivalent are equipped to meet the particular requirements of this group, thus it is vital that they receive a service that is tailored to meet their specific needs. However, numbers are relatively small; while 2,100 new diagnoses are made every year, nearly 75% will survive their illness (TCT Factsheet, 2010), thus the provision of dedicated resources for end of life care in every area might be difficult to achieve and may not be cost-effective. It is therefore essential that models of service are explored to determine how best to provide improved services for this poorly supported group once treatment is no longer curative at the end of their lives.

2. What is palliative and end of life care?

Clark and Wright (2003) provide a summary of the WHO's (World Health Organisation) definition of palliative care as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;

- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling and support, if indicated;
- Will enhance quality of life, and may also positively influence the course of the illness;
- Is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

(Clark and Wright 2003: 1-2)

While terminal, or end of life care, is not the same as palliative care, palliative care can include terminal care (Benini *et al* 2008) Field and Behrman (2003:34) suggest that 'end of life care' is used to describe the care that focuses on the preparation for a death that is anticipated, and that together palliative and end of life care should promote clear and culturally sensitive communication, in order to help patients and families understand the diagnosis, prognosis and treatment options available.

3. Place of death for young adults with cancer

In an epidemiological study of 3,197 children and young people with cancer, Higginson and Thompson (2003) found that there are a relatively high proportion of home deaths. While the figures gives us some idea of where children and young people with cancer die, we can gather little about how – or even if – a choice was made. However, there are some studies which address the more qualitative issues surrounding end of life care and place of death. According to Contro *et al* (2002) families tend to be dissatisfied with communication with health professionals at the end of life and feel that their wishes are disregarded. Montel *et al* (2009) argue that communication difficulties with health professionals or within the family are factors that are likely to interfere with choice of place of care at the end of life.

The first study on place of death for young adults with cancer in France was carried out by Montel *et al* (2009) examined the factors that influence the choice of place of death in TYAs with cancer. As these authors say, it is essential to carry out such research in order to meet the needs of the young patients and their families at the end of life. Of the twenty-one young people in the study, nineteen died in hospital and only two at home. Montel *et al* attempted

to identify the determinants of choice of the place of death. Ninety percent of the families said they had not felt that they actually 'chose' the place of death, but would nevertheless have chosen the hospital where the death did in fact take place had they had a choice. Thus they were not expressing dissatisfaction with the service but with their lack of options.

The training needs of doctors supporting young people at the end of life are addressed by Sheetz and Bowman (2008) who suggest that the proportion of physicians who feel competent in giving difficult news to families is high at 74% while their confidence in managing end of life symptoms is low at 23%. However, few physicians are interested in obtaining additional training, and are more likely to refer their patients to a palliative care consultant. This, as Sheetz and Bowman say, argues in favour of hospital-based palliative care teams and for specialty training in paediatric palliative care.

Given the relative paucity of information on the experience of providing palliative and end of life care for TYAs with cancer, and the clear need for training as evidenced by Sheetz and Bowman (2008), this Report hopes to add to the body of knowledge by:

- evaluating the current provision in the specialist TCT Units
- documenting the challenges of meeting the care needs of the TYAs and their families
- identifying models of good practice for wider use.

4. Methods

The method of investigation was in-depth qualitative interviews with key staff in the seven selected Teenage Cancer Trust Units; these interviews were followed up with short questionnaires to capture any additional material that the participants wished to contribute. In total 23 interviews and 23 questionnaires were undertaken on the Units with:

TYA Clinical Nurse Specialists and TYA Nurse Consultants¹, a Senior Ward Sister, a TYA Staff Nurse, a Consultant in Paediatric Oncology and Palliative Care Lead, POONs nurses (Paediatric Oncology Outreach Nurses), CLIC Sargent Social Workers, a CLIC Sargent Clinical Psychologist, TYA Clinical Lead Nurses*, a Lead for County Cancer Network, Palliative Care Team Leader /Consultant in Palliative Medicine, Activities Co-ordinators, an Occupational Therapists, a TCT Professional Nursing Lead and Regional Development Manager, Head TCT Nurse/Ward Manager and a Children and Young People's Macmillan Clinical Nurse Specialist for Outreach and Symptom Care, and a TYA MDT Co-ordinator.

Visits to the seven Units allowed the researcher to absorb the atmosphere and ethos of the care setting and thus also to use some observational methods. Informal discussions with staff during visits to the Units also provided valuable background information and understanding of the issues and challenges of offering appropriate end of life care for the age group. The researcher also attended a TYA Palliative Care Steering Group meeting at one Unit, and an MDT Meeting at another Unit. The Report is based on the results of both the questionnaires and interviews; however the data have not been presented separately but are interwoven under themes and issues.

For the purposes of this report the Units are referred to by number to preserve anonymity but this National study included Units in England, Scotland and Wales; data gathering took place on the TCT Units in: Birmingham, Cardiff, Clatterbridge, Glasgow, Southampton, The Royal Marsden and University College Hospital. A Teenage Cancer Trust workshop day with key stakeholders and individual staff provided further valuable insight.

¹ These nursing grades are specific to a limited number of posts in the TCT Units, thus where quotes have been used from participants in these roles they have been presented as being from a 'nurse' to prevent the identification of individuals.

