

Document #7

A STATEMENT ON CARE OF THE DYING AND BEREAVED IN DEVELOPING COUNTRIES

Introduction

The International Work Group on Death, Dying and Bereavement was founded in 1974 and consists of an international group of clinicians, scholars, and researchers in this field. At a recent meeting in London, the above members of the group crystallized the following working document which has evolved over a three year period with input from representatives of the following developing countries. Bangladesh, Chile, China, Columbia, Hong Kong, India, Nigeria, Pakistan, Saudi Arabia, Taiwan, Thailand, The West Indies, and Zimbabwe.

This working document may be of value not only to governments and health care systems planners, but also to the public who will be the providers and receivers of health care. It can be used as a basis for developing both educational services and health care delivery systems.

Care of the Dying and Bereaved: Attributes of Existing Cultures

All cultures have developed symbolic systems or religions that incorporate the experience and understanding of death into a larger whole that gives meaning to life. All cultures have developed ceremonies and rituals that convey these realities to the living and the dying. We recognize that many cultures have had a positive and humane approach to care for the dying and their survivors. Some examples are as follows:

1. It is possible for people to die at home.
2. Death is accepted as an inevitable part of life.
3. Members of a community are expected to attend funerals and provide support to the survivors.

Concerns Regarding Changes in Existing Cultures

We are concerned that increasing industrialization in many countries has resulted in erosion of positive traditions affecting the care of the dying and bereaved. Some changes are the following:

1. More people are being removed from their home to die.
2. More family members are working in industrial settings and are no longer willing or able to care for the dying.
3. People expect that advances in medical care will ensure longevity.
4. Funeral costs are rising so that the costs may often exceed the economic means of the people.
5. Funerals may no longer retain their traditional value as a vehicle for social and emotional support for survivors.
6. Traditional symbolic systems or religions are frequently disintegrating.
7. A dichotomy has often developed between traditional practices and highly technological health care and delivery systems.

We are also concerned that limitations on financial and personnel resources restrict the availability of services for the dying and the bereaved in many developing countries. Additional obstacles may be created by prevailing rules and regulations, lack of knowledge, professional biases, and the presence of other priorities in health care services.

In harmony with these concerns about limitations and obstacles are the concerns that:

1. High technology in medical care and/or industrialization provides the potential for overuse of costly resources by a small number of people.

2. Technology tends to lead to marked differentiation between acute and chronic care needs.
3. The adoption of Western and European values and customs in developing countries may contribute to the breakdown of traditional life styles and cultural symbol systems.
4. Many countries are currently in the process of developing and expanding their health care services and the provision of guidelines may facilitate the appropriate use of resources for the care of the dying and the bereaved.

In order to provide such guidelines it is imperative to address a series of myths that have been perpetuated and prevent the development of services for the dying and the bereaved.

Myths about the Dying and the Bereaved

Some common myths have been identified:

1. Frequent and repeated deaths desensitize and insulate survivors; therefore, death is less painful and produces fewer complications for them than for those who seldom experience death.
2. The extended family always meets the emotional needs and provides the necessary support for the dying and their survivors.
3. Cultural rituals are always effective in preventing negative sequelae during and after a death.
4. The modern health care delivery system is always superior to the traditional system.

Principles: We recognize that one of the costs of living is the pain of dying and the impact of death on others. For all people the time comes when cure and remission are beyond the capacity of current curative treatment. It is then that care must be directed to controlling pain and other distressing symptoms and providing personal support for patients and families during the terminal phase of illness. The process must continue on to provide personal care and support for the survivors. Health care systems must assume responsibility for the care and comfort of the dying and the bereaved.

Guidelines for the Provision of Care

We believe that the process of dying and the actual death should ideally be in the home or as close as possible to the home and the family. Therefore, a local primary health care system is required to ensure that high quality care is affordable and fully accessible to the dying and their families.

It is recognized that the organization of such primary health services will depend upon the stage of development of the health care system in each country. For some developing countries, this will mean that such new services will be incorporated into existing systems. For other countries, this may require the initiation of local services.

Inherent in the provision of such services is the recognition that:

- a) Whether care of the dying is provided in the institutions or at home or in both settings, health care professionals and workers must be educated and trained in the care of the dying and bereaved.
- b) Traditional healers have a critical role in the care of the dying and bereaved. It is therefore imperative that such health care workers be included in the education and delivering process.
- c) There must be on-going monitoring and evaluation of all care provided.

Developed by the Care of the Dying and Bereaved in Developing Countries Work Group of the International Work Group on Death, Dying, and Bereavement.

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