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Paediatric Update

Palliative care in paediatric oncology

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1. Introduction

The discipline of Paediatric Palliative Care has emerged in the UK over the last 20 years, primarily in response to perceived gaps in service provision [1]. The speciality subsequently developed within the framework of caring for children dying of malignant disease, underpinned by a belief in the need to collaborate with local paediatric units and Primary Health Care Teams (PHCTs). The aim of this development was and still is to enable families to care for their child in their own home [2]. This article reviews the current status of paediatric palliative care based on the experiences of the team based at Birmingham Children's Hospital in the UK.

It is both desirable and feasible to care for children dying of cancer at home [3] and it is evident that children and families often choose this option during the terminal phase of the disease [1].

The unique needs of the child and family necessitate the input of a paediatric practitioner trained in palliation and symptom management [4]. In the UK, this expertise has developed through the appointment of nurse specialists within regional Paediatric Oncology Centres [5]. There are now paediatric oncology outreach nurses based at each regional paediatric oncology unit in the UK working with families from diagnosis through the disease trajectory and into the palliative phase. There is still, however, a scarcity of specialist medical staff. The relatively small number of children requiring palliation makes it difficult to acquire and maintain skills in the discipline.

It is recognised that children have different needs to adults [6]. They continue to develop physically, emotionally and cognitively throughout the disease process [7]; therefore, near the end of their life the child may be significantly more mature and/or cognisant with the disease process than when he or she was originally diagnosed. This can be problematic. A maturing adolescent, for example, may not agree with his/her management or request an alternative strategy not wholly in keeping with parental wishes. Equally, during consultations, an adolescent will require much more considered interaction than, for example, a 6 year old might.

2. The transition to palliative care

The transition into palliation is marked by a shift in emphasis of treatment goals [8,9], symptom control, not cure, is the main objective. For some children, the transitional period is short and well defined, but for others this period may be prolonged, tenuous and may encompass trials of experimental therapy [10] i.e. phase I trials. Whatever the journey into palliation entails, this is clearly a distressing time for the family and can prove difficult for the care team as they negotiate the way forward. The strength of the continuing relationships with the family will be reflected in the success of the transition [8]. In our experience, relationships with families that have been grounded from the outset in mutual respect, negotiation, dialogue and honesty are more likely to promote acceptance than those where families feel uninformed, unsupported and misunderstood.

Families will often ask for second opinions from other centres. Alternatively they may bring information from sources such as the internet, that appears to offer hope. These initiatives should be supported with information, clear explanations, guidance and practical help. Parental wishes do not, however, always reflect the best interests of the child [11]. Families may wish to pursue

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treatment options that are potentially harmful, unrealistic and offer no chance of cure. These potential conflicts are rare and it is our experience that they can often be alleviated by a combination of time and understanding. An open door policy allowing families back to the treatment centre to review decisions will also facilitate acceptance and prevent feelings of abandonment [8].

3. Phase I trials

Phase I trials have been reported as providing short- and long-term remissions for children with incurable disease [12,13]. They have also been reported as stabilising the progression of disease [14], reducing distressing symptoms such as pain, nausea and vomiting [15] and are considered as offering hope [16]. These considerations would then seem to point towards phase I trials being a therapeutic intervention [14].

There is little doubt as to the potential gains for subsequent children [17]. Paediatric phase I trials are considered critical to the process of evaluating new agents. Adult phase I experience with an agent is not an adequate predictor of toxicity in children [12,17]. Furthermore, since childhood cancer is rare [15], when compared with its frequency in adults, it is considered imperative that as many children as possible should be enrolled into trials [17]. Nevertheless, when discussing the possibility of a child taking part in a phase I trial, it is essential that the benefits of such an undertaking are compared with the inherent discomfort or harm that may possibly be incurred [14]. Pain may be experienced as a result of diagnostic procedures performed to monitor toxicity and there may be added suffering as a result of more chemotherapy. Equally, the child may need to attend the hospital for check-ups and have to endure in-patient admissions as a consequence of inclusion on the trial [14].

