

## **Caring for the Caregiver: Emotional Challenges of Pediatric Palliative Care Nurses**

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**Abstract:** Pediatric Palliative Care (PPC) nurses provide quality-of-life for critically ill children. This paper looks at how PPC nurses cope with caregiver emotions within the conceptual framework of emotional labor and emotional intelligence.

“Maybe this was just a lesson from life and by tomorrow, the tumor would miraculously disappear. I could only hope. That night, the doctors sent us home for rest, but after they told us that our daughter had only 135 days to live . . .” (Desserich, 2009, p.8). This quote is from a parent whose six-year-old daughter was diagnosed with terminal brain cancer. Pediatric nurses have to face patients and families like these on a daily basis. An average of 56,000 children dies every year in the United States (Browning & Solomon, 2005). Pediatric Palliative Care (PPC) nurses provide quality-of-life for critically ill children who have little chance of survival (Liben, Papadatou, & Wolfe, 2007). “Such care includes the family and extends into the domains of physical, psychological, social and spiritual wellbeing” (p.1).

Constant face-to-face contact between nurses and patients obliges nurses to suppress their true emotions. Suppressing emotions is difficult. Hochschild (1983) defines emotional labor as putting on an appropriate face, regardless of actual emotion. Emotional intelligence is described as the ability to recognize and express emotion, “assimilate emotion in thought,” and reflect and regulate emotion in oneself and others (Mayer, Salovey, & Caruso, 2000, p. 396). PPC professionals face constant emotional situations and are at risk for emotional overload (Sandgren, Thulesius, Fridlund, & Petersson, 2006; Zander, Hutton, & King, 2010). Pediatric nurses undergo extensive medical training, but often lack emotional and psychological training (Browning & Solomon, 2005; Papadatou et al., 2002), leading to stress and burnout (Kedem & Bagan, 2005). Emotional psychological education in palliative care is “sporadic and fragmented” (Liben et al., 2007, p. 8). PPC nurses face strong challenges when children suffer, die, and families grieve. This paper looks at how PPC nurses cope with caregiver emotions within the conceptual framework of emotional labor and emotional intelligence.

### **Emotional Labor: Three Perspectives**

There is no established definition of emotional labor, but three main perspectives around the common theme that individuals can adjust emotional expressions in social settings. Hochschild (1983) is perhaps most well known for focusing on the idea of emotional labor with a study showing how airline attendants had to put on a *happy* face at all times, regardless of true feelings, to fulfill the company's service requirements. Hochschild defines emotional labor as putting on an appropriate face regardless of actual emotion:

This labor requires one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others—in this case, the sense of being cared for in a convivial and safe place. This kind of labor calls for a coordination of mind and feeling, and it sometimes draws on a source of self that we honor as deep and integral to our individuality. (Hochschild, 1983, p. 7)

The sustenance of the outward face is accomplished through surface-acting; a regulation of observable emotional expressions (Grandy, 2000). Deep acting is "where one consciously modifies feelings in order to express the desired emotion" (p. 96). Hochschild makes evident how the effort of emotion modification, realized or not, creates internal tension.

Ashforth and Humphrey (1993) define emotional labor as the act of displaying appropriate emotional behaviors with the aim of expected task effectiveness. This display hinders a person's sense of authentic self. Although Ashforth and Humphrey agree with the notions of surface acting and deep acting, they disagree with the focus on the emotion regulation for the benefit of the service provider; rather, the focus is on client satisfaction.

The third perspective put forth by Morris and Feldman (1996) delineates four dimensions of emotional labor: (a) occurrence of emotional displays, (b) extent of interaction and duration of intensity of emotions, (c) diversity of emotions required, and (d) emotional dissonance. Emotional dissonance creates a sense of malaise within the individual with a tug-of-war between wanting to express true feelings and needing to display proper sentiments. The extent of interaction based on intensity of emotions parallels Hochschild's surface acting; however, Morris and Feldman go deeper into the negative consequences of the provider's discord between actual emotions and the false display of emotions. The purposeful use of emotional labor serves as a beneficial outlet for the service provider in terms of offering an appropriate atmosphere, yet may also serve as a detriment leading to burn-out and additional stress. The next section links the components of the described emotional labor concepts to PPC nursing.