Findings from the evaluation

5. Practice across the Units

End of life care pathways and specialist palliative care support

Age specific pathways are being developed in some Units but are not yet finalised. Until such time as these new documents can be accessed and utilised, the hospital palliative care team can draw on one of a variety of *Supportive Care Pathway* documents. These are used at the end of a patient's life on most Units, but are not TYA-specific. Most participants reported that some version of an adult end of life care pathway was adapted and the range of pathway documents drawn upon includes:

- The Liverpool Care Pathway (LCP) (2010)
- The 'University Hospital Board's' (UHB) policy
- A pathway based on the ACT Guidelines (normally for neuro-disability)
- A children's care pathway adapted for use with the TYAs.

CLIC Sargent was reported as having its own pathway but as the Occupational Therapist from Unit 5 said "*We have curative pathways, rather than palliative care.*" However, the importance of a dedicated TYA end of life care pathway (TYA CP) was emphasised by a number of participants who spoke about such a document being in the process of development. The following comments show the importance attached to such a pathway:

"It's helpful to know what to do, the steps to do it in."

"It's helpful to know it's family-centred/driven."

"For whole-team debate about DNR [do not resuscitate], and acknowledgement of being close to the end."

"We've used the adult end of life care pathway twice now – we need to tweak it for TYAs."

"It's good for junior staff – they feel safer with guidelines."

“It gives staff confidence to know they’re following it.”

“It [will] allow us to educate not just the TYA service team, but also the Trust adult team.”

“Hospices should write their own pathways. It’s an aide-memoire for people, whether experienced or inexperienced: [it] triggers, what to consider, and when.”

These comments suggest that a TYA CP will be a document of central significance and as a nurse from Unit 4 said: *“It helps to establish how care will be delivered – and helps consistency between staff.”* However, a note of caution against over-reliance on a care pathway was offered by a nurse from Unit 5 as follows:

Policies and pathways have their place – but there’s always a danger: not everyone fits into a nice neat pathway. Pathways are fine, so long as resources are available.

Thus while the dedicated care pathway documents currently in development for TYAs are to be welcomed, they need to be accompanied by the training and resources (see Section 8) that will make them viable. In the meantime, in addition to adapting the LCP and other adult models, there was usually a link with the hospital palliative care team that could be called on for support when necessary with TYAs as the following quote shows:

The unit has links with the...Hospital palliative care team. There’s a TYA MDT [multi-disciplinary team] meeting...attended by a nurse from the ...[hospital] palliative care team... so they can talk early on to a patient and family about end of life care and pain relief. (Nurse: Unit 1)

While a nurse from Unit 7 acknowledged there was no written policy, she too emphasised the importance of the MDT in contributing to pathway planning for individual patients:

We don’t have one [written down]. We have the TYA MDT weekly [meeting] and discuss every patient who is diagnosed, on treatment or has particular issues. Then there’s an MDT about palliative care and end of life, jointly with consultants, OT, physio, Chaplain, speech and language therapist, psychologist, the relevant nursing team, the adult palliative care team and consultant, and the CYPOSS clinical nurse specialist.

However, while links with the hospital palliative care team and the MDT are of vital importance, this does not preclude the need for a specialist in TYA cancers nor a specialist pathway; as a nurse from Unit 5 said, what is necessary is: *“Dedicated TYA palliative care consultant time – we have a committed consultant, but not a TYA specialist, to reinforce the key worker role.”*

So it can be seen that while there may be no dedicated age-specific pathway document available in most cases, adaptive solutions have been found that draw on the input of the palliative care staff from the wider hospital and the inclusion of other professionals at the MDT meetings. Nevertheless, despite the importance of such a strategy, there is clearly a need for an age-specific end of life care pathway and the training required to implement it.

Where the TYAs die

It is apparent that deaths take place in a variety of locations and that local circumstances shape the options for patients in different units. For example, Unit 3's documentation shows the following distribution of where the young people receiving treatment in that region die: in 2009 across the area network there were 12 deaths of TYAs known to the unit: 5 at home, 1 in the unit, 2 in other hospitals, 2 in intensive care. In 2010 there were 13 deaths: including 5 at home, 1 in the unit, 1 in A & E, 3 in hospital intensive care, 1 in hospital. We can see from these figures that only one death took place on the Unit each year, yet we know from other Units that patients may wish to die there because that is where they feel safe. In contrast to Unit 3, the much larger Unit 5 had 10 deaths on the ward in a single year. Even so the Activities Co-ordinator from Unit 5 said that while their approach is *“family-led and -centred”* they nevertheless *“try to send the patient and family home once they are no longer curative”*. This was further elaborated by the Occupational Therapist on the same Unit who said: *“Some will die here, after being at home, and end their life on the unit. It's not what it's for, but it's their only option”*

While the Units are primarily treatment settings, a nurse from Unit 2 said: *“If here is where someone wants to die, we should pull out all the stops.”* One Unit indicated its flexible approach to accommodating a death there for those who wish it, because they know the staff and are familiar with the Unit, as follows:

The end of life care policy is not specific to the Unit. End of life care and palliative care in an acute setting is very limited. They trust us here, feel safe, may have been

here for two years... We do what's appropriate, rather than what's written down.
(Staff Nurse: Unit 1)

A similar response was reported from Unit 4:

Patients' informed choice: whatever the young person opts for. Their opinions are always [considered]. Home, hospice – if appropriate, medically - or on the ward. We've had 2 [die] on the ward in the last 10 months. (CLIC Sargent Social Worker)

However, these comments contrast starkly with a contribution from Unit 3 suggesting a reason why the number of deaths on that Unit was so low:

