An Overview of Paediatric Palliative Care

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Introduction

Paediatric palliative care is an active, holistic, positive approach for children with life-limiting conditions. It includes physical, emotional and spiritual elements and focuses on enhancing the life of the child and family. It includes pain and symptom management, and care of psychosocial needs through death and bereavement. This overview will highlight a few examples of conditions necessitating paediatric palliative care services and care at home.

Four groups of children might benefit from palliative care:

- curative treatment is possible but may fail; including those patients with malignant diseases and those susceptible to organ failure from such ailments as renal and cardiac disease;
- premature death is likely, but long periods of intensive treatment may prolong a good quality of life as in cystic fibrosis and HIV and AIDS;
- treatment is exclusively palliative from the time of diagnosis of progressive conditions such as metabolic diseases and mucopolysaccharidoses;
- severe neurological disability or cerebral palsy or damage following trauma or illness, conditions which, although not progressive, cause serious vulnerability to complications bringing about death before adulthood.

Symptom Management

The approach to managing symptoms, including pain and psychological symptoms, needs to be systematic and careful. For pain, the details of its cause, severity, timing, nature and interference with daily life should be identified. After careful assessment, treatment approaches can be devised which take into consideration the broadest picture and include an appropriate combination of pharmacological and holistic treatments. Regular review ensures that treatment is adjusted as the situation alters.

Psychosocial Needs

Psychosocial support includes the ill child, the parents, siblings and family. The child should be helped to retain dignity despite the progressing illness. Honestly providing information about treatment allows the child to express feelings about what is happening. Communicating with children about their impending death will never be easy. Children almost always understand more than adults anticipate. Assessing the age and developmental level of the child and having some knowledge of the family to provide background regarding the child's level of understanding is important. Each child's situation and family is different. Professionals need to respect the family's culture and pattern of communication and its influence and work within those limits.

Children need the opportunity to use their remaining time in a way that is meaningful to them so they still have some choices and hopes and achieve some goals.

Helping children do the things that are important to them is part of the way we can help them and their families retain some sense of normal living and purpose. Goals may need to be quite modest but can still be valuable.

Bereavement

Palliative care includes support for bereaved families and the health care team should send messages of condolence upon the death of the child, attend the funeral, meet with the family in the weeks after the death, and continue to maintain formal contact with families after the child has died.

Examples of Palliative Care Services

To develop services that support families, a model of the child's world is represented as concentric circles. At the centre is the dying child and family. Relatives and friends who surround them most closely are in the next circle. A network of local facilities and professionals comprise the third circle. These include the family doctor, community nurses and therapists, the school, the local hospital, the pharmacist and voluntary organisations. Many in this circle are not specifically trained in palliative care or paediatrics, but will have expertise in more general aspects of medical, social or educational care. Those with specific paediatric and palliative care expertise work particularly with those less specialised professionals who are more local to the family, offering them

information, advice and backup. In the outermost circle are specialists who are more unfamiliar and distant from the child.

Palliative Care at Home

To enable a family to care for their child at home, access to paediatric and family care at all times is needed. In the UK, this is provided by community paediatric nursing services, which are part of the National Health Service. Access is also needed to expertise in paediatric palliative care. A key worker who coordinates the care of all professionals involved can relieve this burden from the family. Respite care, provided by volunteers coming to the home, gives family members an opportunity to renew their own strength. It is also important to provide immediate access to hospital should this be necessary.

Conclusion

Death in childhood is much less common. We expect children to be well and reach adulthood. One result of this expectation is that, since we are much less familiar with the death of infants and children, we tend to avoid any knowledge of these unfortunate circumstances. Facing the death of a child forces a family to think about spiritual and existential issues. The spiritual needs as well as psychosocial needs are an important aspect of palliative care for the terminally ill child. The field of palliative care is a relatively new specialty.