Finding a New Normal

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Purpose
To pull together relevant findings in the literature into a meaningful model of functional behavior related to the experiences of parents with a chronically ill child.

This model:
- describes the evolution towards a 'new normal' in response to the dis-equilibrium caused by the impact of stressors.
- explains the improvement of functionality of balancing factors (perception of the problem, coping mechanisms, and support systems) through repatterning in order to avoid crises.
- recognizes the omnipresence of chronic sorrow and the need for parents to constantly adapt to their individual situation over time.

Background
Chronic illness in a child creates significant parental stress, often punctuated by episodic waves of heightened distress, sadness, or uncertainty as new problems or losses evolve. Parents of children with chronic illness live with the chronic stress of potential crisis. The use of repatterning behaviors to deal with actual or potential crises can foster adaptation and lead to a state of equilibrium or a 'new normal'.

After initial diagnosis, which itself is devastating and elicits a feeling of grief to deal with the loss of what the parents consider to be a perfect child, chronic illness poses a constant threat. The ever-present threat of potential acute exacerbations and/or new symptoms or health concerns keeps parents of a chronically ill child at constant risk of crisis.

Parents may avoid crises and achieve a 'new normal' if balancing factors are functioning effectively to reduce the impact of stressors.

Parental behavior and coping mechanisms related to caring for a chronically ill child can be explained by the following frameworks.

- Theory of Chronic Sorrow
  - a middle range theory applicable to understanding parental sadness in response to loss, including loss of idealized perfect child, and loss situations where ongoing disparity is created (Olszansky, 1962)

- Crisis Theory
  - explains parental use of balancing factors to maintain equilibrium (Aguilera, 1998)

- Complexity Theory
  - describes parental experience as non-linear, complex, and dynamic, undergoing periods of stability and change (Pierce, 1995)
  - explains use of repatterning in which one responds to triggers or stressors by seeking behaviors to restore equilibrium (Northington, 2000)

Model of New Normal
Our model depicts how parents experiencing chronic sorrow can utilize repatterning behaviors in order to avoid crisis, obtain balance, and adapt into a state of ‘new normal’.

- Chronic Sorrow is:
  - defined as persistent suffering that is permanent, periodic, and potentially progressive (Olshansky, 1962).
  - a normal grief response that need not progress to clinical depression.

- Repatterning is:
  - the application of normalizing behaviors such as redefining one’s reality, re-adjusting to make sense of one’s situation, and using coping skills to gain control over one’s reactions (Northington, 2000).
  - a process which leads to healthy adaptation or a ‘new normal’, avoiding crisis and/or depression by maximizing the functionality of balancing factors and decreasing the impact of stressors.

- Crisis is:
  - characterized by disruption in equilibrium due to a stressor for which usual coping mechanisms and problem solving are ineffective (Aguilera, 1998).

Summary of the Model of New Normal
- Illustrates the overriding chronic sorrow experienced by parents of chronically ill children.
- Depicts a desire for equilibrium, or a ‘new normal’, in an effort to avoid crisis.
- Promotes a healthy state of ‘new normal’ by maximizing functionality of balancing factors through repatterning.
- Describes the relationship between the impact of stressors and the functionality of balancing factors.

Balancing factors include perception of the problem, coping mechanisms, and support systems (Aguilera, 1998).

- Perception of the problem:
  - refers to the framing mechanism by which one assesses threat or attaches meaning to an event or situation.
  - is affected by past experiences, reality base, and emotional tone.
  - may be distorted by overgeneralized or unrealistic insights, contributing to a dysfunctional view and greater risk for crisis.

- Coping mechanisms:
  - are those behaviors that allow one to deal with threats or stressors in daily life situations.
  - that are functional serve the purpose of attempting to regain a state of equilibrium.

- Support systems:
  - comprise a variety of assets, both people and resources, which bolster one’s capacity to handle stressors.
  - include people who are recognized as trusted and knowledgeable advocates who will provide guidance, coaching, emotional relief, assistance with health-related decisions, or coordination of care.

Conclusions
The Model of New Normal is suggested for application to parents experiencing chronic sorrow in caring for a child with chronic illness.

The model presents an alternative perspective allowing for normalizing the experience through the use of repatterning to change the impact of stressors and the functionality of balancing factors.

Implications
- Practice: Parents experiencing chronic sorrow are often categorized as depressed or abnormal in their feeling states. Proper assessment can identify the occurrence of chronic sorrow and allow for timely interventions to promote repatterning towards a ‘new normal’.
- Research: The efficacy of the model in specific circumstances needs validation through research. Potentially, the model could apply to other situations where populations experience chronic sorrow.
- Education: Providing education for health care professionals on interventions related to finding a ‘new normal’ is necessary so they may properly assess and educate parents about chronic sorrow.