

**COURSE RESERVE READING**

**SAMPLE PAPER TITLE: An Analysis of the Concept 'Chronic Sorrow'**

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### An Analysis of the Concept 'Chronic Sorrow'

A nurse walked into a patient's room in a rehabilitation hospital to find the patient's father, crying, sitting on the edge of the bed with his head lowered. The patient, a 20 year old male, had sustained a traumatic brain injury as a result of a motor vehicle accident following recreational drug and alcohol use. Bone flaps had been removed from his left and right temporal areas leaving his skull grossly misshapen. He suffered from autonomic dysfunction, often referred to as neurostorming, where his blood pressure and heart rate accelerated, he perspired profusely and appeared anxious and frightened. He periodically suffered from seizures. He required frequent suctioning via a tracheostomy tube. Pictures of his soccer star days adorned the walls. Upon hearing the nurse enter, the father, Paul, lifted his head, revealing a tear-stained face, and simply asked, "Did I do the right thing?" Knowing the father relatively well, the nurse knew that he was considering if he had made the right decision by withholding a DNR status and allowing his son to be resuscitated, intubated, mechanically ventilated, brought into surgery, given a percutaneous endoscopic gastrostomy tube, and eventually weaned off the vent to be transferred to this rehabilitation hospital where he remained in a minimally-conscious state a year following the accident. Instead of being alarmed or discomfited at the father's state, the nurse recognized the symptoms of chronic sorrow as a normal reaction and offered emotional support by nonjudgmental listening as the father expressed his sorrow for the loss of the soccer-playing son he had had.

Chronic sorrow is a concept that is generally accepted among nurses, pediatricians, social workers, counselors, and psychologists to apply to parents of disabled children as a way of describing long-term pervasive sadness regarding the experience of loss. The term was coined in 1962 by a rehabilitation counselor, Simon Olshansky, based on his interviews with parents of

children with mental retardation. He refers to the emotions and experiences perceived by these parents as cyclical and recurring in response to ongoing grief (as cited in Peterson & Bredow, 2004, p. 166). Furthermore, chronic sorrow can be experienced at different degrees of intensity over time and need not be considered pathological (Peterson & Bredow, 2004). In other words, it is a normal grief reaction to an ongoing experience of loss.

More recently, the Nursing Consortium for Research on Chronic Sorrow (NCRCS) has expanded the definition of chronic sorrow to include experiences of individuals and their family caregivers to loss associated with chronic illness (Eakes, Burke, & Hainsworth, 1998). Chronic sorrow has been redefined to encompass the experiences of people who suffer from an ongoing disparity due to a significant loss (Eakes et al, 1998). Eakes et al (1998) characterize chronic sorrow as “the periodic recurrence of permanent, pervasive sadness or other grief related feeling associated with a significant loss.” The critical distinction between Olshansky’s original description of chronic sorrow and that of Eakes et al centers around the recognition of an ongoing disparity that leads to recurring feelings of sadness and sorrow. These feelings persist for the duration of the disparity. Disparity is understood as “a loss/situation when an individual’s current reality differs markedly from the idealized, or when a gap exists between the desired and the actual. This lack of closure sets the stage for grief to be periodically re-experienced” (Peterson & Bredow, 2004, p. 167). Although the original description of chronic sorrow by Olshansky provided an understanding of the experiences of parents of mentally disabled children, the concept is now understood to apply to a variety of chronic illnesses and disability.

The North American Nursing Diagnosis Association’s (NANDA) approved nursing diagnosis of chronic sorrow is defined as, “A cyclical, recurring, and potentially progressive pattern of pervasive sadness that is experienced by a client (parent or caregiver, or individual

with chronic illness or disability) in response to continual loss, throughout the trajectory of an illness or disability” (Wilkinson, 2000, p. 443). Defining characteristics include feelings that vary in intensity, occur periodically, and “may interfere with the client’s ability to reach his/her highest level of personal and social well-being” (Wilkinson, 2000, p. 443). In addition, the client may have feelings of “anger, being misunderstood, confusion, depression, disappointment, emptiness, fear, frustration, guilt/self-blame, helplessness, hopelessness, loneliness, low self-esteem, recurring loss, overwhelmed” (Wilkinson, 2000, p. 443).

