Middle-Range Theory Of Chronic Sorrow
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Purpose: To introduce a middle-range nursing theory of chronic sorrow that presents this sorrow as a normal response to ongoing disparity due to loss. Chronic sorrow is the periodic recurrence of permanent, pervasive sadness or other grief related feelings associated with a significant loss. The theory provides a framework for understanding and working with people following a single or ongoing loss.

Organizing framework: The model of chronic sorrow includes antecedents, trigger events, and internal and external management methods.

Scope: Theory is useful for analyzing individual responses of people experiencing ongoing disparity due to chronic illness, caregiving responsibilities, loss of the "perfect" child, or bereavement.

Sources: The theory was developed using concept analysis, critical review of research, and validation in 10 qualitative studies of various loss situations.

Conclusions: Chronic sorrow has been shown to explain the experience of people across the lifespan who encounter ongoing disparity because of significant loss. Nurses need to view chronic sorrow as a normal response to loss and, when it is triggered, provide support by fostering positive coping strategies and assuming roles that increase comfort.


[Key Words: grief/mourn; loss; chronic sorrow]

Chronic sorrow was introduced into the literature more than 30 years ago to characterize the recurring waves of grief observed in parents of children with mental deficiencies as they struggled to cope with the loss of a "perfect child" (Olshansky, 1962). The pervasive, recurrent sadness Olshansky characterized as chronic sorrow was viewed as a normal response to disruptions of anticipated normalcy.

Subsequent research validated the occurrence of chronic sorrow among parents of mentally or physically disabled young children and expanded the emotions commonly experienced to include not only sadness and sorrow, but also fear, helplessness, anger, frustration, and other feelings characteristic of grief (Burke, 1989; Damrosch & Perry, 1989; FraJey, 1986; Hummel & Eastman, 1991; Phillips, 1991; Seideman & Kleine, 1995; Wikler, Wasow, & Hatfield, 1981). Concluded in these studies was the idea that the never-ending nature of the loss of the "perfect" child prevented resolution of grief and precipitated periodic episodes of re-grief or chronic sorrow.

Research undertaken by the Nursing Consortium for Research on Chronic Sorrow (Eakes, Hainsworth, Lindgren, & Burke, 1991) has expanded the relevance of the concept to individuals experiencing a variety of loss situations, as well as to their family caregivers (Burke, 1992; Eakes, 1993; Eakes, 1994; Eakes, 1995; Eakes, Burke, Hainsworth, & Lindgren, 1993; Hainsworth, 1994a; Hainsworth, 1994b; Hainsworth, 1995; Hainsworth, Burke, Lindgren, & Eakes, 1993; Hainsworth, Eakes, & Burke, 1994; Hainsworth, Busch, Eakes, & Burke, 1995; Lindgren, 1996). Our middle-range theory of chronic sorrow was inductively derived and validated through a series of 10 qualitative studies conducted by members of the Nursing Consortium for Research on Chronic Sorrow (NCRCS) and a critical review of existing research.

According to Walker and Avant (1995), in concept analysis the attributes or defining characteristics of a particular idea are examined. Moreover, this defining is an essential step in theory development. Analyses of the concept of chronic sorrow documented in the literature (Lindgren, Burke, Hainsworth, & Eakes, 1992; Teel, 1991) provided the foundation upon which the theoretical model of chronic sorrow was built. Defining characteristics of chronic sorrow, as noted by Lindgren and colleagues (1992, p. 31), include the following: (a) A perception of sadness or sorrow over time in a situation with no predictable end. (b) Sadness or sorrow that is cyclic or recurrent, (c) Sadness or sorrow that is triggered internally or externally and brings to mind a person's losses, disappointments, or fears, (d) Sadness or sorrow that is progressive and can intensify.

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Accepted for publication October 3, 1997.
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In addition to setting forth the critical attributes of chronic sorrow, analyses of the concept provide descriptions of events and circumstances antecedent to the occurrence of chronic sorrow. These events include involvement in the trajectory of a chronic illness or disability, either as the one affected or as a caregiver; a recognized negative disparity between the past and present; and the occurrence of events that bring the disparity into focus (Lindgren et al., 1993; Teel, 1991).