The literature has recognised that some children and their families experience difficulties in reconciling themselves to the option of no further treatment [15]. Moreover, the opportunity to take part in a phase I trial is often viewed by them as a means of 'buying time' and giving hope [10]. For these families the relative risks of inclusion in the trial are heavily outweighed by what they determine as the more important benefits [14]. Their desperate circumstances do, however, render them vulnerable. Children and families may misinterpret the motivation behind the trial and believe that cure is still a possibility. Others may be blinded to the potential side-effects of the agents in their struggle to keep their child alive longer [17]. Conversely, families may fail to appreciate that phase I trials are unlikely to contribute to haemorrhage or infection or to hasten death and therefore reject involvement [18]. Some families actually feel morally obliged to participate "for the greater good of society" [19].

Inclusion in trials during the terminal phase of a child's disease can result in tension between the organisation of palliative care and management of disease-related symptoms and the ongoing treatment process. The focus on treatment makes it difficult for family and professionals to consider the palliative issues.

The many and complex ethical nuances make it essential that decisions are made with the support of an suitable informed consent process [19] and open communication throughout. It is our belief that phase I trials should be presented hand-in-hand with good symptom management and palliation.

4. Multidisciplinary working

Paediatric palliative care is most successfully delivered using a multidisciplinary approach [9]. The concept of multidisciplinary working, highlighted by Martinson [3], is now standard practice within the field. Table 1 outlines the members of the regional team who should be accessible during the palliative phase of a child dying from malignant disease. The care plan should be tailored to the needs of the child and family. The family's personal, philosophical and cultural perspectives will all influence that plan and the overall aim of any strategy must be best quality of life for the days that remain [11]. In our experience, teams that meet regularly to review palliative patients, conducting meetings that are grounded in a review of symptom management, psychological issues, social and spiritual concerns are best able to successfully meet the unique needs of each family unit.

Outreach Nurse specialists are recognised in the UK as the favoured model for providing 'good practice' in the paediatric palliative care setting [20]. Outreach nurses act as the interface between the hospital and community to provide the delivery of optimum quality care. In supporting and educating professional and lay carers, reviewing symptom management and visiting families at home, they are able to promote teamwork and communication, essential components in the delivery of

Table 1
Possible members of a multidisciplinary team

Consultant
Paediatric Outreach Nurse Specialist
Social Worker Sargent
Psychologist
Dietician
Pharmacist
Physiotherapist
Play Specialist
Occupational Therapist

a seamless service [21] (Fig. 1). Their work is enhanced by the contribution of specialist social workers who can provide both financial and psychosocial support to the family. The inclusion of psychologists, counsellors and pastoral carers within the wider team will ensure that both spiritual and cultural issues are more readily addressed.

5. Place and time of death

Home is the commonest place of death for children dying of cancer in the UK [1]. Data from five other nations also confirms that home is the place of choice for families, regardless of whether home care services are available [22]. Nevertheless, the importance of choice throughout the palliative process is paramount. As symptoms develop, or change, the decision for the child to die at home should be regularly revisited to ensure that the child and family remain comfortable with their choice. Many families at the outset of palliation are uncertain as to how they will cope within the home environment. With the time and support of a proactive Primary Health Care Team (PHCT) and Oncology Outreach nurse, these fears are usually allayed [8]. For families who continue to fear the death of their child at home, other options such as hospital or hospice should be considered. Whilst parents often ask ''How long have we got?'', it is impossible to answer this question [9]. Although the median period of palliation in Paediatric Oncology has been quoted as 6 weeks [1], it is our experience that this time-frame is not practically helpful due to the wide range [1]. Families hold on to time-scales and will re-organise their lives accordingly.