A model has been established, and we should fit in to that to ensure young people's needs are met. For instance, do we allow them to choose to die here, or follow the protocol of getting them home? The Teenage Cancer Trust is about pain relief, preferred place of care, not about death. (CLIC Sargent Social Worker: Unit 3)

The contrast between the comments from Units 1 and 4 and from Unit 3 clearly reflects local conditions, culture and policy. There may also be differing perceptions within the Unit, as other participants from Unit 3 said:

TYAs are asked where they'd like to be at the end of life: home or hospice. Dying on the ward is not typical, but it is an option. (CLIC Sargent Clinical Psychologist: Unit 3)

We establish where a young person wants to be, and facilitate that... perhaps away from the hospital. But young people [may want to die here] because it's very friendly in a teenage unit, unlike on an adult ward, and they have rapport with staff, so there's not the drive to get out. (Lead Nurse: Unit 3)

Ensuring that the patient's voice is heard is crucial as they may have individual reasons for their choices for end of life care, which may conflict with their parents' wishes. As the Lead TCT Nurse from Unit 6 said:

It's still in formulation, but it's the patient's choice: at home if they wish. Some may want to end their last days on the Unit, and we can facilitate that, too... What the patient wants is the most important – and that can be very different from what the parents want. We have to tread carefully. We had a recent case of a young man who

was frightened to die at home, because he had memories of his grandfather dying in the room his parents had prepared for him. (Lead TCT Nurse: Unit 6)

Responses on how a specialist Pathway would help provision is summarised as follows by comments from Unit 3:

- *Clearly establish roles*
- *Structure the approach to end of life care,*
- *Provide guidance around avoiding previous difficulties*
- *Improve communications between professionals*
- *Give confidence in consistency of practice, and uniformity of care.*

We can see from the preceding evidence that the range of services and the difference in staff expectations of what it is reasonable to offer in terms of end of life care varies widely across Units. It is for this reason that a gold standard TYA-specific end of life care pathway implemented across the Units would assist in clarifying the process. However, as resources or facilities may be restricted in some Units and geographical considerations may also affect local implementation, a specialist EOL Care Pathway for TYAs would need to offer a framework that could be adapted to meet local requirements, conditions and constraints.

Summary

The following issues were raised in relation to what Units can provide to TYAs at the end of life:

- There are currently very dissimilar policies being operated in different Units
- A TYA specialist end of life care pathway could act as the basis for more consistent policy and practice
- Such a document would need to be adaptable to local conditions but still provide a framework for guidance
- A young person should be able to choose the unit as the place to die
- Links with the palliative care team are important.

6. The challenges of supporting TYAs at the end of their lives

It was clear from the evaluation that there are a number of challenges to providing age-appropriate end of life care for TYAs with cancer. Some respondents attributed this to the lack of a specialist paediatric palliative care service. In one setting, despite access to a palliative care consultant and Macmillan nurses, this lack of specialist services was perceived as problematic, as those working in adult services could consider TYAs 'too young' for palliative care. As a nurse from Unit 7 said: *"My biggest issue is that adult services don't know about paediatric **practice**. For instance, feeding tubes for children in a home setting, for their meds and food."*

Transition from paediatric care could also be problematic, in contrast to what was perceived as a more seamless process for young people with cystic fibrosis. For those TYAs who do not die on the Unit, there was concern that communications with other services can break down and the following issues were raised:

- Hospice care can be experienced as inappropriate, as adult hospices are not used to the age group and children's hospices care for few cancer patients.
- Dying at home can be a frightening experience, and was described by the Lead Consultant in Palliative Medicine from Unit 2 as being *"outside the Primary Care Team's comfort zone."*
- There was a suggestion that community-based teams could be traumatised by the death of a TYA with cancer, putting yet more pressure on the family.

These anxieties suggest that once the TYA has been discharged, the PTC has little further input. The lack of communication that can ensue after discharge from the Unit was a matter of concern for a nurse from Unit 7 who said: *"We had a young person who died, and we didn't hear from the hospice team for ten days – the day of the funeral. It's the CNS's responsibility to communicate this – and it didn't happen."*

There was an additional concern that community-based services can fail 16 -18 year olds who 'fall through a gap' between them. This was identified by a number of participants including the CLIC Sargent Clinical Psychologist from Unit 3 who said: *"There was a lack of community support after discharge, it fell short of expectations"* and similarly the Nursing Lead from Unit 6 said: *"Home, hospital, hospice if appropriate – but not 16 – 18-yr olds."*

The discrepancy for this particular age-band was summed up as follows by a nurse from Unit 7:

There's still a debate about 17-year olds. They are often outside children's services but not old enough for adult services. So we twist the arm of the children's services – or we work very closely with the district nurses. Young adults (20+) in adult services are discharged and their palliative care is provided by the local hospice. 17-year olds fall out of both camps.