Although the process of concept analysis is formal and rigorous, Walker and Avant (1995) warn that results are always tentative. Indeed, findings from research studies conducted by the Nursing Consortium for Research on Chronic Sorrow have not consistently demonstrated progressivity of the emotions associated with chronic sorrow (Eakes, 1993; Eakes et al., 1993; Bakes, 1995; Hainsworth, Burke, Lindgren, & Eakes, 1993; Hainsworth, 1994b; Hainsworth et al., 1994; Hainsworth et al., 1995). Rather, the potential for progressivity and intensification of chronic sorrow over time has been identified.

Further modification of the defining characteristics of chronic sorrow has resulted from recent NCRCS research demonstrating evidence of chronic sorrow among people who have experienced a single loss event rather than an ongoing loss (Burke, 1994; Eakes, 1994; Hainsworth, 1994a). Therefore it is the ongoing disparity created by the loss experience, rather than the ongoing nature of the loss situation as originally hypothesized, that is antecedent to chronic sorrow. Recognition of the common denominator of disparity, the difference between the current reality and the desired, was a major breakthrough in that it explains the occurrence of chronic sorrow in both ongoing and circumscribed loss situations. Chronic sorrow has been rethought based on these research findings and is now defined 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; indeed, research has shown that it is universally experienced by those who suffer a significant loss. Normalization of the process of chronic sorrow in no way diminishes the validity or intensity of the feelings experienced.

**Overview of the Chronic Sorrow Model**

Our theory of chronic sorrow offers an explanation of how people may respond to both ongoing and single loss events. The model of chronic sorrow not only offers a framework for understanding responses to various loss situations, but also offers a new way of viewing the experience of bereavement. The model of chronic sorrow is in Figure 1.

Chronic sorrow experience is cyclical and continues as long as the disparity created by a loss remains. Chronic sorrow is viewed as a normal response to an abnormal situation. While episodes of sadness abate and individuals do go on with their lives, as long as the disparity created by the loss exists, chronic sorrow is likely to be periodically experienced. This periodic return of grief is experienced by individuals and caregivers whose anticipated life course has been disrupted. Chronic sorrow is characterized as pervasive, permanent, periodic, and potentially progressive in nature. These attributes are reflected in the words of mother whose child had died:

> The pain will never completely go away, but like anything else, you just learn to live with it You learn how to live with an amputated limb. You learn how to live with a broken heart (Burke, 1994).

As shown in the model (Figure 1), the experience of chronic sorrow may occur subsequent to a loss experienced at any point across the life span.

Chronic sorrow is clearly differentiated from prevalent time-bound models of grief and from pathological grief and depression (Burke, Hainsworth, Eakes, & Lindgren, 1992; Lindgren et al., 1992; Teel, 1991). Whereas traditional grief theorists (Bowlby, 1980; Lindemann, 1944) purport that resolution is the necessary and normal outcome of grief reactions associated with loss, the theoretical premise of chronic sorrow allows that people may periodically re-experience the pervasive sadness or other grief-related feelings that occur when initially confronted with the loss. 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. Because of the cyclical nature of chronic sorrow, periods of happiness and satisfaction are interspersed with episodes of re-grief, thereby preventing the grief from becoming incapacitating (Burke et al., 1992; Copley & Bodensteiner, 1987; Lindgren et al., 1992; Teel, 1991).

The need for alternative models of loss is widely recognized. Moreover, there is growing recognition that the unique nature of losses, both real and symbolic, that accompany chronic illness and disability prevents closure or resolution (Davis, 1987; Stephenson & Murphy, 1986; Worthington, 1994). Interestingly, Quint's (1969) definition of chronic illness as one that is progressive, periodic, and permanent mirrors the experience of chronic sorrow.

Cyclical models of grief that allow for the feelings of grief to be revisited have been posited not only by professionals working with families with children who have chronic illnesses or developmental disabilities (Copley & Bodensteiner, 1987; Worthington, 1994) but also by those who counsel the bereaved (Martin & Elder, 1993). However, unlike these descriptive open-ended grief frameworks,
the model of chronic sorrow represents an alternative way of viewing cyclical responses to loss experiences that is based on extensive research.

