SAMPLE PAPER TITLE: Evaluation of the Middle Range Theory of Chronic Sorrow

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Evaluation of the Middle Range Theory of Chronic Sorrow

Exactly one month after my daughter, Maria, turned two years old, she fell backwards onto the floor; her eyes were blank, glassy, staring; her body limp and floppy. This lasted for less than a minute. This was the beginning of what would be hundreds and hundreds of seizures. My husband and I brought Maria home from the hospital and, although she looked like Maria, she acted like some other child we had never met. She cried and screamed most of the time, banged her head on the floor repeatedly and for no apparent reason, punched herself in the face, lost all eye contact and communication, and stopped sleeping at night.

Through all this, we found little support and direction from healthcare providers. We were left to care for our little girl’s overwhelming needs which we neither understood nor could handle by ourselves. We were exhausted, emotionally drained, and financially-strapped. Our sons were at times neglected, left to put themselves to bed at the ages of 3 and 5 because we could not leave Maria’s side lest she pull out her hair in fistfuls or bang her head on the floor, not to mention the frequent seizing. Within a few months, the daughter who had seemed “normal” was now described as autistic, severely mentally retarded with intractable epilepsy, gastroesophageal reflux, dysphasia, Celiac’s Disease, and a neurodegenerative disease of unknown etiology. I because Maria’s case managers because there was no one to play that role in coordinating medical care, home care, education, equipment and supplies, therapies, multiple medication changes, complex medication regimens, insurance company denials for reimbursement, and frequent medical appointments, ER visits and hospitalizations.

I suffer from chronic sorrow. This is a term that had never been explained or
presented to me by healthcare providers, let alone interventions offered. I discovered this term while performing independent research and immediately recognized the symptomology in myself and my husband, who becomes quiet and sad when he sees a little girl in public holding the hand of her dad, or when he walks by a display of dolls in a retail store.

Chronic sorrow is a term that I seek to understand more fully not only for personal and intimate reasons, but also for professional reasons. I am a nurse in a specialty hospital that exclusively serves the disabled population. Patients, parents, and family members are in need of nursing interventions that recognize the presence of chronic sorrow and provide effective and necessary support, services, and comfort.

Similar to my own story, chronic sorrow was first identified and described based on the telling of personal, lived experiences of parents with profoundly disabled children. In 1962, Simon Olshansky coined the term after listening to parents of children with mental retardation describe their experiences. He refers to the associated emotions as a normal reaction that is cyclical and recurring in response to ongoing grief; furthermore, the intensity of the sorrow can fluctuate over time (as cited in Peterson & Bredow, 2004).

The Middle-Range Theory of Chronic Sorrow expands the understanding of chronic sorrow to include the concept of disparity (Eakes, Burke, & Hainsworth, 1998). Disparity is described 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). Eakes et al (1998) use this definition of disparity to apply the term chronic sorrow to a variety of loss situations, including chronic illnesses and disability,
and even death of a loved one, with loss identified as the primary antecedent.

Eakes et al (1998) drew in part from research garnered from 10 qualitative studies conducted by the Nursing Consortium for Research on Chronic Sorrow (NCRCS) to define chronic sorrow as, “the periodic recurrence of permanent, pervasive sadness or other grief-related feelings associated with ongoing disparity resulting from a loss experience. Chronic sorrow is viewed as a normal response to ongoing disparity associated with a loss situation” (p. 180). Traditional time-bound grief models do not adequately describe the experiences of those suffering from chronic sorrow. Rather, the nature of the sorrow is cyclical, which prevents resolution of grief over time: “Although each episode of sadness abates over time, circumstances or situations in which the individual is confronted with the disparity created by the loss trigger recurrence of the grief-related feelings” (Eakes et al, 1998, p. 180).