The Paediatric Oncology Outreach Nurses (POONs) can enable young people to die at home. However, in the catchment area of Unit 6, 16 – 24-yr olds have only one specialist outreach nurse, so some may choose to, or need to, die in hospital. The Ward Manager confirmed that of 12 deaths in 2010, 4 were on ITU, 4 at home, and 4 in the TCT Unit – 3 of whom wanted to be at home, but lacking facilities in a community setting stayed in hospital, suggesting that while there is a clearly identified problem for 16 -18 year olds it is not confined to this age-band. As she said:

We're a victim of our own POON success – but we now need to start working in conjunction with the hospices. I thought about replicating POONs with TYA support nurses, but the young people don't fit that model. (Nurse: Unit 6)

While there may be a number of options for end of life care, the complex range of services may create confusion and uncertainty, as we can see in the following quote:

Young people have a choice about their place of care. We can refer them to the community Macmillan nurses to make them aware of the change of treatment emphasis. In the event of death, they can (a) remain at home with Macmillan support, (b) go into an adult hospice (because there are no TYA beds), or (c) they can die here. One lad died here suddenly [recently] within 48 hours. Another patient went home, then asked to be readmitted [to the unit] – but ended up dying in a local hospice. (Nurse: Unit 1)

The options at the end of life may suggest that young people have a choice, but death can take place unexpectedly, readmission on request may not be possible and services may be unavailable for either age-related or geographic reasons. There was also recognition that hospice care may be problematic; as a CLIC Sargent Social Worker from Unit 2 said: “Young people are terrified of hospices for older people. We don't want [TYA palliative care

services] centralised - people want to be close to home.” The following comment from a nurse from Unit 3 further illustrates the challenge of finding appropriate provision on discharge from the Unit:

Scrap the ridiculous situation of under-16s in the community, and 18+ going to adult services! It leads to begging for paediatric services. There are not enough TYAs to warrant TYA community services. If money were no object, [we need] specially-trained TYA nurses in the community to provide the same level of care at home. They would have met the young person in hospital to build up a relationship. And consistency of staff visiting young people at home – not a different person every day.

Further problems after discharge were identified by the Occupational Therapist from Unit 5 who said:

Realistically, often a local case [will die] at home, or in a hospice, but there are problems because 16 – 18 yr olds, and those over 13, may not belong to a local service. If they are offered a place in an adult hospice, it can be a complete nightmare.

The concern over the inadequacy of community-based services was expressed by a number of participants and contrasted with the skill with which end of life care and symptom control is now managed in the hospital setting. A nurse from Unit 5 said staff need to be honest with parents about the limitations of the support they could expect in the community. These challenging issues may be exacerbated in cases where the TYAs have additional problems to manage; this was recognized as a difficulty by a CLIC Sargent Social Worker from Unit 5 who said:

There’s a real gap for older teens and younger adults. For instance, we have a 20-year old with learning disabilities - like a 5 to 6-year old. She would be better in a children’s hospice, but was only offered a hospice for the elderly.

Other social or psychological issues unrelated to their cancer may also make the sourcing of suitable care problematic. As a nurse from Unit 5 said:

People make assumptions that all our young people were upright members of society before they got cancer – that’s a bit naïve! A patient came in to die, and asked for his

probation officer... These are still young people, and we ignore these issues at our peril. We need to be far more realistic.

While the opening of new Units for TYAs is to be welcomed, the increase in the workload for some staff can be immense, as a CLIC Sargent Social Worker from Unit 3 said: *“My work’s trebled since the [new] TCT unit opened: I’m firefighting... The new social worker will allow me more time, and we’ll be able to split the Network between us.”*

Respondents mentioned other challenges to the effective support of TYAs at the end of life, which are summarised as follows:

- *The need to be sensitive to cultural and religious practices*
- *The slowness of obtaining equipment at the end of life, described as “a postcode lottery”*
- *Identifying the most appropriate professionals to support the TYAs and their families*
- *Problems can arise when parents will not ‘give in’ or a patient does not believe no more can be done.*

Summary

The following issues were identified as challenges to providing end of life care:

- Transition problems from hospital to community-based care
- A lack of specialist paediatric palliative care services
- A lack of consensus between staff about allowing TYAs to die on the Unit
- A breakdown in communications between PTC and community-based services
- Unsuitable hospice care in both paediatric and adult settings
- The gap in services for 16 -18 year olds
- The range of services may result in lack of clarity about the ‘best’ option.

Case Studies

During the course of the interviews a number of cases were described that demonstrate some of the challenges addressed in this section. The two examples from Unit 3 presented below illustrate the effect end of life care can have on the patient, their family and the staff when a clear end of life care plan or pathway is not in place:

Case 1:

In this instance the CLIC Sargent social worker saw the patient on the Friday morning, prior to her having a scan which showed “whiteout”, indicating imminent death, so a rapid discharge was arranged for that afternoon. The social worker, however, was unaware of the scan results and so was not involved in the arrangements. The patient left the hospital at 4.00 pm, arriving home at 10.00 pm, leaving the mother to cope alone until her daughter died at 7.00 am next morning. Comments on the case from team members are as follows:

There was a rapid discharge on a Friday evening, involving the PCT [and the hospital] – but it went to pot. [The patient] died at home before anyone from the community team had visited. It’s still under investigation. (MDT Co-ordinator)

Her Mum promised her “no pain” – but she didn’t get home until 10.00 pm. I think this was an unsafe discharge. (MDT Co-ordinator)

[The social worker] wasn’t aware she was at the end of life, so couldn’t offer appropriate support. There was a meeting of all the professionals after the patient’s death a few weeks later, to reduce stress to the family. (CLIC Sargent Clinical Psychologist)

There was, however, one positive outcome: the patient’s mother expressed a wish to the social worker to open a CLIC Sargent shop in her daughter’s memory, and this eventually happened, the first CLIC Sargent shop in the area.