**Loss Situations**

The primary antecedent event that must occur before the onset of chronic sorrow is involvement in an experience of significant loss. The loss may be ongoing with no predictable end, as with the birth of a disabled child or diagnosis of a chronic illness, or it may be a more circumscribed loss like the death of a loved one. Since interpretation of loss is highly individualistic, it is difficult to generalize about what may constitute a significant loss. What is described as a significant loss by one person may not be viewed the same by another. However, research has shown overwhelmingly that the never-ending loss of a "perfect" child experienced by parents of young children with physical or mental disabilities places them at high risk for chronic sorrow (Burke, 1989; Damrosch & Perry, 1989; Fraley, 1986; Golden, 1994; Hummel & Eastman, 1991; Mallow, 1994; Olshansky, 1962; Phillips, 1991; Seideman & Kleine, 1995; Shumaker, 1995; Wikler et al., 1981).

Similarly, family caregivers of adult children, spouses, parents, or other close relatives with physically or mentally debilitating diseases confront losses associated with watching their loved one's condition deteriorate and experiencing the personal sacrifices that accompany caregiving (Atkinson, 1994; Cockerill & Warren, 1990; Miller, 1991; Miller, Dworkin, Ward, & Barone, 1990; Parks & Pilisuk, 1991). These experiences of ongoing loss imbedded in the role of caregiver often lead to chronic sorrow (Burke, Eakes, & Hainsworth, 1997; Bakes, 1995; Hainsworth, 1995; Hainsworth et al., 1995; Lindgren, 1996).

The presence of a chronic condition with its concomitant uncertainty creates a situation for which there is no predictable end (Loveys, 1990; Mishel, 1990). Moreover, both the actual and symbolic losses associated with living with chronic illness or disability are ongoing. Involvement in ongoing losses associated with a chronic or life-threatening condition such as infertility, cancer, or multiple sclerosis is likely to lead to the development of chronic sorrow (Burke et al., 1997; Eakes, 1993; Eakes et al., 1993; Hainsworth, 1994a; Hainsworth, 1995; Hainsworth et al., 1993; Hainsworth et al., 1994; Hainsworth et al., 1995; Lindgren et al., 1993; Teel, 1991). The unresolved disparity that characterizes chronic sorrow may be equated with experiencing loss in bits and pieces. The lack of closure of the gap created by the loss event sets the stage for grief to be experienced periodically as reflected in the comments of a mother whose child had died:

> It's a continual process and people who say it just ends after two years ... that after that you should be okay. Well that's crazy. Time does change you and you can adapt, but for me personally, it doesn't completely heal the scar that's left (Burke, 1994).

**Trigger Events**

Within the theoretical framework of chronic sorrow, trigger events are closely connected to the disparity. 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 (Burke et al., 1997; Eakes, 1995; Teel, 1991). Events that are likely to trigger confrontation with ongoing disparity vary depending upon whether the loss is associated with having a chronic or life-threatening condition, being a family caregiver, or experiencing the death of a loved one.

(Bereaved Individual Version), a semi-structured interview guide. The words of one man whose wife had died 10 years earlier provide a portrait of the chronic sorrow associated with the death of a loved one:

> There are people that tell you that time will erase or time will change things, but that's not true. Time will make it easier, but time does not erase what you have built up over many years. It doesn't erase it so don't expect them (periodic grief-related feelings) to go away. You can deal with it as years pass, but I don't think that I will ever, if I live to be 100, get over it. My wife will always be a part of me. She left an impact on my life and my child that nothing in this world will ever take away (Eakes, 1994).

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.
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**Affected Individuals**

Chronic sorrow is most often triggered in individuals with chronic or life-threatening conditions when the individual experiences disparity with accepted norms. These norms may be social, developmental, or personal (Burke et al., 1997; Eakes, 1993; Eakes et al., 1993; Hainsworth, 1994b). Individuals with chronic or life-threatening illnesses may be stigmatized by society. Moreover, their abilities to fully participate in and meet the expectations of “normal” development brings the disparity clearly into focus.