#### **Emotional Labor in Relation to PPC Nursing**

Therapeutic relationships between PPC nurses and patients develop through long-term duration of the care process, which involves intense emotions (McQueen, 2004). This relates directly with Morris and Feldman's dimension dependent on duration and intensity of emotions. The emotional bond creates a vast sense of loss when the young patient dies. PPC nurses expectedly experience emotions of anger, sadness, anxiety, and helplessness (Morgan, 2009). Not only do PPC nurses have to deal with their own emotions, but they are often the target of frustration and anger from the patients and their families. In a study of Greek nurses who cared for children dying of cancer, nurses grieved with greater frequency than physicians over the loss of the special relationship they had developed with the patient (Papadatou et al., 2002).

Emotional labor, from all three perspectives, allows PPC nurses to put on an appropriate face through surface acting when dealing with the difficult and traumatic situations when caring for dying children and their families. "A dead child and you are alone—unable to talk about it, not even to say a word to some other person" (Papadatou et al., 2002, p. 8). This is a quote from a 33-year-old female PPC nurse expressing her frustration. Nurses are expected to remain strong when faced with suffering and death (Liben et al., 2007). Nurses can be described as "emotional jugglers who are able to match face with situation but not necessarily with feeling" (Bolton, 2001, p. 86). Ashforth and Humphrey would argue that the goal is to reinforce the service outcome, in this case, to provide a sanctuary for the sick, not to provide the nurse with a tool for self-purpose.

Additionally, the frequency of interaction and intensity of emotions plays a unique role with PPC nurses. Critical patient care is constant and intense when every patient's outcome is usually extreme suffering and death. Working under such stressful circumstances requires that nurses give of themselves, which can have personal costs (Swanson, 1993; Watson, 1990). "The more emotionally demanding the circumstances, whether due to intensity, acuity or length of contact time, the more important it is to learn to balance the two- engagement and detachment"

(Henderson, 2001, p. 133). It is precisely this strain between engagement and emotional disconnect that defines emotional dissonance.

Emotional dissonance resonates strongly in PPC nursing. Traditional nursing programs promote the concealment of true emotions to maintain a professional stance (McQueen, 2004). In a study by Henderson (2001), nurses expressed deep concern about the emotional engagement versus detachment as a component to meeting the expected organizational objectives:

An approach of detached concern forces health professionals into a paradoxical bind; on one hand, they are expected to show concern by becoming emotionally involved, and, on the other hand, they are expected to maintain intellectual distance in order to preserve their objectivity. They are consequently taught to dissociate their emotion from their thinking. (Papadatou, 1997, p. 58)

As a result, the stressful environment and internal dilemma can lead to emotional exhaustion for nurses (Kedem & Bagan, 2005; Sandgren, Thulesius, Fridlund, & Peterson, 2006). Institutions reinforce nurse alienation by discouraging any expression of grief (Liben et al., 2007). Stress and tension from continuously concealing true feelings of distress can lead PPC nurses to emotion overload and eventually to burnout.

Burnout is a term created by Freudenberger (1977) to describe physical and psychological distress. PPC nurses can experience burnout, grief, and overall stress due to constantly concealing their emotions. Nursing is considered one of the high-risk professions with respect to burnout because of the continuous exposure to patients in need as well as their family. Grief is defined as a "process that comprises a person's grief responses and coping strategies in his or her attempt to adjust to an experience that is perceived as a loss and accommodate it into one's life" (Papadatou et al., 2002, p. 2). A study of a neonatal intensive care unit showed only 4 out of 12 nurses remained in place due to burn-out (Morgan, 2009). Clinical findings in a study of Greek PPC nurses suggest that in order to cope effectively with the death of young patients, nurses need to go through a grieving process taking into account the "fluctuations between experiencing and avoiding grief" (Papadatou et al., 2002, p. 11). PPC nurses have to alleviate anxiety and suffering of patients and patients' families, in addition to easing their own feelings of grief.

