

Document #2

Palliative Care for Children

The International Work Group recognizes the wide variation of attitudes, beliefs and behaviors pertaining to childhood death, dying and bereavement. The purpose of this statement is, therefore, to identify a set of assumptions which can serve as guidelines, across cultures, in the care of children with terminal illness and their families.

Children Die

Despite advances in health care, children continue to die. The premature death of a child disrupts human development and is therefore perceived in many societies as less acceptable when compared to the expected death that occurs with aging. A child's sudden death precludes adequate time for preparation of the family and health care providers for the unexpected loss. In contrast, the diagnosis and treatment of a life-threatening illness or chronic health condition, usually imposes a prolonged and cumulative strain on everyone involved, and requires collaborative efforts to provide quality care for the dying child. Regardless of the cause of death, supportive care should be extended to all those who are affected by the child's death.

Needs of the Dying Child

Children's needs differ according to their constantly changing developmental levels. Effective care requires knowledge of the physical, psychological, social, educational, and spiritual levels of childhood development. Respect for the child as an individual must be inherent in the provision of care. Every effort must be made to help the child live life fully until death.

Needs of the Family

From the time of diagnosis of a life-threatening illness or chronic health condition until the child's death, the family is confronted with several crises which affect its functioning. When the terminal disease progresses, the recognition of the child's deteriorating condition causes increasing strain on the family. Pressures on parents, siblings, grandparents, and others need to be acknowledged and alleviated. The pain and emotional anguish of loss does not end with the death of the child, and may only be integrated into the fabric of daily life over time. Families express their feelings and react within the context of their own cultural background. Cultural customs may enhance or inhibit their ability to accept illness and death.

A System of Quality Care

An individualized, co-ordinated system of health care which provides continuity of services between the hospital, home, and the community must be developed as soon as feasible after diagnosis. This coordinated system must be maintained throughout the illness and death, with follow-up support for family members after death. It is mandatory that this system of care be made accessible to all children and their families regardless of race, sex, culture and/or ability to pay. The system of care must be flexible in providing services in the community, the home and the hospital. Since most children wish to be at home, necessary and appropriate support must be provided by an inter-disciplinary team which fully respects the family members and volunteers. Professionals should include parents in the planning and provision of care and never attempt to replace them. Recognizing the 24-hours-a-day, 7-days-a-week responsibility of caring for a terminally ill child is crucial.

Health Care Providers

Health care providers must be formally educated in understanding the impact of terminal illness and death on children and families. Moreover, health care providers must use effective methods of helping themselves cope with the various crises caused by the disease. They must also possess the knowledge and skills for under-

standing the subjective, cultural perceptions and meanings attributed to illness by both children and adults. Professionals require continuing education and ongoing personal collaborative support from colleagues in order to address caregiving problems and to make informed decisions.

Community Support

The terminally-ill child becomes increasingly dependent upon family relationships and the community of neighbors, friends, teachers and classmates. Family members also need support and sustenance from the larger community to which they belong. In order to be supportive, the community must be committed to the concept of palliative care which can only evolve from well-grounded knowledge of what palliative care is, what it can do, and how it is effectively applied.

Continued Research

Experiencing the final stage of life-threatening illness profoundly affects the child and family members; the child's death has long-term implications for surviving family members. The scarcity of empirical study of these experiences dictates the need for continued research which focuses on exploring, from a cross-cultural perspective, how the ill child and individual family members experience the progression of the illness, the threat, and the reality of death. From a developed body of knowledge will evolve suggestions and interventions that will provide optimal assistance to families during and after the death of the child.

Developed by the Work Group on Palliative Care For Children

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