



Children Born Prematurely: Risk of Parental Chronic Sorrow

Susan Ann Vitale PhD, RN, PNP, ANP-C^{a,*}, Carina Falco BS, RNC^b

^a*Nursing, Molloy College, Rockville Centre, NY*

^b*North Shore Long Island Jewish Hospital, Manhasset, NY*

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The middle range nursing theory of chronic sorrow offers guidance in the care of families dealing with an ongoing disparity. One such example is the reality of having an infant born prematurely with serious medical conditions. Nurses working in a neonatal intensive care unit, and other pediatric settings need to assess families for symptoms of fear, helplessness or sadness and signs of chronic sorrow. A case scenario provides an example of chronic sorrow. Nurses need to assist families in developing healthy coping strategies so as to alleviate any effects of chronic sorrow that they may experience.

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BECOMING A PARENT can be a significant and life-altering experience. It may be anticipated as a transformative juncture with exciting new dimensions of purpose and meaning. However, high expectations may be quickly replaced by unexpected realities of challenge and complexity. One unforeseen and potentially frightening experience for parents occurs when an infant is born prematurely and needs to be transferred to a neonatal intensive care unit (NICU). A specific example of such a situation was a case scenario involving the birth of twins at 25 weeks gestation. The parents spent 3 months visiting their newborn twins in an NICU. Upon discharge to home, the family faced a future of lifelong developmental and medical challenges.

Nurses can utilize the middle range nursing theory of chronic sorrow to help provide anticipatory guidance to parents in such situations. Chronic sorrow is considered a normal response to an ongoing disparity developing in the experience of a loss. The reality of having a child with a

developmental disability and chronic medical problems is one such example.

Description of a Case Scenario: Twins Born Prematurely

Mr. and Mrs. Mason (names changed) were overjoyed to discover that they were finally expecting twins after a successful in vitro fertilization treatment. Mrs. Mason was placed in the hospital on bed rest at 24 weeks gestation due to complications with her pregnancy. One week later, while in her hospital bed, she experienced a severe pain and began to bleed copiously. She required an emergency delivery by caesarian section because of a placenta abruption. Her husband was not able to be there with her to provide support due to the timing of the emergency.

The Masons saw their newborn infant twins, a girl and a boy, for the first time in the NICU. Each weighed a little more than one pound. The infants were intubated on high frequency oscillators with central lines in their umbilical cords. Over the next 3 months in the NICU, they were

* Corresponding author: Susan Ann Vitale, PhD, RN, PNP, ANP-C.
E-mail addresses: svitale@molloy.edu, savwcv@yahoo.com.

extubated and re-intubated several times. They also developed pneumonia and had multiple surgeries, accompanied by numerous complications.

The most serious event was the diagnosis of a grade IV hydrocephalous for both twins. Each required neurosurgical implantation of reservoirs. Weekly tapping procedures were also performed to remove extra cerebral fluid. Eventually, both of the infants were able to tolerate the implantation of a ventriculo-peritoneal shunt. The parents were cautioned by the neurosurgeon who explained that the shunts would be a lifelong treatment to divert excessive cerebral fluid into the peritoneal cavity.

The infants slowly learned to tolerate bottle feedings after weeks of intravenous and nasogastric tube feeding support. The procedure to learn sucking was challenged by choking episodes and sucking refusals. A 5 ml intake was considered a success but difficult for them to achieve. One twin did require positive pressure ventilation after becoming cyanotic during a feeding attempt in front of the parents. After a second choking episode, the parents were told the infant might have to be discharged to home with a feeding tube. A bottle feeding was again tried a week later, which was successful. The parents were overjoyed with this sign of progress.

A harsh prognosis for the future gradually became evident. The parents were advised that there would be serious developmental delays and were given no reassurance that the children might ever sit up, walk, talk, or be able to feed themselves. It was clear that their children would need a great deal of medical and therapeutic support throughout their lives.

Mr. and Mrs. Mason were able to finally take their twins home from the NICU after 3 months of mixed progress and devastating setbacks. They reported expressions of joy in that the twins were alive and could finally go home. This was tempered by contemplation of the future for their two tiny infants. The parents were experiencing signs of both joy and sorrow. Chronic sorrow (Fraley, 1986) is an experience that has been identified in parents of children born prematurely. Nurses can help parents become aware of the potential for this occurrence while providing resources and coping strategies.

The Middle Range Theory of Chronic Sorrow

The term chronic sorrow was first described by Olshansky (1962) in an observation of parents of children with intellectual disabilities. The parents reported recurrent feelings of sadness. Cyclic feelings of sorrow were subsequently identified in mothers of school age children with a myelomeningocele by Mary Burke (1989) during her doctoral research.

Researchers continued exploration and development of this theory within a variety of settings involving children with other

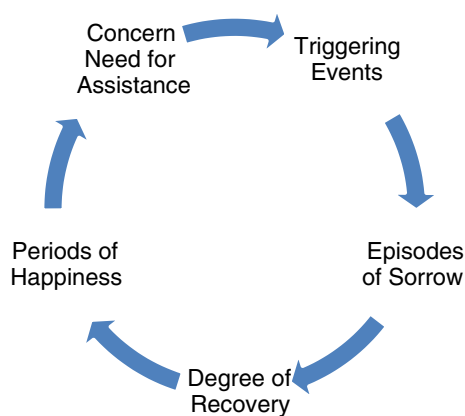


Figure 1 Cyclic nature of chronic sorrow.

developmental disabilities. A research consortium was eventually formed for the purpose of further studying the concept of chronic sorrow (Schreir & Droes, 2010). Eakes, Burke, and Hainsworth (1998) published a summary of research findings of the concept that presented the basis for evidence of a middle-range theory of chronic sorrow. Middle-range theories are specific to practice situations and outcomes, are precise in focus, and are intended to answer particular practice questions. The theory of chronic sorrow has since been investigated in both patients and caregivers with many other ailments and illnesses. It was also accepted as a nursing diagnosis by NANDA in 1998 (Schreir & Droes, 2010).

The theory of chronic sorrow involves cyclic periods of sadness caused by traumatic changes in cognitive or physical health. Cycles of sorrow may be present in an individual or a family member. There are four main components to the theory. Sorrow is observed as being recurrent or intermittent, having no end, intensifying over time, and something that can be triggered by internal or externally predictable events (Melvin & Heater, 2004).

Chronic sorrow is different from the grief that subsides within a reasonable time, such as after the death of a loved one. Grief resolution typically occurs after a grieving or mourning period. The emotional experience felt by parents raising a child with a disability or chronic medical illness may not include the possibility of closure. Parents may initially feel both grief and sorrow over the loss of what might have been the birth of their envisioned child. They must come to accept a new role and adjust to its limitations. Although they may come to terms with an illness or developmental disability, they may still experience sorrow in periodic cycles thereafter (Teel, 1991). Such cycles can be triggered by new events and require adjustments in previous coping skills (Figure 1).

Melvin and Heater (2004) established that chronic sorrow is not caused from a single event but by the multiple effects of loss over time. Certain rites of passage or milestones, such as the child's birthday, can trigger an episode of chronic sorrow. A parent with a child who uses a wheelchair might feel an extended episode of sorrow after

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