While the benefit of using emotional labor is evident in helping nurses provide personal and warm environment to patients despite the nurses' state of mind, it is important to recognize the detriment of the status quo. Nurses need to be able to explore their feelings and have an emotional outlet to share and work through those feelings (Papadatou et al., 2002). The purpose of emotional labor is to promote the feelings of being cared about in others, but who cares about the caregiver?

### **Three Models of Emotional Intelligence**

Currently there are three major models of emotional intelligence: (a) the Mayer-Salovey model which defines EI as the ability to perceive, understand, manage, and use emotions to facilitate thinking (Mayer, Salovey, & Caruso, 2000); (b) the Goleman model based on five areas such as knowing one's emotions, managing emotions, motivating oneself, recognizing emotions in others, and handling relationships an array of emotional and social competencies that contribute to managerial performance (Goleman, 1995); and (c) the Bar-On model which describes emotional intelligence as a cross-section of interconnected emotional and social competencies, skills, and facilitators that impact intelligent behavior (Bar-On, 2006).

Mayer and colleagues (2000) classify emotional abilities into four categories. The first category represents perception and expression of emotion, where one identifies and expresses

self-emotions and the emotions of others. The second classification entails recognition and assimilation of patterns of emotions. The third area pairs emotions with actions. Anger and frustration come about because of injustice or unfairness. "Emotional intelligence involves the ability to recognize emotions, to know how they unfold, and to reason about them accordingly" (p. 400). The final and most complex grouping involves self-reflection and regulation of emotions. It is in this final area, where emotions are dissected, analyzed, and regulated, permitting closure and emotional growth. The Bar-On and Goleman models not only incorporate abilities as classifications, but also add non-ability traits, such as "personal independence, self-regard, and mood" (p. 402), making these mixed models of emotional intelligence.

In contrast to the interpersonal aspect of emotional labor, emotional intelligence depends on the intrapersonal ability to effectively understand and articulate true emotions. Emotional intelligence means to effectively manage personal and social change by rationally coping with circumstances. To be emotionally and socially intelligent is to effectively understand and express true emotions, to understand and relate well with others, and to successfully cope with daily demands, challenges and pressures (Bar-On, 2006). This presents the rationale for emotional intelligence to play a significant role in PPC nursing.

#### **Rationale for Emotional Intelligence in PPC Nursing**

Although emotional intelligence has been emerging in psychology literature for more than 15 years, its application to the nursing profession is more recent (Akerjordet & Severinsson, 2007; Smith, Profetto-McGrath, & Cummings, 2009). In addition to technical health skills, a central element in nursing is caring (Swanson, 1993; Watson, 1990). However, caring is twofold. In nursing, caring for someone is generally associated with physical tasks, but in pediatric palliative care, nurses care for and about their patients (McQueen, 2004). An education that disregards the value and development of emotions is one that "denies the very heart of the art of nursing practice" (Freshwater & Stickley, 2003, p. 93). Emotional intelligence allows nurses to acknowledge their emotions, rather than suppress their emotions (McQueen, 2004).

"There is a call within nursing scholarship to explore the influence of emotion within caring relationships, health and healing, and organizational contexts" (Smith et al., 2009, p. 1624). PPC nurses must respond not only to patient emotions on a daily basis, but also to self-emotions, a task that is customarily overlooked. Smith et al., (2009) affirm the importance of using and supporting emotional intelligence skills related to stress in nursing to improve future retention rates. Nurses use emotional labor as a bookshelf to shelve emotions, but need to engage in emotional intelligence to process the shelved emotions for personal resolve.