Case 2:

In contrast to Case 1, this account relates to a young man near the end of life who wished to die on the Unit. While his wish appears to have been agreed, it is clear that not all staff were comfortable with this state of affairs. The following quotes show staff members' concerns and reservations about whether this was indeed the best option for the young man, his family and other patients.

A young patient came in, in November, with spinal cord metastases - he wants to die here. It's brought up issues of how professionals respond, the week-to-week management [of his case]... If this sets a precedent we need to be sure we have the right things in place. (CLIC Sargent Social Worker)

This patient has an agreement with the Trust to stay here till he passes away. There's been lots of discussion: should he have this when there are hospices nearer home? He feels safe here... Staff tried to get him a home visit, but it didn't happen. He's been here since the end of September. It's made the Trust and the team look more carefully at the question: if you do it for one, do you do it for all? ... [In my view] he should have gone to a hospice, because we only have 4 rooms. (MDT Co-ordinator)

When the CLIC Sargent Social Worker was asked how he regarded allowing this young person to stay on the ward as his preferred place of care, he said he did not believe this was best practice:

We're trying to find our place in relation to the hospital. [The Lead Nurse] made a decision about the young person dying here. My concern is that we may not have the resources to enable him and his family to have a good experience. We've not challenged him about this choice. His parents are saying we should [all] do what he wants. His Mum is distressed – when's he going to die? First they had to get through Christmas, and it's his twenty-first birthday next month... He's withdrawn from the world, waiting to die. He needs to be treated with equity to older people. (CLIC Sargent Social Worker)

These two case studies raise very different issues but both demonstrate that wherever the death takes place, adequate resources need to be available, effective communication between services must be in place well in advance of the death, and an end of life care plan for that young person is required, taking account of personal factors and the local context of care.

7. Training and resource needs

It was clear from the findings that there are a number of training and resource needs associated with offering palliative and end of life care to TYAs with cancer. Some of these were raised in Section 5 in relation to the need for a specialist end of life care pathway. While there are pathway models designed for adults, there was nothing available specifically for TYAs whose needs may be very different. Once the model currently in development (see Section 5 above) is available, it will contribute to addressing the expressed concern that there should be standard practice across the country. In the interim, a number of comments on the need for a pathway model were expressed by concerned staff, for example: “A protocol specific to YPs would be useful, with pathways for pain management, sedation etc.” (Staff Nurse: Unit 1). Yet as the Nursing Lead from Unit 6 said, the introduction of a TYA Care Pathway brings with it training needs: “There’s an issue with staff training – one member of staff felt ‘fewer interventions’ meant not doing much at all.”

Education and training in the management of end of life care symptoms and the need for dedicated embedded specialist palliative care posts was thought essential – as evidenced in the quote from a nurse from Unit 5 (see Section 5). While commitment is important it is not enough – as the Consultant in Palliative Medicine from Unit 2 said: “[We need] people with dedicated time – not just passion and enthusiasm. The secondment for a year of [the Palliative Care Clinical Nurse Specialist] has helped. I’d like to be seconded, too”.

There was also an expressed need for specialist staff to be available out of hours as end of life care pain control and symptom management can be difficult for SHOs because of their relative lack of experience. Although concern was expressed about this lack of experience, the staff nurse who mentioned the problem acknowledged that staff could phone the ‘TYA doctor’ at home ‘even at midnight’ if necessary.

Other staffing issues included possible shortages; as a nurse from Unit 1 said: “there [might] be only one nurse on for the eight patients – though we can borrow staff from the adult ward.” The Lead Nurse from Unit 6 also mentioned staffing levels as an issue: “if someone’s palliative, you need to free up your time to talk, sit with them. You don’t want them to have to wait for anything. It stretches staff. And facilities don’t lend themselves – in one cubicle I had four camp-beds for the whole family!” This participant also said a bedroom or a sitting-room big enough for the whole family was needed as current accommodation in two flats available to parents was not suitable for small children.

Other suggestions for additional training and resources reiterate some of the points above:

- *If they can't be at home, they need an adult hospice – and they need to improve TYA care.* (Lead Nurse: Unit 4)
- *The education programme here for TYA cancer doesn't include palliative care. Macmillan nurses have attended, but no GPs yet.* (Lead Nurse: Unit 4)
- *Money for age-appropriate hospice accommodation. And money to give families in this situation, over and above the initial CLIC Sargent compassionate grant of £300 after a death, for funeral expenses. It'd be good to have a pot for "Let's do what YOU want".* (CLIC Sargent Social Worker: Unit 4)
- *Funding for equipment.* (Occupational Therapist: Unit 5)
- *Flexible staff, as more than one patient [could be] dying.* (Occupational Therapist: Unit 5)
- *Protocol for the patient, outwith the MDT, once they are no longer curative.* (CLIC Sargent Social Worker 2: Unit 5)
- *We could do with two more outreach nurses, to link in to everything else out there. If I'm sending a young person home, [I know what they're likely to get].* (Head Nurse: Unit 6)
- *Another palliative care consultant - someone who's interested in TYAs.* (Lead Nurse: Unit 7)
- *I'd like another nurse on the team – particularly for the 20+ age-group. And a research person: for symptoms and the service generally.* (Lead Nurse: Unit 7)

Not only do the TYAs have specific needs; so do the staff who care for them and a number of concerns were expressed about their support needs. Emotional support was found to some extent to be provided between team members, but there was also a more formalised need for clinical support. As a CLIC Sargent Social Worker from Unit 3 said:

[There have been] distressing deaths – a young person came [in] already at the end of life, and died within a week. It threw people completely, including staff: the "journey" was compacted into a week.