Developmental norms refer to those predictable, anticipated milestones of individual or family development. One example of disparity with family developmental norms is an infertile woman of child-bearing age. People diagnosed with progressively degenerative conditions such as multiple sclerosis, experience ongoing disparity with previously established personal norms almost certainly precipitate the chronic sorrow experience. Such a situation may arise when one can no longer participate in an activity previously enjoyed.

In addition to disparity with norms, events associated with management of the illness such as hospitalization may bring the ongoing disparity into focus for those affected by a chronic or life-threatening condition (Burke et al., 1997; Eakes, 1993; Eakes et al., 1993; Hainsworth, 1994b; Lindgren, 1996).

**Family Caregivers**

For parents caring for young children with physical or mental infirmities, confrontation with disparity between the idealized and the actual is overwhelmingly associated with developmental milestones (Burke, 1989; Clubb, 1991; Damrosch & Perry, 1989; Fraley, 1986; Fraley, 1990; Golden, 1994; Hummel & Eastman, 1991; Mallow, 1994; Olshansky, 1962; Phillips, 1991; Seideman & Kleine, 1995; Shumaker, 1995; Wilder et al., 1981). The discrepancy noted between a child’s performance and the parents’ expectations of “normal” development brings the disparity clearly into focus.

For other family caregivers, chronic sorrow is most often triggered by management crises associated with the family member’s illness and by events that reinforce the unending nature of their caregiving responsibilities (Burke et al., 1997; Eakes, 1995; Eakes et al., 1993; Hainsworth, 1995; Hainsworth et al., 1995; Lindgren, 1996). The potential for comparisons of abnormal conditions with norms to trigger chronic sorrow is also apparent in family caregivers. Situations and circumstances that precipitate awareness of disparities between self and others, especially in regard to developmental expectations, relationships and abilities are commonly cited in this regard (Burke, 1989; Burke et al., 1997; Eakes, 1995; Fraley, 1986; Hainsworth, 1995; Hummel & Eastman, 1991; Olshansky, 1962; Wikler et al., 1981). As the husband of a woman with multiple sclerosis noted, “I can’t stand seeing couples walking around the mall or taking their grandchildren out because I know that will never happen with us” (Hainsworth, 1995).

**Bereaved Individuals**

In bereavement situations, the disparity that triggers chronic sorrow is not the presence of a person with a chronic condition. Rather, it is the disparity from the ideal created by the absence of a person who was central in the life of the bereaved. Stated another way, for bereaved individuals, it is the presence of the absence that triggers chronic sorrow. The chronic sorrow experience for bereaved people is most frequently triggered by confrontation with disparity associated with memories of a past reality, often associated with anniversary events, and with recognized variances from social norms (Burke, 1994; Eakes, 1994; Hainsworth, 1994a). Moreover, role changes necessitated by the death of a “significant other” also serve as reminders of the negative disparity between the past and the present and may precipitate chronic sorrow.

**Management Methods**

Management methods refer both to the coping strategies used by a person with chronic sorrow (internal) and to interventions provided by professionals (external). Use of effective coping methods and provision of appropriate interventions can assist those with chronic sorrow to regain their emotional equilibrium and achieve an increased level of comfort. Employment of effective management methods may also extend the period between trigger events and reduce the degree of perceived disparity.

**Effective Internal Management Methods**

Individuals draw on a variety of strategies to cope with the periodic re-grief associated with chronic sorrow. Positive personal coping styles used by those with chronic sorrow are consistent among affected individuals, family caregivers, and bereaved individuals and are congruous with styles identified in established theories on stress and coping (Lazarus & Folkman, 1984). Individuals most frequently cope positively with chronic sorrow by using action strategies designed to help them feel more in control of their lives (Burke, 1989; Eakes, 1993; Eakes, 1995; Hainsworth et al., 1994; Hainsworth, 1995; Hainsworth et al., 1995; Lindgren, 1996).