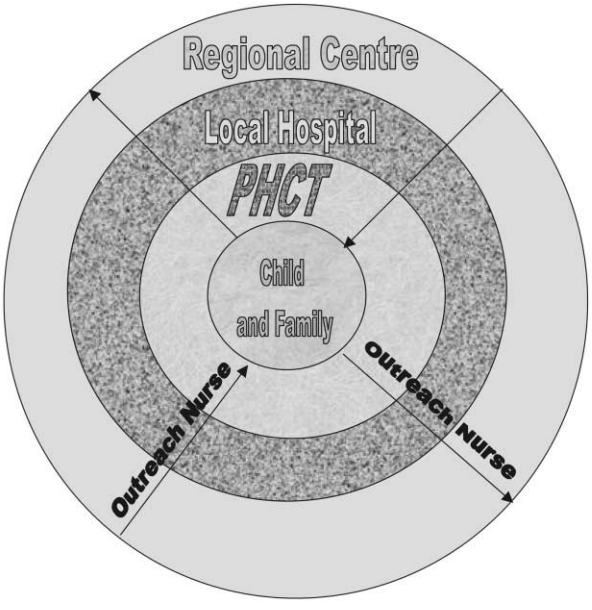

Fig. 1. Interaction of Outreach Nurse specialists with hospital and community. PHCT, Primary Health Care Team.

It can therefore be counter-productive to suggest, for example, that a child will live for 6 months. It is our experience that if a child dies sooner or later than the suggested date parents can feel cheated or frustrated by events. Any statements, therefore, suggesting the course of palliation need to be based on reality rather than conjecture.

Families need guidance on how best to cope with the uncertainty. Should they allow the sick child to return to school? Should they themselves return to work, trying to create normality, saving time off for when the child deteriorates? In our experience, each family's approach will be unique to their circumstances. The care team can, however, assist their decision-making by acknowledging the genuine uncertainty of when the child's condition will worsen and offering gentle guidance. They may look to repeated blood tests and scans to chart their child's deterioration. Here, our approach would be to dissuade a dependence on blood counts and imaging, concentrating more on the physical well-being of the child. Open discussion about expected symptoms, for example, increasing analgesic requirements and fatigue, can equip parents with indicators of potential deterioration.

6. Practical considerations/organisation

Few General Practitioners encounter a child with palliative care needs during their career [4] and many areas lack the input of Paediatric District Nurses. The challenge for the Outreach Nurse is to empower the Primary Health Care Team (Table 2), utilising adequate education and support, to enable them to provide proficient hands-on care. Regular telephone communication between the Paediatric Oncology Outreach Nurse and key members of the Primary Health Care Team combined with joint visits to the child's home helps to ensure that care is optimal. It is considered best practice that the Paediatric Outreach team provide 24 hour access for specialist advice and information, thus enhancing the input of the PHCT [4].

7. The sick child

The sick child should be involved as much as possible in decisions about their care [9]. The ability to apply this

Table 2
Members of Primary Health Care Team routinely involved in paediatric palliative care

General Practitioner
District Nurse (Paediatric and/or Adult)
Health Visitor
School Nurse/Teacher

ideal is, however, limited, if the child is not fully aware of their disease status. Honesty is acclaimed as 'best practice' in providing information to children [9]. Children with malignant disease may, however have a better understanding of the concept death than their healthy peers [23]. Their experiences during treatment might include the deaths of other patients. It has been demonstrated that, despite professional encouragement, families often do not communicate impending death with the sick child [24]. Still, without the means to express their hopes and fears, children have the potential to become withdrawn and isolated. Families may also adopt 'mutual pretence' strategies to avoid upsetting each other [25].

Cultural practices and beliefs may influence the degree of open communication that takes place. In Southern Europe, for instance, the custom of 'non-disclosure' would clearly be of impact [26]. Whilst it is important to acknowledge these cultural differences, it must be reinforced that it is our belief that honest and open communication is the gold standard. For those families who are able to achieve open awareness, the rewards can be substantial, encompassing both the spiritual and psychosocial domain. In our experience, children, especially adolescents, use their remaining time to organise their affairs. They may plan their funeral and/or write a will. They might seek dialogue with regard to interpretations of the meaning of their shortened life and/or the existence of a deity. When, as a professionals it is possible to engage with a child or adolescent in this way, it is apparent how powerful and empowering honesty can be. It must be acknowledged, however, that this level of communication is not universally achievable.