Similar concerns were expressed by the Nursing Lead from Unit 6 who said:

The lack of experience of some staff, especially those from a paediatrics background, [has] caused them distress both during and after the event. They're outside their comfort zone. And it's not a hospice... [It's] open, and a TYA-friendly ethos – but

palliative care in that setting: you're on show when distressed. It could be good for parents and young people – but can be difficult for staff.

Interestingly, this quote makes the distinction between acute hospital care and a hospice, and clearly in this case staff confident in offering the TYAs support during treatment do not feel they have the skills to do the same at the end of life. There was a concern that some staff becoming over-involved with the patients can be problematic. As a CLIC Sargent Social Worker from Unit 2 said: *“It’s worrying: they want to be [the patient’s] friend. Many nursing staff get over-involved with younger patients, want to be their friends, get too involved and over-emotional.”* The Lead Nurse from Unit 5 said that clinical staff would benefit from pre-bereavement and bereavement support training to address this issue.

The need to keep developing and building skills was thought important and among the list of training needs identified in several settings were:

- palliative and end of life care advanced communication skills
- assessment of needs
- pre-bereavement and bereavement support skills
- disease management and pain control
- group-work facilitation skills
- training in teamwork dynamics
- training and awareness-raising with others: community networks, hospices
- service development training for working with hospices
- support to attend conferences, as keeping up to date is regarded as a necessity

While a Senior Ward Sister from Unit 1 said she would benefit from both pre-bereavement and bereavement support skills, a nurse on the same Unit said she would benefit from palliative and end of life care training, but did not feel counselling skills were appropriate. As she said: *“I wouldn’t want the boundaries to be crossed – as a nurse, I would refer [a patient or family member] to a counsellor.”* Nevertheless, a nurse from Unit 5 pointed out the difficulties of truly understanding what a bereaved family was enduring in terms of their loss, the implication being that clinical staff need counselling skills to support the families:

Why do we think we know it all, when we haven’t been through it? Bereavement support is expensive – but incumbent upon us. Good supervision is the key, for staff getting involved in [this aspect of the work]. Is there something we can do, be bold?...

The team wants to believe a family's fine...we [need to] find a space to talk about the reality, rather than what we want to believe...

Summary

The following training and resource needs were identified:

- An age-specific end of life care pathway
- A specialist in TYA palliative and end of life care accessible at all times
- Training in pain management and control for TYAs
- Advanced age-appropriate communication skills
- Pre-bereavement and bereavement skills training
- Counselling training for staff where appropriate
- Emotional support for staff
- Training on how to maintain appropriate boundaries
- Training in group-work and team-work skills

8. Examples of best practice

We're aiming towards a model of best practice. It depends how we define best practice. For me, it's the gold standard: [this is] a new Unit and [we're] bringing together paediatrics and adults. We're looking for best practice in both areas, to incorporate into TYA best practice. (Lead Nurse: Unit 6)

Examples of best practice were offered by some of the Units where there was greater experience of supporting TYAs at the end of life. The philosophy was “*Getting patients to where they want to be: physically, mentally and socially.*” (Palliative Care Nurse: Unit 2), which included allowing the young people to die where they wanted. As the CLIC Sargent Clinical Psychologist from Unit 3 said, gauging how much input a family wants and tailoring input to their needs is also important: letting them know support is available as, when and how they would benefit from it.

From a practical point of view, providing the best experience for the TYAs required excellent links between the TYA team and the specialist palliative care (SPC) team – where this works it was described as “*More than the sum of its parts*” with all clinicians sharing an electronic patient record, described by a Consultant in Palliative Medicine from Unit 2 as being “*very joined-up*”. A Lead Nurse from Unit 3 emphasised the importance of a palliative care team who recognise TYAs’ needs and attend the MDT meetings, while the TCT Team also attend Palliative Care Team meetings. A CLIC Sargent Social Worker in the same Unit said continuous communication, integration and co-working with the allied healthcare professionals such as physiotherapists, dieticians and occupational therapists could improve planning and resources, especially at the end of life. The need for good communication was taken one step further by the TCT Professional Nursing Lead from Unit 6 who discussed the possibility of reciprocal training as follows: “*working with hospices on a training exchange, especially if we start using hospices - and it'd be an education for them!*” If this was established as a mutual exchange the resource implications could be minimal yet deliver significant benefit for both parties.

With the co-operation of a wide variety of professionals, including the ambulance service, pharmacists and district nurses, getting a patient home to die can be achieved in as little as 4 hours, thus demonstrating that collaboration and co-operation between services both within and outwith the hospital makes the logistics possible. Once the TYA has been discharged and is living at home, equipment is likely to be required; however an

Occupational Therapist from Unit 5 indicated that her role extended beyond arranging equipment such as stair-lifts or hoists, to include more personal support:

I may put equipment in at home and I help them with positioning, pressure care, and tasks like writing, looking at photos. Families may not want equipment, so we talk things through. I do what I can even if there's no future.