These strategies include maintaining involvement in personal interests and activities, pursuing respite opportunities, and seeking information related to one’s loss experience. Cognitive methods of coping are also frequently used to manage the feelings associated with chronic sorrow (Burke, 1989; Eakes, 1993; Eakes, 1995; Hainsworth et al., 1994; Hainsworth, 1995; Hainsworth et al., 1995; Hainsworth et al., 1995). These strategies involve having a “can do” attitude, taking one day at a time, and concentrating on the positive aspects of one’s life.

Another category of strategies for coping with chronic sorrow is the interpersonal (Burke, 1989; Eakes, 1993; Eakes, 1995; Fraley, 1990; Hainsworth et al., 1994; Hainsworth, 1995; Hainsworth et al., 1995; Wikler et al., 1981). These strategies include talking with others involved in the same or a similar loss situation, talking with someone close, or talking with a trusted professional. Other positive coping styles that are sometimes described, although less frequently, are emotional (e.g., having a good cry) and spiritual (e.g., relying on religious or personal beliefs and practices for comfort).

**Effective External Management Methods**

It is important to note that management methods provided by health care professionals should be based on a conceptualization of chronic sorrow as normal rather than pathological. Normalization
of the experience is, in and of itself, the foundation upon which other interventions are built. Nurses and other providers should recognize that individuals who have been diagnosed with chronic or life-threatening conditions, parents of young children with disabilities, caregivers for ill or disabled relatives, and individuals bereaved through the death of loved ones may experience the periodic recurrence of grief-related feelings defined as chronic sorrow. Awareness of the circumstances and situations that are likely to trigger chronic sorrow allows for provision of anticipatory guidance. Personal coping styles can be assessed by simply asking, "What helps?" Once identified, positive coping strategies should be strengthened and supported. For those lacking effective coping abilities, strategies identified as effective in dealing with chronic sorrow can be taught.

Further, specific actions by health care professionals have been identified as helpful in reducing the emotional pain of chronic sorrow. These interventions can be categorized as roles that nurses and other health care providers can assume in their contacts with individuals experiencing chronic sorrow (Burke, 1989; Copley & Bodensteiner, 1987; Eakes, 1993; Eakes, 1995; Eakes et al. 1993; Fraley, 1990; Hainsworth, 1995; Hainsworth et al., 1995; Hummel & Eastman, 1991; Wikler et al., 1981).

For people diagnosed with chronic or life-threatening illnesses, as well as bereaved individuals, interventions demonstrative of an empathetic presence and a caring professional are most helpful (Burke, 1989; Eakes, 1993; Eakes et al., 1993; Hainsworth et al., 1995). The interventions that typify the role of empathetic presence include taking time to listen, offering support and reassurance, recognizing and focusing on feelings, and appreciating the uniqueness of each individual and family. The complementary role of caring professional is exemplified by being sensitive, respectful, non-judgmental, tactful, patient, and compassionate in contacts with those experiencing chronic sorrow. Also beneficial to affected individuals are interventions reflective of the teacher and expert role highlighted below.

Parents of young children with disabilities and other family caregivers receive the most benefit from interventions associated with the role of teacher/expert (Burke, 1989; Clubb, 1991; Eakes, 1995; Fraley, 1990; Hainsworth, 1995; Hainsworth et al., 1995; Hummel & Eastman, 1991; Warda, 1992; Wilder et al., 1981), including provision of accurate, situation-specific information in a manner that can be both heard and understood, and practical tips for dealing with the challenges of caregiving. Empathetic presence, as described above, also assists these caregivers to cope with the experience of chronic sorrow (Burke, 1989; Clubb, 1991; Eakes, 1995; Fraley, 1990; Hainsworth, 1995; Hummel & Eastman, 1991; Olshansky, 1962; Phillips, 1991; Teel, 1991; Warda, 1992).

**Summary and Conclusions**

Our middle-range theory of chronic sorrow provides a framework for understanding the reactions of individuals to loss. This theory has been derived from interviews with 196 individuals, from young adults to me elderly, who have shared their experiences as people with chronic conditions, family caregivers of the chronically ill, or as bereaved family members. Whatever the nature of the loss situation, if ongoing disparity is created, chronic sorrow is likely to be experienced. Indeed, a total of 169 (86%) of those studied showed evidence of chronic sorrow.

