Abstract
This article describes the work of the Diana community nursing teams, a new nurse-led service funded by the Department of Health (DoH) to commemorate the life and work of Diana, Princess of Wales. It identifies paediatric palliative care as an emerging specialty within children’s nursing and discusses how children and young people with life-limiting/threatening conditions and their families may benefit from this new service. It is anticipated that the Diana teams will work with existing services such as children’s hospitals, outreach services, children’s hospices, social services and education and voluntary agencies. A key element of this service will be the ability of Diana team members to work across professional and organizational boundaries to provide a seamless care service and promote the concept of ‘joined-up working’ (Hyman, 1998). Education in this specialty, preferably multidisciplinary education, is needed so that healthcare professionals in this field can share knowledge, skills and research findings and deliver up-to-date care based on clinical effectiveness.

Table 1. The roles of the Diana community nursing teams

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<th>Role</th>
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<td>Support (emotionally and practically) children with life-threatening conditions and their families</td>
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<tr>
<td>Provide a high-quality service which helps the children and their families maintain their autonomy, choice and dignity</td>
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<td>Involve other agencies (statutory and voluntary) in the provision of services to children and their families to meet physical, emotional, educational, social and spiritual needs</td>
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PALLIATIVE CARE: A SPECIALISM WITHIN CHILDREN’S NURSING

In most areas of the UK there is a need for a community palliative care service for children with life-limiting conditions such as muscular dystrophy and life-threatening conditions such as cerebral palsy. Palliative care may now be regarded as an emerging area of practice within children’s nursing. It is thought of as:

‘...an active and total approach embracing physical, emotional, spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes management of distressing symptoms, provision of respite and care through death and bereavement’ (Association for Children with Life-threatening and Terminal Conditions and their Families and the Royal College of Paediatrics and Child Health (ACT/RCP), 1997).

A substantial number of children and young people in the UK are in need of this type of care. While et al (1996), in a major study carried out in England and Wales, were able to show that the incidence of deaths from life-limiting conditions in children aged between 1 and 17 years was 10 per 10,000. The same study also showed that between the ages of 1 and 9 years over two-fifths of deaths are caused by such conditions. The majority of these children do not have access to a community children’s nurse for care, advice or support.

The House of Commons Select Committee (1997) demonstrated that only 50% of children in the UK have access to a children’s programme for children with life-threatening illness (NHS Executive, 1997). It is envisaged that the roles of the Diana community nursing teams will be as outlined in Table 1.
community nursing service and of these only 20% have access to a 24-hour service.

**Diana Teams: Supporting the Child and Family**

Caring for children with a life-limiting/threatening condition in their own home calls for an informed and knowledgeable healthcare professional. Personal attributes such as compassion and the willingness to take on the role of an 'informed friend' to the child, parents and siblings is crucial as is the ability to recognize and respect the expertise of parents in the care of their child. Many life-limiting conditions, such as muscular dystrophy and mucopolysaccharide disease, are genetic in origin and parents often blame themselves and have to deal with guilt (Clarke, 1994).

Caring for a child with complex needs as well as looking after the interests of other siblings, partners, and the everyday responsibilities of family life, often leaves the main carer, usually the mother, exhausted. One area where it is anticipated that Diana community nursing teams should be able to help is in offering respite care in the home or by working with social services, children's hospices and other voluntary organizations to arrange respite on a regular basis or in times of crisis. This respite may involve local voluntary organizations that can provide help with housework, shopping or transport.

Parents are often keen for information about their child's diagnosis and prognosis. Many life-threatening/limiting conditions are rare and information is not readily available. Liaison with paediatric or genetic services may be useful and putting families in contact with some of the excellent self-help groups for carers (Figure 1) can enable parents to better understand their child's condition as well as give them the opportunity to meet fellow carers.

**Working with Existing Services**

Diana community nursing teams will complement existing services. These may be generic (such as community children's nursing and district nursing outreach services and children's oncology and special care baby teams), as well as the small but growing band of specialist children's nursing services which specialize in the care of children in the community with conditions such as epilepsy or cystic fibrosis.

The Diana teams will also work closely with GPs, health visitors, special needs health visitors, hospital and community paediatricians as well as social workers, physiotherapists and occupational therapists.

By accessing existing expertise and pooling such a diverse range of knowledge and skills the aim of the Diana teams is to deliver seamless care and facilitate the process of 'joined-up working', i.e. the need for all agencies to work in harmony across organizational boundaries (Hyman, 1998).

Diana nurses working within these teams may take on the role of keyworker or they may liaise with existing family keyworkers to achieve this cooperation. Identifying one person to take on the role of keyworker for a family means that professionals can respond quickly and effectively to the changing needs of children. Woolley et al (1989) suggest that this 'cornerstone carer' may result in families receiving more help as well as preventing the duplication of services.