It was also thought important that the SPC service was involved early in the process to help build “relationships between them and patients, and help in alleviating the fear sometimes associated with palliative care.” (Nurse: Unit 2) The terms ‘strong links’ and ‘communication’ kept recurring, referring both to the links between the TYA and SPC teams and to services outside the hospital. This was summed up as follows:

Communication is key! Linked-up working, someone as the key worker to link everyone, our team providing education in EOLS with young people, we offer support to district nurses who're upset etc. (CLIC Sargent Social Worker: Unit 2)

There may be a need to communicate with a variety of services, for example, in Unit 3 staff were caring for a young person in homeless accommodation where there was concern about how to support him at the end of his life. As a result the CLIC Sargent Clinical Psychologist said: “three clinical staff in the team put together an informal training package for the staff there.” Outreach work can also be extended to other hospitals in the region, as was reported in Unit 4 where 2 Clinical Nurse Specialists advise staff in non age-specific care settings about the needs of TYAs.

The Clinical Nurse Specialist from Unit 7 identified additional ways their 24-hour support service liaises with local services:

There's a Multi-professional Operational policy on the hospital intranet, which I review and update every day. And we have the PATCH [24-hr telephone advice] service. We have 3 years' funding for this out-of-hours service, which gives phone advice to families and professionals, wherever the patient is. Once the medical decision has been made that a patient is no long curative, PATCH kicks in, and we arrange to meet with local services.

The involvement of patients can also be empowering, as the CLIC Sargent Social Worker at Unit 4 noted:

There's an ethos behind CLIC Sargent guidelines which includes user participation. For example, there was a patient on the interview panel for the new social worker here. And CLIC Sargent send out questionnaires to families after treatment, for service-user feedback.

Other suggestions for best practice included:

- Successful transitioning to adult services
- The need for flexibility and sensitivity
- Choice of place of death, and to feel supported with all relevant information
- A joint supportive MDT approach
- Ensuring the family is offered support following an assessment of their needs
- To be both patient-centred and family-centered and to follow the individual's wishes as much as possible
- Recognise that a good death is not necessarily a textbook death
- A Mortality/Morbidity Meeting (M&M) after the patient's death, which is minuted to record what needs to change.

There was however a suggestion from a nurse from Unit 7 that a model of best practice needs to be flexible because 'one size does not fit all'. Explaining why she would resist a uniform model she said:

...because each case is so individual. We have principles... Working with the patient: they lead if they want to. If not, we work with the family or whoever the patient delegates. For example, we have a 17-year old young woman who knows she's dying, but doesn't want to talk about dying. So the consultant will go to her home, and the patient will give her mother the questions. The patient is upstairs until the conversation is over, then her mother texts her, and the patient comes downstairs to talk with the consultant.

It is clear that the context of this example could not be predicted nor could this arrangement be prescribed; rather such a strategy needs to be worked out with the patient and their family. Thus 'best practice' needs to be flexible and adaptive rather than consisting of a rigid set of guidelines – perhaps the term 'good practice' based on the 'principles' referred to above would be the basis of a more useful way of thinking. Many examples used in this

report assume the patient has a family; to draw up guidelines based on such a premise would be inadequate under some circumstances. Thus the 'guiding principles' approach would have greater applicability as demonstrated in the case summarised below by two staff from Unit 7 as exemplifying 'best practice':

Example Case

In February 2010 we had an "index case": a young man of 17 who was a looked-after child. His care involved the adult treatment team, the children's community services, children's social care, the children's hospice, his GP and the looked-after children's nursing team – plus friends and his foster-mum. He was a patient here for 6 months, and was palliative from diagnosis. He went into a hospice at the end and died 3 days later. His last MDT, 3 days before his death, led to a rapid discharge on the Thursday night, and he died on the Saturday morning. (TCT Nurse)

A young man died a year ago – he was in care, with no blood ties. We supported him at home with carers but it got too much for them. He died in a children's hospice. He said he didn't want paid carers – he'd had that all his life. He was a young man with a mature outlook. (Nurse Specialist)

While the examples of good practice discussed so far relate to the palliative and end of life care phase, after the death of the young person the family continues to have needs which require support. There was recognition that the Unit where their son or daughter was cared for, and continued contact with the staff, were significant to parents. This was acknowledged in Unit 4 where the Lead Nurse said: *"Patients' links back here are never withdrawn...Continuity of care for the TYA and family – the TYA team remain in contact."* Bereaved families' ongoing need for support, and the importance of recognizing this, were expressed by a nurse from Unit 5:

Parents want [their child's] funeral to be their 18th birthday and wedding all in one. Staff [from here] attend, and come back saying, 'What a lovely funeral...', and think the family will be fine. But the first year [after losing a child] is hard, and the second year even harder. [A parent will say] 'Once I've survived this length of time, I thought they'd come back to me.' It never heals – and suicide thoughts may be very close.

The importance of getting it right for the young person at the end of their life and for the family for the rest of their lives was recognised by a Staff Nurse from Unit 1 who said: “*This is a time I will forget about – but the family will remember it forever.*”

Summary

The following were thought to contribute to good practice:

- Listening to what TYAs and their families want and need at the end of their lives
- Not assuming a ‘nuclear family’ is available to support the TYA
- Being flexible and adaptive within a set of guiding principles
- Providing resources to care for TYAs in the place where they want to die
- Building strong links with other services both inside and outside the hospital
- Bringing SPC services in at an early stage
- Recognising families’ possible continuing need for contact and support after bereavement.²

² The issues raised by the evaluation have been presented thematically. However a number of themes overlap, making it difficult to draw clear boundaries between the different concerns. As a result, discussion of specialist end of life pathways, training and resource issues, and challenges to caring for the age group at the end of life may be found in more than one section.

