

MARGARET H. ROLLINS SCHOOL OF NURSING
Nursing 201 – Nursing Care of Special Populations
Death, Loss, and Grieving Across the Lifespan

Chronic Sorrow

Term which describes the persistent effect the birth of a special needs child brings.

Acute grief – intense, limited in time

Chronic grief – prolonged and recurrent

Chronic grief follows the same stages as acute grief, but since a special needs child requires continual care, parents cannot complete the final stage of mourning. The final stage for chronic grief is **Restitution** (acceptance) rather than **Resolution**.

Stages of Chronic Sorrow

- I. Defense mechanisms – denial and disbelief
May not be able to totally deny something is wrong, but hope is a minor transient cause
Will ask the same questions over and over as they absorb reality.
Important to stress reality *gently*, they are unable to cope with the situation just yet.
They may accept intellectually, but not emotionally
- II. Phase of developing awareness – characterized by overwhelming emotion
Feelings of helplessness, hopelessness, anxiety, acute pain, sadness
Frustrations at not being able to cure the problem
Feelings of inadequacy and failure
Guilt abounds – “if only”
Find everyday routines annoying and callous
Disorganization phase – does not reflect parents usual way of responding and interacting
- III. Restitution, acceptance
Don’t consciously grieve now for loss of perfect child, but sorrow over defects the child will have to live with
Fear for child’s future
Experience transient periods of intense sorrow as certain developmental landmarks occur
**Chronic grief does not prevent parents from feeling joy, happiness, satisfaction, and accomplishment – they love the child, and marvel at every advance!

Pathological reaction patterns
 - Extreme guilt may lead parents to dedicate themselves exclusively to the welfare of the child. Look for signs of excessive over protectiveness.

OR

 - Parents may be intolerant of the child and deny relationships

Grieving in families with a special needs child

Telling the parents

- Evasive, nervous responses increase parental anxiety
- Important! Tell both together if possible with the baby present
- Never delay telling if the defect is apparent
- Allow them to see the defect – will have realistic input; prevents frightening fantasy
- Don't rush the explanation! Use simple terms
- Never minimize the defect
- Allow hope without encouraging denial

Dealing with the emotional impact

- Convey warmth and caring, sit nearby
- Touch is important!
- Say "I'm sorry"; don't be afraid of crying in front of parents
- Do not react defensively if parents react with anger (is not reflected toward you, it reflects the parents bitter disappointment)
- Answer all remarks with understanding
- Parents may initially express death wish – listen sympathetically. Don't make them feel guilty; remarks are made out of concern for the newborn. Later, after attachment, parents will really feel possible loss
- Factual information provides some help towards realistic planning
- Premature reassurances hinder opportunity to express feeling
- Respect initial need for withdrawal – parents need time for acceptance. Stay near, stop in and out of room frequently to convey warmth, acceptance of feelings, caring.
- "Leave me alone, but don't leave me"
- Respect autonomy in decisions

Nursing interventions related to infant care

- Watch your facial expressions and comments
- Parents will be sensitive to treatment that differs from norm, i.e. placing infant away from nursery windows (conveys non-acceptance of society)
- "Touching" the defect is important!
- Treat as normal labor & delivery, postpartum mom. Be an interested listener! Encourage her to review her experiences. Teach her self and baby care.
- Encourage interaction with newborn; have parents hold and care for baby
- Give explanations at level of readiness when parents are ready for more info
- If mother is using delay tactics, 'paint a picture' of the baby's unique personality, i.e. feeding, crying, and sleeping patterns. This helps the mother to focus on the infants' positive aspects and makes the child seem real to her.
- Always keep the family informed on the newborn's condition if told acute physical problem is also present
- Allow extended visitation with family and supportive members if desired. Note: they may initially decline other visitors

If the parents reject the infant and choose foster care:

- This is their choice!
- Don't give your opinion!
- Present alternatives, accept their decision