Nurses and other health care professionals should recognize that chronic sorrow is commonly experienced by individuals across the lifespan who have encountered significant loss or experience ongoing loss. Further, it is important that they view the recurring periodic episodes of sadness and other emotions characteristic of grief as a normal response to the ongoing disparity created by the loss and provide needed support when chronic sorrow is triggered.

There are numerous implications suggested by this study for research on the theory of chronic sorrow. First and foremost, a concise instrument to identify the presence of chronic sorrow must be developed to facilitate future research and guide practice-related assessment and intervention. Second, further study is needed to test the theory and its generalizability to populations and loss situations not yet studied. More specifically, its relevance for various cultural groups should be explored. Along with empirical testing of the theory of chronic sorrow, intervention studies focused on the identification of strategies to reduce disparity created by loss should be conducted. Strategies already described in the chronic illness and grief literature, such as individual counseling and support groups, should be tested for their effectiveness in reducing the disparity associated with chronic sorrow. Such additional study will be useful in determining if ongoing disparity can be substantially reduced and chronic sorrow can be alleviated in those who experience this phenomenon. Tłej?—

**References**

Clinical Sidebar by Susan R. Redding

- The teen-aged hospice patient and her family when her cancer goes into remission but leaves her blind.
- The 54-year-old man who suffers severe head injuries on the way to his wedding.
- The feelings of loss expressed by the 28-year-old infertile woman as she cares for her slowly dying father.
- The 78 year old who finally shares her feelings associated with her loss of four babies prenatally—

Each of these exhibit disparity in response to loss and had symptoms of chronic sorrow, as described by Eakes and colleagues. This middle-range theory of chronic sorrow has wide application for nurses in clinical practice.

Nurses in all practice settings can benefit from knowledge of trigger events as well as internal and external management methods of coping with chronic sorrow. This knowledge can benefit nurses in their professional practice and in their personal lives. No one who lives is exempt from loss and, consequently, from the potential for chronic sorrow.

Nurses in acute-care and long-term care settings can anticipate symptoms associated with chronic sorrow, in both patients and caregivers when people with chronic diseases require hospitalization or slowly lose abilities to perform activities of daily living. "Wellness-illness is a human experience of actual or perceived function-dysfunction through the interaction of cognitive-affective dimensions." Jensen and Allen's study (Dossy, Keegan, Guzzetta, & Kolmke, 1995). Given the fact that patients may have physical manifestations of psychological, emotional, or spiritual problems—nurses should be alert to triggers of chronic sorrow and incorporate appropriate responses in assessments of those at-risk.

Hospice programs typically provide support to loved ones of the dying and deceased and offer anticipatory counseling. Sorrow, however, is not time-limited and may be present, in some manner as long as memory is intact and, perhaps longer. One 80-year-old woman with advanced dementia sometimes awakened sobbing uncontrollably about the events associated with her mother's "recent" death.

Nurses should make provision for bereavement counseling when events trigger symptoms of chronic sorrow that can occur years after the loss. They should provide for anticipatory counseling for trigger events as well as reinforce effective internal and external coping mechanisms.

The emphasis on normalization of the experience of chronic sorrow as the foundation for intervention deserves emphasis. Feelings have a function and should be respected as integral to the process of meaning reconstruction, rather than controlled or eliminated as unwanted by-products of loss (Neimeyer, 1993).

Nurses in hospice programs have long realized that meaningful and appropriate involvement of caregivers in meeting the needs of their dying loved ones contributes to more healthful grieving. Indeed, hospice nurses can contribute to research on the theory of chronic sorrow by identifying ways to reduce disparity created by loss.

Kubler-Ross, among others, has given us models for dealing with loss. However, "Because you loved, grief continues to walk by your side" (Grollman, 1997, p.154). The theory described by Eakes, Burke, and Hainsworth can help us develop models of intervention for those suffering chronic sorrow.

References


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