8. School

School attendance continues to be an important activity for many children with progressive disease [9]. This routine can prompt both social support and normality. Understandably, the inclusion of a dying child within the classroom can be worrying for both the family and teachers. It is the role of the Oncology Outreach Nurse to support staff and facilitate strategies with the school to enable the child to attend and sustain other pupils. When a child is no longer able to attend school, the support of home tuition services may be of benefit.

9. Siblings

Inevitably, a great deal of family attention is centred on the dying child, which can result in siblings feeling alone, afraid and jealous [10]. In consequence, the involvement of siblings in aspects of care is critical [10]. Siblings, however, also need a continuous sense of normality through their school and peer group. The specific concerns of bereaved siblings are addressed elsewhere [27,28].

10. Symptom management

Following a step-wise process in symptom management is essential. The use of techniques such as spinal analgesia, nerve block, or even alternative opioid's should be avoided before exhaustive manipulation of conventional therapies. Failure to utilise basic measures to counteract symptoms before employing more sophisticated techniques can give rise to subsequent questioning about the role of the neglected component. This is of particular concern if symptoms continue uncontrolled.

Likewise, over-prescribing should be avoided. Administration of multiple drugs in paediatric symptom management is likely to result in failed overall compliance, including essential analgesia. Careful weighing of the benefits against the costs of adjuvant medication is essential and constant review should be gold standard practice.

11. Medication

This section is grounded in the experiences of the West Midlands Paediatric Macmillan Nursing Team, UK. The basic tenet that pervades our management of all symptoms is continual reassessment.

12. Analgesia

For parents of children with cancer, the fear that their child will be in pain is one of the foremost concerns [29]. The majority of children dying from malignant disease will require opiate analgesia at some stage of their disease process [1]. There is often a sense of uneasiness associated with the use of opioids in children, particularly in relation to increasing doses. Many of these fears, which usually concern side-effects and addiction, are unfounded [30,31] (Tables 3 and 4). These concerns permeate professional groups unused to paediatric practice. Such professional anxiety will fuel any mis-

Table 3
Side-effects of opioids in paediatric palliative care

- Temporary drowsiness—2/3 days
- Constipation—aperient should always be prescribed
- Pruritis—seen regularly in paediatric patients
- Nausea/vomiting—generally uncommon in children

Table 4
Opioids—the facts

- The assumption that a child will require small doses of analgesia is incorrect as there is no evidence to suggest that children experience less pain than adults
- Opioids are no more effective i.v. than orally
- Opioids will not usually sedate after the first 24–48 h following initiation
- The onset of opioid administration is not synonymous with death

Routes of administration
- Oral
- Rectal
- Transdermal
- s.c.
- i.v. (central line/vascuport)

i.v., intravenously/intravenous; s.c. subcutaneous.

conceptions and fear that the family have about the use of such medication. The Outreach Team has a responsibility to address such concerns with both professional colleagues and families. Known side-effects of medication [29], particularly opioids, should be reviewed with families and the salient facts highlighted (Tables 3 and 4).

The World Health Organization (WHO) guidelines for cancer pain relief and palliative care are directly applicable in the paediatric setting and ensure systematic practice in pain control [32]. Nevertheless, modification is acceptable should expert assessment indicate the need to move directly to opioid administration—for example, a child with advanced disease presenting in extreme pain [10,31]. Dose titration with a short-acting opioid is not always practical or necessary within the paediatric setting. If pain has been well controlled to date and the move to opioid administration is measured, it is acceptable to commence a slow-release opioid at a dose related to weight and to administer breakthrough doses of short-acting medication as required. If breakthrough medication is required persistently, the dose of slow release medication should be increased accordingly [32], thereby reducing the requirement for breakthrough medication. Others routes of administration can be considered if oral administration is problematical (Table 4). In particular, transdermal fentanyl patches have been reported as offering an acceptable alternative [33].

