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HOMECARE FOR THE CHILD WITH A LIFE THREATENING ILLNESS:

DIGNITY DURING THE PROCESS OF DYING

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Introduction

Being aware in order to listen to both the patient and the family, allowing the expression of feelings and demonstrating solidarity, is a very important attitude to be considered in the Homecare program. To provide the patient the possibility of being at home, allowing him/her the contact with comfortable objects, to live with people he/she cares about such as mother and friends during the end of his/her life, allowing at in any age, inclusively the baby's stress and suffering reduction. The psychological care and supportive measurements to the child and parents at home, result in an humanized and individualized care, capable of giving better quality to the rest of his/her life. More and more families have preferred to respect the patient's will, sharing the experiences with the disease or even death, at the same home where his/her experiences in life were shared. To take care of the patient at home can be compensatory, but it is a physical and emotionally exhaustive task, not only for the caretaker but also for the family. Therefore it is necessary to give assistance, orientation and psychosocial support to the patient, caretakers and family members aiming to promote relief of suffering through of specific techniques. The process of dying has always been considered a challenge, and the relief of pain, the support for the patient and the family in facing the disease and the mourning process, should be the basic principles of the professionals. However, the most important goal in order to guarantee dignity in the process of dying is to be conscious that death is not a therapeutical failure, suffering is.

Objectives

- To demonstrate a homecare performance with the multiprofessional team of the Pediatric Palliative Care.
- Guarantee adequate attitude with patients without chance of cure, relief of pain and symptoms, and dignity in dying.

Methodology

Study Case

Clinical history: M.C.C, a baby 6 months old with the diagnosis of ALL made on July 26, 2000. After a complete remission period he presented a bone marrow relapse on January 2, 2001. Two months later was considered without chance of cure and being oriented to the Palliative Care and Pain Program. Death occurred in 6/05/01.

Psychological and Nursing Assistance in Ambulatory, Hospital and Home

The Palliative Care team has taken place after the medical communication to the mother about the patient's condition considered out of therapeutical possibility of cure.

The psychotherapeutic assistance has begun with the mother's boy, bringing up conflicts experienced inside the familial context, with repercussion on the other children, 6 and 3 years old age, whom presented irritability, aggressivity with the parents and among themselves, on a ground of emotional instability and intense anguish. The therapist's interventions contributed giving an understanding based on previous life history interpretation of the subjective experience in the relationship mother-child.

The fact of this baby to be a consequence of an unwilling pregnancy, mobilized enormous feelings of guilt, unacceptability of the reality of the disease and death. Attitudes of superprotection, conferring privileged position for the ill child concerning maternal care and attention, was a way of reparation to her unconscious desires.

The analytical work, which had as a frame of reference the work of Esther Bick, in the analysis of the bond between the mother and the baby allowed the interpretation and symbolization of the traumatic experience. Eventually, the mother could understand her difficulties in facing the loss and could talk openly about those questions to her children. She could prepare herself and participate in all the ritual of saying good-bye to her child and also requested the presence of the psychologist and the nurse in the funeral so that the siblings could also be provided with a meaning for this experience of life and death.

Conclusion

Applying the hospice principles in the care of high-risk babies is not only possible, but necessary. It is important to give support not only to the baby but to the family's emotional, psychosocial and spiritual needs.

Based on the analysis of this case, some proposals for intervention could be elaborated as mentioned below:

Care with the mother

- Offering continence to anguishes, anxieties and fears related to the baby's death.
- Developing feelings of self-confidence in the capacity of being a participative and integrative element in the child's therapeutical care.
- Facing the loss of her child, helping her in the separation and mourning processes.

Care with the father and siblings

- Offer a continent space for the siblings to express their anxieties and fears related to the baby's death.
- Comprehend the meaning and role which this ill child plays in their inner world as well as in their familial history.
- Become conscious of the disease seriousness and the possibility of death to the ill child, allowing the mourning elaboration.