9. Conclusions

The evaluation of palliative and end of life care services for TYAs with cancer in the TCT Units which participated in this study indicates that high quality support is offered to TYAs throughout their treatment and that a commitment to continue this support at the end of life is of importance to staff. However, local factors have considerable influence on the extent to which individual Units are able to extend services to the final stages of a TYA's life. Nevertheless, even in those Units where facilities and resources limit the ability to offer end of life care, there is a commitment to liaise with local hospitals and hospices to ensure some continuity of care. Whether this is successful or not depends to some extent on strong links and communication with other service providers and the age of the young person. The lack of community-based services in some locations, and for the 16 -18-year age group in particular, coupled with the lack of age-appropriate hospice care in some areas, is a concern for the Units who as a result make a commitment to provide the care themselves if they can.

Nevertheless, the TCT Units, being primarily places of treatment rather than end of life care, may have limited expertise and resources to cover this additional responsibility. For this reason a dedicated end of life care pathway for TYAs, and training and resources to facilitate such provision, are both necessary. While there was an expressed need for a model or pathway for TYA palliative and end of life care, it became clear during the evaluation that such a model is being developed. Because it is still in draft form it has not been possible to append it to this document, but there is a commitment to roll it out across the sector once it has been finalised. However, it is also important to note that while a TYA End of Life Care Pathway will be a useful addition to the guidelines currently available, Units vary in ways that may mean a universal document has to be adaptable for local conditions. For example, the challenges experienced in a Unit situated in an urban environment may be very different from those faced by a Unit in a semi-rural location.

Once such a pathway has been finalised, if links with other care providers in the hospital, community and hospice-based services are strong and good relationships have been established, the pathway may become central to a shared care arrangement. However, individual family circumstances and relationships may also shape how end of life care can best be offered, thus flexibility within a set of guiding principles is necessary.

Much of the practice identified in the evaluation is endorsed by the work of George and Hutton (2003) who suggest there are certain core principles in the support of dying teenagers. These include the willingness to treat patients as equals, being open and honest

because while non-disclosure may be a short-term advantage, distress inevitably results from the patient imagining the worst rather than being able to enter into a truthful dialogue. They also claim that facing reality and engaging with it makes the young person's acceptance of their lost future as healthy as possible. These authors also say that despite death being inevitable, markers of achievement such as exams are also important, as are any activities that foster socialisation and normality. Professionals also need to accept that they cannot make everything all right, and that crises and emotional challenges are inevitable, and can be used positively to move the patient forward. Team-work is also vital as is the interdisciplinary care needed for this age group. Indeed, as George and Hutton say, the disparate views of paediatric and adult care need to be overcome, as both groups can make a valuable contribution to the young person in transition

10. Recommendations

The findings of this evaluation suggest there is a commitment to providing the best possible experience but some Units face greater challenges to achieving this. Recommendations for how these challenges could be addressed are as follows:

- A dedicated TYA end of life care pathway is needed as a framework for use across all TCT Units. This could also be used as a document to support the end of life care of TYAs in other non-specialist care settings. The pathway would need to be flexible because of the differences between Units in city, town and rural settings.
- A set of guiding principles is needed that allows for responsiveness to individual cases and offers flexibility and adaptability likely to be more useful than a rigid framework.
- A specialist in TYA palliative and end of life care needs to be accessible at all times. This may mean additional training is needed for core TCT staff, or that alternatively links need to be established with wider hospital palliative care staff trained in TYA end of life care. SPC services need to be brought in at an early stage so that planning can be done in good time.
- While consistency of the end of life care policy is needed both within and between Units there also needs to be an allowance for adjustments to be made for local conditions. To avoid uncertainty at times of crisis, a clear policy needs to be agreed for each care setting.
- Strong communication needs to be established between the TCT Units and other care settings in their catchment area. This may extend to reciprocal training visits between the Unit and e.g. a hospice, which would make limited demands on resources.
- Building on such links, the development of partnerships between TYA principal treatment centres, the hospice movement and community palliative care teams in both paediatric and adult sectors should ensure a smoother transition to other services.
- The problem of community-based care for 16 -18-year olds cannot be resolved by the TCT, but where a Unit is aware of such a deficiency in provision for those TYAs discharged from the Unit, they should draw attention to this. It may be that a national campaign is needed, organised by TCT centrally, to bring this deficiency to the attention of those who are in a position to address the issue.
- Additional training and resources are needed to support staff used to the treatment of TYAs but not to their end of life care. Such training should include pain management, end of life care symptom control, advanced age-appropriate communications skills, and training in group-work and team-work skills.

- Pre-bereavement and bereavement support training would provide emotional support for staff who may be unused to caring for a TYA at the end of life and contribute to the maintenance of appropriate boundaries.
- Increased staffing to cover perceived shortages of both outreach and inpatient care would be welcomed.
- The ongoing needs of bereaved families need to be considered and addressed. Not all Units may have the resources to run bereavement support groups, but other measures can be taken to continue the support of families on an individual basis, whether this is achieved by advising them on options for local bereavement support services, for example, CLIC Sargent working in tandem with Maggie's Centres, attending funerals, sending anniversary cards, holding an annual remembrance service for the families or simply understanding that the families may have a need to maintain contact with the Unit after their loss.
- Records of preferred place of death and actual place of death for each patient who dies should be collected from Units annually to form a knowledge base and provide some statistical data. Units could also return information on any local difficulties in arranging care on discharge. A pro-forma for this purpose could be distributed for Units to enter the data in a uniform manner.

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