This section shows how the use of emotional labor is an explicit tool for self-protection and how emotional intelligence could be useful in ameliorating the backside of those stored emotions, using two specific examples found in the literature. Clarke and Quin's (2007) study on the emotional cost of providing palliative care identifies a nurse's expression:

With muscular dystrophy you might know the child for 16 or more years, so there is a lot of closeness there, so that's very distressing. I think the relationship is built up . . . then when the child has died and the family is not sure "can I stay in contact?" The parents always want to come back, they need that. (p. 1227)

In line with the fourth dimension of Morris and Feldman's model of emotional labor, the duration of the intensity of the relationship plays a significant part in this instance. The nurses have shelved emotions throughout the long caring process. The family moved on to grieve with support from the nurses, yet "negotiating these endings was also important to the caring professionals" (Clarke & Quin, 2007, p. 1227). Instead of a dead end to pent-up feelings,

emotional intelligence models permit the nurses to become aware of these emotions through a process of self-reflection. Although “understanding and labeling feelings does not diminish their intensity” (Papadatou, 1997, p. 588) it does help prevent burn-out by airing out and working through emotions. Morgan (2009) reports a story from a pediatric oncology nurse. The nurse had been taking care of a 10-year-old girl and was informed one afternoon that the child’s cancer was out of remission and she was going to die:

The nurse recalled the little girl screaming and repeatedly saying that she was not going to die. The nurse stood silently almost in shock from the news and fear for the child. She did not know what to say. She just held the child’s hand and silently said a prayer.  
(Morgan, 2009, p. 88)

Morgan points out the heavy emotional burden this nurse faced. In terms of emotional labor, the nurse remains silent and stoic in front of the dying child, yet is experiencing extreme sadness and distress. Mayer and colleagues’ (2000) model of emotional intelligence describes this as the third stage of emotional intelligence, pairing emotion with reaction. A step further in the model would be to analyze and break apart the emotions to permit closure.

### **Implications**

PPC nursing programs would benefit from implementing training and education components that include both emotional labor and emotional intelligence as tools allowing nurses to be prepared to face demanding emotional work. Emotional labor provides nurses with an immediate outlet to put on an appropriate face in front of dying patients and their families and to ensure a safe and caring environment. In this sense, emotional labor is a tool for explicit support of PPC nurses. Emotional intelligence is a tool for implicit support of nurses that provides a method for validating and working through their own feelings of stress, grief, and sadness. PPC training should not be aimed solely to knowledge and skill, but also to the emotional support that will prevent burn-out and grief (Liben et al., 2007). Training may not reduce the intensity of emotions when dealing with death or suffering, but it can help nurses fluctuate their feelings by experiencing grief and preventing burn-out (Liben et al., 2007).

We propose a model shown in Figure 1 of continual interaction, not necessarily linear or circular, but integrative and situational. The external facet entails the nurse using emotional labor in a specific situation to benefit the patient. The internal facet includes the integration of all components in the model. Although the external and internal dimensions can be simply labeled and recognized, the complexity lies in the phases or instances of the interaction of the four components. Emotions can lead to the use of emotional labor and emotional intelligence in order to validate the nurses' emotions. However, it can also be that through use of emotional labor, nurses are forced to suppress their emotions. The sheer recognition of needing to suppress emotions indicates nurses' use of emotional intelligence to cope with the situation. There is no starting or end point in this model. The presence of emotional intelligence is essential to counterbalance the stress of emotional dissonance brought on by emotional labor.

Increased awareness and management of emotions within the realm of PPC nursing can lead to less stress and burn-out. Establishing a structured link between emotional labor and emotional intelligence may contribute to a better handling of stress, sadness, and grief by providing useful coping strategies. Emotional balance is beneficial to the nurses, patients, and employers. As important as it is for nurses to provide the right face at the right time, it is equally as important for them to have a means to work through their true feelings of distress. Further studies on the effectiveness of emotional labor and emotional intelligence, specifically of PPC nurses, are needed to explore how best to care for the caregiver.