An important component to the middle-range theory of chronic sorrow, then, is trigger events, which “are closely connected to the disparity” (Eakes et al, 1998, p. 181). Northington (2000) described chronic sorrow in parents of children with sickle cell disease. She validated the role of trigger events in causing recurring feelings of sadness through her interview sessions with parents: “just to see her not being able to play like other children, that’s basically the hardest part” (p. 148). One common trigger event for parents of physically and/or mentally disabled children is the disparity realized at important developmental milestones: “confrontation with disparity between the idealized and the actual is overwhelmingly associated with developmental milestones” (Eakes et al, 1998, p. 182). Trigger events bring new feelings of sadness to the forefront. The concepts of loss, disparity, and trigger events, as well as the relationship among these, are logically
Eakes et al (1998) identify intervention strategies that encompass internal and external interventions directed at the formation of coping methods and the assessment of the presence of chronic sorrow by healthcare providers. The interventions are termed "management methods," and include the following: positive coping and action strategies such as "maintaining involvement in personal interests and activities, pursuing respite opportunities, and seeking information related to one's loss experience" (p. 182). Interpersonal coping strategies include "talking with others involved in the same or a similar loss situation, talking with someone close, or talking with a trusted professional" (p. 182). Lastly, another strategy includes focusing on emotional and spiritual comfort.

A key criteria for a middle-range theory is the description of a phenomena that is directly applicable to practice. The middle-range theory of chronic sorrow does provide a framework with substantial discourse at the middle-range level for understanding chronic sorrow, its antecedents, defining attributes, and triggers. The assumptions are specified, and are congruent with the focus of chronic sorrow. The concepts are clearly defined and encompass only those necessary to adequately cover the phenomenon: chronic sorrow, loss, disparity, trigger events, and management methods.

This midrange theory also offers nursing implications for developing concrete and appropriate interventions to assist individuals living with chronic sorrow. It is well within the discipline of nursing, and, in fact, has evolved through nursing inquiry and research. Assessment and intervention have been introduced in the literature with Mazurek Melnyk, Fischbeck Feinstein, Moldenhauer, & Small (2001), who describe a variety of assessment tools for parents of children who are chronically ill, as well as a theoretical
framework to guide interventions with an emphasis on parental coping strategies and the need for strong social support services.

The methodology used to explore the concept of chronic sorrow through data collection is largely inductively-derived based on qualitative, interpretive research studies of experiential descriptions of individuals touched by a significant loss. Themes are uncovered from phenomenological interviews. The strength of this type of exploratory, descriptive research design method is that it provides the actual words of those living with the condition under study. Thus, the origins are firmly rooted in practice and research experience.

Chronic sorrow has been linked specifically in research studies to parents of children with neural tube defects, newly diagnosed diabetes, and premature children; caregivers of school age children with sickle cell disease; and individuals with multiple sclerosis, among others (Eakes et al., 1998; Fraley, 1986; Hobdell, 2004; Lowes & Lyne, 2000; Northington, 2000). The theory continues to be applied to a variety of client groups as the scope is expanded to include chronic sorrow suffered in a variety of loss experiences and chronic conditions.

A growing list of empirical tools examine the presence of chronic sorrow and its effects; most notably, the Burke/NCRCS Chronic Sorrow Questionnaire, modified as the Burke/Eakes Chronic Sorrow Assessment Tool in 2003, offer empirical validation of the concept (Peterson & Bredow, 2004). The Middle-Range Theory of Chronic Sorrow claims that findings were derived from not only a review of literature, but also from 10 qualitative research studies conducted by the NCRCS (Peterson & Bredow, 2004). The Direct Question tool "measures the intensity dimension of chronic sorrow" and Teel

Hobdell (2004) displays a table with no less than sixteen assessment tools published for chronic sorrow research with authors, subjects, instruments used, and results.

As shown, the theory of chronic sorrow demonstrates substantive foundations, structural integrity, and functional adequacy. Further, it guides nursing actions in assessing, diagnosing, planning, intervening, and evaluating chronic sorrow, its presence and effects. One particularly relevant and clear need for nursing intervention is in case management. Gravelle (1997) identified the amount of time caregivers are required to give up to perform amateur case management was particularly stressful:

Negotiating for services was seen as necessary but often stressful. Changes in the child’s condition often meant a change (or addition) in service, resulting in new bureaucracy, paperwork, service providers, equipment, and funding sources. In dealing with new services or service providers, parents often had to fight or negotiate for what they perceived to be in their child’s best interests. (p. 742)

In my experiences and practice, I have found that this is borne out regularly among caregivers. It is a particularly stressful aspect of being the caregiver in a situation that seemingly has no end.

Future studies should focus on the effectiveness of interventions in alleviating the sorrow associated with ongoing experiences of loss. Early, proper and ongoing case management as an interventional aid should be studied for effectiveness at alleviating stress, anxiety and time-consuming activities for caregivers. Ideally, future research should measure the effectiveness of various strategies to better approximate which should be targeted through nursing interventions.
References


