

PROTOCOL FOR: Grieving: Care of the Parents Who Are

DESIRED PATIENT

- OUTCOMES:
1. Parents and family members will demonstrate grieving behaviors that they have identified as appropriate for themselves.
  2. Parents will verbalize the different options for support that are available to them.

CLINICAL  
ASSESSMENT  
AND CARE:

1. Assess parents' perception and awareness of feelings regarding the baby's birth and death when applicable.
2. Assess parents' available support systems.
3. Explore with parents and significant other(s) past and present coping strategies. Identify those that have been successful.
4. Review the role each family member plays under normal circumstances and how these roles have altered. Role designation changes are common when crisis occurs.
5. Explore the feelings the parents had about the pregnancy.
6. Assess family reaction to the loss.
7. Identify those factors that might increase stress during this time, i.e., finances, child care of siblings, etc.
8. Assess parents' knowledge base and cultural beliefs regarding grief, grieving, effects on relationships, sibling reaction, etc.
9. Assess parents emotional status and parents' perception of their coping mechanisms.

INTERVENTIONS:

1. Provide emotional support as parents are informed of their loss in a quiet, private atmosphere.
2. Provide an opportunity for parents to see, hold, baptize and spend time with their baby in a private, quiet environment.
3. Encourage the parents to name the baby.
4. Provide parents with mementos (these may include a lock of hair, name bracelet, diaper, footprints, etc.). In the event of death, these mementos will be kept for 5 years in the NICU's H.E.A.L file (if parents don't wish to take them immediately following the baby's death).
5. Reinforce the physician's explanations. Use simple terms and keep explanations short and concise. Validate with parents their understanding of this information.
6. Encourage open communication among family members and health care providers.

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7. Refer parents to appropriate support systems when necessary (these may include social services, psychiatric liaison, clergy, H.E.A.L support group, other support groups and genetic counseling). A H.E.A.L support parent may be available to help parents when death of the baby is inevitable but has not yet occurred.
8. Validate appropriateness of family members' feelings and be nonjudgmental of coping mechanisms.
9. Do not use clichés (these may include "You're young and you can have more children"; "It was God's will"; "It was for the best").
10. Encourage parents to talk about their experience. Encourage verbalization of fears and feelings.
11. Provide the parents with reassurance. Allow them to cry, give them permission to cry, and be understandable and patient with their anger.
12. In cases of multiple births, explain that part of their grieving process involves separating their babies and coming to terms with them as individuals.
13. In the event the infant dies, photograph baby with entire roll of 12 exposure, 35mm film (this is located in the narcotic cabinet) and give roll to parents for developing. Be creative to enhance quality mementos. Give parents a choice as to how and with whom they want their infant photographed. (Elective Terminations are not photographed.)
14. Photograph infant with the First Foto camera for complimentary photos. Leave film with information for the H.E.A.L. facilitators to process.
15. When the baby dies, complete the H.E.A.L. Referral and place it in the H.E.A.L. mailbox.

- EDUCATION:
1. Instruct parents in feelings which they may have while grieving including shock, disorganization, volatile emotions, guilt, loss/loneliness, relief.
  2. Prepare parents about how their loss might effect their marital and personal relationships in the weeks and months to come.
  3. When a death has occurred or seems inevitable, provide parents with the H.E.A.L. bereavement packet.

ASSISTING  
PARENTS WITH  
SIBLINGS AT HOME:

Knowledge about grief responses in children and how to facilitate healthy grieving in their child will give parents a goal and sense of control in a previously uncontrollable

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situation. Discuss with parents how best to deal with the subject of death and the "less than perfect infant" with their children with special regard to the age of the child.

1. Discuss that how death is understood varies with the age of the child until adolescence when an adult interpretation begins to develop.
2. Suggest that honesty and simplicity in explaining the sibling's birth and/or death and the sadness that they (the parents) feel enables the child to share emotions with his/her parents. This facilitates the child's understanding of, and trust in, his/her parents and avoids pain of confusion.
3. Explain death as a natural course of life, using examples (flowers dying, death of a pet). The natural component of death will make it less frightening and threatening for the child and facilitate his/her understanding of the concept.
4. Expect an element of developmental regression and unusual behavior in the months to follow.
5. Explain that the child's teachers should be notified. The increased awareness by the teachers will facilitate accurate assessment of the child's behavior.
6. Suggest that the child be supported in his emotions, reactions and behavior. Suggest that professional counseling is an option if the parents feel that the child is not coping or reacting appropriately.
7. Children, overall, are very accepting of the "less than perfect" infant and will focus on the child rather than the prematurity, deformity and/or equipment.

REPORTABLE

- CONDITIONS:
1. Inappropriate coping mechanisms.
  2. Misconceptions regarding medical causes of infant's birth and/or death.
  3. Inadequate support systems.

DOCUMENTATION: 1. Complete H.E.A.L. Referral.

EFFECTIVE DATE: 1/86

REVISION DATES: 9/87, 3/92, 5/92, 6/93, 12/94, 12/97, 10/00