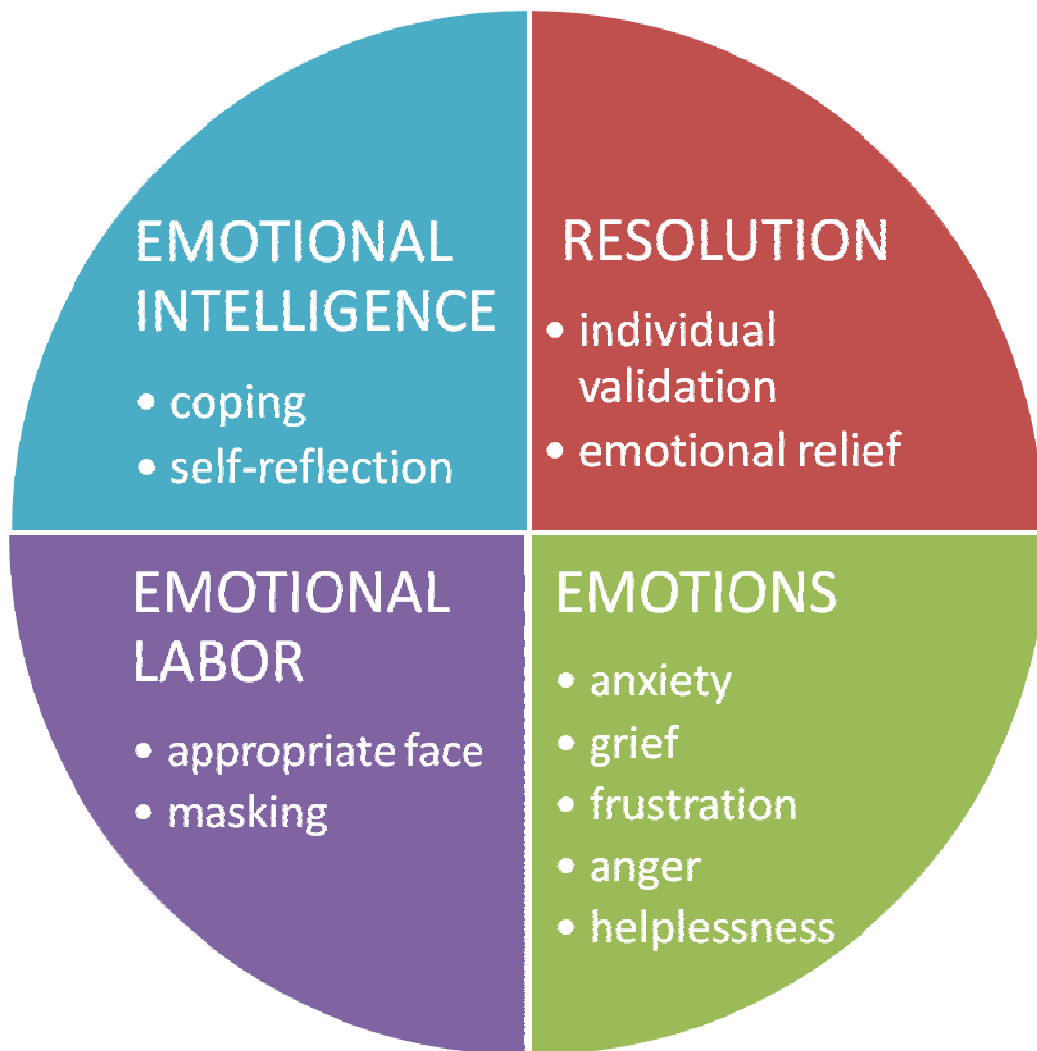


Figure 1. Proposed model of interaction of emotional labor and emotional intelligence.

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