13. Co-analgesia and corticosteroids

There is undoubtedly a role for co-analgesia in the paediatric setting [32]. Non-steroidal anti-inflammatory agents such as ibuprofen may be valuable for bone pain [10], whilst membrane-stabilising agents such as carbamazepine, amytriptyline and gabapentin are useful for neuropathic pain. Radiotherapy is used in palliation for localised bone pain.

Corticosteroids have widespread application in oncological symptom management for such problems as raised intracranial pressure, bone invasion or nerve compression. Although they may provide good initial symptom control [31], their role is controversial [34]. The long-term side-effects often result in distress for the child and family and practice has highlighted how quickly children become cushingoid. Young people are image conscious and rapid weight gain, skin changes and altered body image are unacceptable to many of them. Labile mood and behaviour changes may distress both the child and family [10]. This in turn may cause additional stress in the care of the child who is likely, in any case, to be emotionally labile. Commencement of steroids for palliative symptom management should only be contemplated after careful consideration and exhaustive manipulation of other medication.

A related difficult issue is the discontinuation of steroids once introduced. If initiated in the palliative phase, a detailed explanation can be given about the severity of side-effects and a plan agreed with the family for a defined course preferably of short, sharp duration. Such pulsed therapy will minimise side-effects and the need to gradually reduce doses. Furthermore, it will reduce the potential to increase doses again as symptoms break through resulting in continued administration throughout palliation.

For some diseases, however, the use of steroids will already be established as part of disease management. Children suffering from brain tumours may require dexamethasone during radiotherapy. In those with brain-stem glioma, it is often extremely difficult to withdraw dexamethasone post treatment. The very slow reduction of doses that they require mean that dexamethasone is still in use when the child relapses. In this situation, discontinuation of the steroids is often impossible.

14. Other symptoms

If a dying child is to be cared for at home, preparation and education is vital. Warning the family about impending symptoms can often encourage confidence [35]. It may appear callous to discuss particularly alarming symptoms, for example seizures, if they are not a certainty, but it can be more traumatic to have omitted information about such potential problems if they then occur.

15. Seizures

If seizures are a significant possibility the family should have practical advice on how to deal with them. Rectal diazepam should be available in the home with

the family instructed in its administration. It is our experience that families do not recoil from learning to administer rectal diazepam. For the minority that need to give it, the ability to take control and 'do something' to alleviate their child's distress is reassuring. Contingency plans should be made for a continuous infusion of anticonvulsants via syringe driver if seizures prove to be refractory to initial treatment.

These interventions should, however, be secondary to rigorous analysis of current anticonvulsant therapy:

- When were the blood levels last checked?
- Is the child on the most appropriate anticonvulsant?
- Has the child been absorbing the drug?

16. Bleeding and blood products

During treatment for childhood cancer, it is routine for blood product administration to be based upon full blood count results, the child being transfused once the count has fallen below a predetermined level. During palliation, a change in emphasis may provoke anxieties about bleeding and invoke vivid and unpleasant images for child, parents and carers. Fears that without transfusion support the platelet count will continue to fall and that profound bleeding will therefore be inevitable are very real for families. However, experience has shown that this is unlikely to be the case (Table 5).

17. Nutrition

Anorexia is common in children in the palliative phase of their illness [10]. It is important to provide practical, appropriate advice to parents, with the help of a paediatric nutritionist in some cases. Food supplements can be helpful, whilst naso-gastric feeding needs careful consideration, taking into account the child's general condition, their other symptoms, bulbar function and cultural beliefs.

Table 5
Bleeding and blood products

- The majority of children will not have significant bleeding problems despite a low platelet count [36]
- Routine full blood counts are generally of little use in the palliative phase of disease [10]
- Platelet transfusions should be given only if bleeding is frank and persistent [10]
- Bruising and petechiae should not be indicators for transfusion [10]
- Blood transfusions are most appropriately administered symptomatically and whilst the patient continues to experience benefit [36]
- Tranexamic acid (topically or systemically) can be a useful adjunct to prevent/control mucosal bleeding [36]
- It is prudent to agree a plan, regarding the use of blood products, with the family early in the palliative phase [10]

18. Vomiting

Children do not usually require prophylactic antiemetic treatment when commenced on opioid analgesia. It is therefore our practice to commence antiemetic therapy as required and to encourage consideration of other causes before an assumption that emesis is related to opioid administration.