In comparing chronic sorrow to normal grieving, NANDA differentiates chronic sorrow as continuing “unabated” and “the condition remains as a constant reminder of loss” (Wilkinson, 2000, p. 444). The feelings do not lessen in intensity over time unlike the prevailing view of acute grief that follows a time-linear model with a decrease in intensity with time (Teel, 1991). It is important to make a distinction between the sadness associated with chronic sorrow and that associated with grief following death: “Response to ongoing loss is differentiated from bereavement following death in that the relationship deprivation is not because of a physical death, but is due to the symbolic death of a loved one” (Teel, 1991). The continual presence of the chronic illness and its effect on the individual serves as a constant reminder of the perceived loss. It is also important to note that chronic sorrow precludes a more effective coping mechanism than that associated with dysfunctional grieving, which is defined by NANDA as an extended, ineffective use of coping resources to combat the perception of loss (Wilkinson, 2000). Normal or anticipatory grieving may have some of the same defining characteristics of chronic sorrow and dysfunctional grieving; however, grieving is considered dysfunctional when it is prolonged or the symptoms “unusually numerous or severe” (p. 179). The description of feelings is emphasized in defining chronic sorrow, whereas grieving is defined primarily in terms of

“behaviors used in trying to cope with the loss” (p. 179).

The prime goal for nursing and counselors in dealing with grieving focuses on adjusting to and resolving the experience of loss. In chronic sorrow, the experience continues for the duration of the loss and the disparity created by the loss. As a normal human response to loss, resolution is not considered a prime goal for intervention for those suffering from chronic sorrow. Interventions are directed at allowing individuals to express “feelings of guilt, anger, or sorrow” and to “verbalize the impact of the loss(es)” (Wilkinson, 2000, p. 444). Wilkinson (2000) adds a goal of working “toward acceptance of the loss(es)” (p. 445); however, this does not follow the chronic sorrow model which “contends that parental reaction is one of functional adaptation rather than acceptance” (Fischbeck Feinstein, Mazurek Melnyk, Moldenhouer, & Small, 2001). The nature of the loss is typically ongoing with no foreseeable end. Thus, chronic sorrow continues due to the continuing disparity created by the loss. It follows a “non-linear model of response to loss” rather than the time-bound model of grief which progresses “through stages of (a) shock and disbelief, (b) developing awareness of the loss, and (c) prolonged recovery, in which occurs the work of mourning and the re-establishment of well-being” (Teel, 1991). Olshansky explained chronic sorrow as “a pervasive psychological reaction, a natural rather than neurotic response to a tragic fact (the birth of a disabled child” (Teel, 1991, p.1313). Mazurek Melnyk et al (2001) suggest a hybrid model of grief that contains elements of the time-bound model and that of the chronic sorrow model since achieving closure is often not possible. This recognizes that perhaps there is a progression through stages, but also re-experiences of “peaks in the grieving process during developmental transitions and high-risk periods” (Mazurek Melnyk et al, 2001, p. 549). Teel (1991) supports a non-linear understanding of chronic sorrow in stating that the “orientation should be broadened to include support of people in their recurrent

experiences of sorrow rather than to hold acceptance and resolution as the ultimate goal for all victims of loss”(p. 1317). This understanding directs interventions at providing primarily emotional support and validation of feelings of loss based on an understanding of the concept of chronic sorrow as a normal grief reaction to an ongoing loss that is distinct from bereavement suffered after the loss of a loved one.

Recognizing that disparity is significant to the development of chronic sorrow, researchers have described the experience of chronic sorrow associated with a variety of chronic illnesses and loss situations such as the birth of premature infants, childhood diabetes, sickle cell disease, developmental disabilities, neural tube defects, and multiple sclerosis, among others. Eakes et al (1998) include circumscribed losses from the death of a family member as a prelude to chronic sorrow:

While traditionally chronic sorrow has been associated only with individuals involved in ongoing loss situations with no predictable end, these latest findings about bereaved individuals validate the experience of chronic sorrow not only for those experiencing ongoing loss, but also for those who have experienced a single loss. Therefore, we assume that any type of significant loss experience may result in the development of chronic sorrow. (p. 181)

The main antecedent event that precipitates chronic sorrow is an experience of significant loss. This is generally described as ongoing with no predictable end, yet Eakes et al (1991) have also described bereaved individuals of a single loss as experiencing chronic sorrow as well. The second main antecedent event is the perceived disparity created by the loss (Eakes et al, 1991). Disparity often comes into sharper focus when “trigger events” occur. “Triggers, also referred to as milestones, are defined as those circumstances, situations, and conditions that bring the

negative disparity resulting from the loss experience clearly into focus or that exacerbate the experience of disparity” (Eakes et al, 1991, p.180). For example, parents of a developmentally-delayed child may experience sorrow when the child is unable to meet developmental milestones such as walking. Teel (1991) describes an additional component as an antecedent to chronic sorrow: “A relationship of attachment is disrupted through loss other than death” (p. 1317). Unlike Eakes et al, she distinguishes chronic sorrow from bereavement/grief following the death of a loved one. Thus, a borderline case would consist of a single loss rather than an ongoing loss with an unpredictable end, as occurs with a death of a loved one.