The ACT/RCP (1997) working party also recommends that each family has a keyworker to take on responsibility for the co-ordination of the care plan. A keyworker may also prevent the bureaucracy that families experience in obtaining equipment and entitlements. As Adams (1996) notes, it is not unknown for six different government departments and two

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**Figure 1. List of relevant children’s organizations.**

**Relevant organizations**

- Association for Children with Life-threatening or Terminal Conditions and their Families, 65 St Michael’s Hill, Bristol BS2 8DZ. Tel: 0117 922 1556
- Association of Children’s Hospices, 151 Whiteladies Rd, Bristol BS8 2RA. Tel: 0117 973 7299
- Child Bereavement Trust, Harley Ford Estate, Henley Rd, Marlow, Bucks SL7 2DX. Tel: 01628 488 101
- Compassionate Friends, 53 North St, Bristol BS3 1EN. Tel: 0117 953 9639
- Muscular Dystrophy Group of Great Britain and Northern Ireland, 7–11 Prescott Place, Clapham, London SW4 6BS. Tel: 0171 720 8055
- Nigel Clare Network Trust, 85 Moorgate, London EC2M 6AS. Tel: 0171 256 8313
- Society for Mucopolysaccharide Disease, 46 Woodside Rd, Amersham, Bucks HP6 6AJ. Tel: 01494 434 156
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Figure 2. Association for Children with Life-threatening and Terminal Conditions and their Families Charter.
levels of government to be involved in the case of one family with one child.

CARE AIMED AT PROVIDING QUALITY OF LIFE FOR THE CHILD

Diana teams will come into contact with children suffering from a range of conditions in an age group spanning infancy to late adolescence. For babies born with inoperable heart conditions, palliative care may begin and end in infancy. For others born with degenerative conditions such as muscular dystrophy, care may be prolonged over many years. Whatever the age and condition of children the overriding goal of palliative care must be to provide quality of life during the child’s lifetime.

The control of pain and other distressing symptoms (such as vomiting or constipation) require nursing skills that are based on an understanding of the child’s condition and level of cognition. Nurses also need to be aware of the communication difficulties associated with children who are non-verbal or developmentally delayed.

Children and their families will need to be supported in their decision about where the most appropriate location might be to receive care as the child approaches the end of his/her life. This may be in hospital, at home or in a children’s hospice. For children who wish to remain at home, the Diana team will have a key role in providing a ‘hospice at home’ service and in order to achieve this will need to work closely with hospitals, outreach teams and children’s hospices (Davies, 1998). The aim of this care will be to maintain quality of life for children. This will include assessment, management and evaluation of pain and symptom control.

Parents have an important role in this process and will need to be involved in care planning (Goldman and Burne, 1994). Goldman et al (1990) have described the effectiveness of the ‘symptom care team’ in delivering palliative care to children who are terminally ill with cancer. Such a model of care could be applied to children living with other life-limiting/threatening conditions. Effective pain and symptom control is dependent on informed and knowledgeable practitioners as well as a multidisciplinary approach and Diana teams can make a major contribution to this process.

Parents also need support in the immediate aftermath of their child’s death and this may include practical help in arranging the funeral or help with everyday household tasks. The Diana team, working with social workers and voluntary organizations, can arrange this help. Liaison with organizations that offer bereavement support and friendship to parents and family members (such as the Child Bereavement Trust and Compassionate Friends) (Figure 1) can also ensure that families are supported in their grief.

WORKING ACROSS PROFESSIONAL AND ORGANIZATIONAL BOUNDARIES

The Diana teams will be led by a senior children’s nurse who will have a multifaceted role comprising expert practitioner, leader, networker and advocate for children with life-limiting/threatening conditions. Team leaders will need to share the knowledge and skills of the team and use their diplomatic skills and political acumen to work around any territorialism that may exist and to ensure that existing services do not feel threatened by this new service.

The DoH (1998) has stated that:

‘...this service should incorporate the values and approaches associated with Diana, Princess of Wales and should be based on partnership and cooperation across organizational boundaries’.

The following acronym sums up the role such teams will play in caring for children and their families:

This article is dedicated to James — born 9 August 1992, died 2 January 1997 aged 4 years.
Deliver nursing care in the home for children with life-limiting/threatening conditions

Implement standards for care based on need and clinical effectiveness

Act at all times in the interests and for the benefit of the individual child — respecting his/her rights as set out in the ACT Charter (Figure 2)

Network across professional and organizational boundaries to provide a seamless service and promote the concept of ‘joined-up working’ (Hyman, 1998)

Assess the needs of the individual child and family, access existing services whenever possible and audit own practice.

UNDERPINNING PRACTICE WITH AN EDUCATIONAL PROGRAMME

To underpin this new service and the work already being done in palliative care by children’s nurses in hospital, community nursing teams, special schools and children’s hospices there is a need, as the ACT/RCP (1997) report recommends, that specific children’s palliative care courses should be established.

At present there are only two children’s palliative care courses: at Southbank University and Oxford Brookes University. This new service may provide an impetus for more to be established. Diana teams may wish to play a part in the planning and delivery of children’s palliative care courses as well as providing learning experiences for students.

CONCLUSION

The work of the first Diana teams will be evaluated and it is envisaged by the DoH that the best practice will be adopted and applied to other new teams that will be set up over the next few years, eventually leading to a nationwide network of Diana community nursing teams.

This will be a ground-breaking nurse-led service which will serve as a lasting and fitting memorial to the life and work of Diana, Princess of Wales.


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KEY POINTS

- The Diana community nursing teams will provide a unique nurse-led service.
- Palliative care is emerging as a specialty within children’s nursing.
- The work of the Diana community nursing teams will be evaluated and will draw on the best of practice leading to a network of teams throughout the UK.
- Educational courses are needed so that nurses can provide evidence-based care.