19. Complimentary therapies

Pharmacological intervention has traditionally been the principal therapy of choice in pain management for children [37]. Complimentary therapies have now, however, become accepted as an adjuvant means of managing pain [38]. It is our understanding that by recognising the existence and potential therapeutic value of these therapies, the care team can manage the multidimensional experience that pain represents to the child. Often families approach us with a diverse range of therapies that they wish their child to undertake. Advice should be sought from a pharmacist to ensure that liquids, tablets or oils are scrutinised to certify that they will not interact adversely with those medications already prescribed by medical staff.

20. Talking about death

Talking with the family about what to do when their child dies can prevent the scenario of a family contacting the Emergency Services in a panic and then having to witness resuscitation attempts. Families should be informed that, although there is a legal requirement for a doctor to see and certify the child as dead, there is no urgency. They should be aware that, after death, they can have time with their child and can hold and caress them. Parents may otherwise not do so for fear of disturbing their child's body and anxiety about what may happen. A gentle but accurate description of how their child's body will look and feel after death should be undertaken. Families will also need to be given guidance on how to care for the body should they wish to keep their child at home. Immediate advice after the death should include keeping the room cool and closing windows. More long-term specialist advice, e.g. keeping the body in the home for more than 10–12 hours, should be sought from the Funeral Directors.

21. Bereavement

After the child has died, families should be invited by their lead physician to return to the treatment centre for consultation. It is our experience that this meeting can be used to review treatment strategies and address any unresolved issues. Some families find a series of meetings useful, whilst others find a more informal visit to the ward more manageable. The care team should not, however, underestimate how difficult visits to the unit can be for bereaved families.

Within our centre, families are contacted regularly during the first 2 years of their bereavement by the Macmillan nurses. Within this time-frame, they will be directed towards agencies providing formal counselling if they either make a request for such an intervention or are displaying signs of complex or dysfunctional grief [39]. It is our belief that families should be guided in a direction that facilitates a natural disengagement from the care team by the end of the 2-year period. Failure to instigate such a philosophy can promote an unnatural dependency on individuals and/or the institution.

22. Research

For a variety of reasons, there is little research in paediatric palliative care [40]. The ethics of the use of randomised controlled trials to test the benefit of an intervention is questionable since the number of patients is usually small and consent for such trials is fraught with difficulty. Ideally, one would obtain consent from both the parents and child. Informed consent, is much more than giving permission [41]. To give informed consent, the child would need to be fully conversant with his or her situation. The competence of the child to give consent would need to be considered and assessed [42]. There is also potential for disagreement between the child and family about the best way forward.

23. Education

There is a lack of palliative care training for doctors at both undergraduate and post-graduate levels [43], with a scarcity of information on palliative care in general medical textbooks [44]. Often, the anxiety of caring for palliative patients is heightened when associated with the care of dying children, a much rarer event than adults. In the UK, the founding of a special interest group of The Royal College of Paediatricians and Child Health is already proving to be an effective catalyst in the provision of 'best practice' and in the development of effective training programmes in Paediatric Palliative Care [7].

Take home points

- Despite recognition as a discipline for two decades, there is a scarcity, internationally, of palliative care paediatricians. In the Oncology setting, therefore, nursing has been at the forefront of practice.
- Most families prefer their child to be cared for, and die, at home. Paediatric palliative care necessitates a flexible, co-ordinated, multidisciplinary approach incorporating primary and tertiary care.
- Whilst the need for expertise in symptom management is obvious, experience, knowledge and confidence in dealing with sensitive issues such as honesty with children about disease status, and the understandable quest for cure, against professional advice, is just as important.

The future—a wish list

- More research into evidence-based symptom control in paediatric palliative care
- Improved training for both doctors and nurses in paediatric palliative care
- The emergence of more paediatric palliative care consultants
- The provision of 24-hour paediatric district nurses throughout geographical regions

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