The consequences of chronic sorrow center around a variety of feelings and emotional reactions to the loss and disparity, notably, “shock, disbelief, feelings of isolation, sadness, loss, guilt, anger and frustration” (Cameron, Snowdon, & Orr, 1992, p. 98). Episodic sadness recurs with increases in intensity at times. The defining attribute of these feelings is the chronicity of them. “The sorrow is not constant yet is chronic and recurs periodically” (Teel, 1991). More research is needed to better define the lasting effects of chronic sorrow.

One instrument used to measure the presence of chronic sorrow is the Burke/NCRLS Chronic Sorrow Questionnaire (Peterson & Bredow, 2004) which is a set of ten questions to determine the impact of loss situations on individuals. It is used as a guide in conducting research in the literature, sometimes adapted for certain populations. This particular instrument uses a Likert scale to rate feelings of disparity, grief, characteristics of chronic sorrow, triggers, and internal and external coping mechanisms. Researchers often use qualitative studies in identifying recurring themes of certain populations experiencing chronic sorrow (i.e. parents of children with neural tube defects, parents of children with newly diagnosed diabetes, parents of premature children, caregivers of school age children with sickle cell disease, individuals with

multiple sclerosis) (Eakes et al, 1998; Fraley, 1986; Hobdell, 2004; Lowes & Lyne, 2000; Northington, 2000; ). Mazurek Melnyk et al (2001) have developed an assessment guide to use with parents of children who are chronically ill. The assessment tool examines parent(s) perception of the child's abilities, stressors, and needs; parental coping outcomes; and, potential or actual barrier to coping (Mazurek Melnyk et al, 2001) . Although much of the literature continues to focus heavily on parents of chronically ill children, researchers are currently expanding the scope of chronic sorrow suffered in a variety of chronic conditions.

The prevailing concept of chronic sorrow and the actual lived experiences of parents with disabled children can, at times, conflict. For instance, much of the literature assumes that the primary cause of chronic sorrow for parents of chronically ill children is due to the loss of the 'perfect child.' "Parents lose their image of the 'perfect child.' They are suddenly bereft of the images of the baby they expected, with cute physical characteristics and predictable delightful behaviors" (Fitzgerald Miller, 2000, p. 128). Kearney and Griffin (2001) examined themes commonly found in interviews of parents with chronically ill children, and their findings are significant for shared elements in the cause of chronic sorrow:

the anticipated possibility of the child dying; finding out about the child's changed potential; being treated as if there were a death in the family; being left on their own by other people and the health system; being vulnerable as public parents. . .and feeling powerless; having many fears and worries, particularly for the future; and a perplexing and complex grief. (p. 586)

In short, the majority of the sorrow experienced by these parents could be contributed to being "inundated with negative messages from 'other people'-from professionals with their hopeless prognoses, along with families and friends, all of whom were responsible for feelings of

isolation, rejection, anger, hurt, failure and despair” (Kearney & Griffin, 2001, p. 586). Parents of chronically ill children fear an untimely death of their child, exacerbations of illness, repeated hospitalizations, and pain experienced by their child through the trajectory of disease or illness. “Uncertainty and fear about the future is a constant worry for parents of children who are chronically ill” (Mazurek Melnyk et al, 2001, p. 550). This can hardly be described as sorrow stemming primarily from the loss of a ‘perfect child.’ Indeed, parents generally love the child they have, though not the disease, and find them quite cute and delightful exactly as they are, despite Fitzgerald Miller’s (2000) perspective [and that of many researchers] that parents are in sorrow because they view their child as not meeting perfection. This misunderstanding can lead to false beliefs about interventions required and parental responses.

Thus, my interest in this concept is founded on similarities and discrepancies between my lived experiences as a parent of a severely disabled child, on my experiences as a nurse working in a specialty hospital for children and young adults with disabilities, and on my interactions with patients, their parents and families. It is beyond the scope of this paper to further discuss interventions necessary in assessing and meeting the needs of parents suffering from chronic sorrow due to having a child with a chronic illness. Therefore, I would like to conclude with my own understanding of chronic sorrow as profound sadness in response to an ongoing situation of loss that brings about new and recurring experiences of sadness, that is chronic, and fluctuates in intensity in response to stressors and anxiety evoked from the effects of the loss situation.

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