Psycho-emotional Stress in Pediatric Cardiac Units

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Abstract
Healthcare professionals working with cardiac patients routinely confront emotionally challenging situations. Whether delivering bad news to families during the prenatal period, helping families make difficult decisions about treatment options, providing care to critically ill children, or experiencing patient losses, the cumulative experience of this work may have lasting impact on providers. A vast literature documents the psycho-emotional distress of critical-care providers, detailing experiences with constructs including burnout, compassion fatigue, secondary trauma, and moral distress. Characterizing such experiences and examining the contexts in which they emerge is essential for supporting the well-being and increasing the longevity of professionals working in critical-care environments.

Keywords
Burnout • Compassion fatigue • Coping • Critical-care providers • Death of a child • Difficult conversations • Emotional distress • Ethical issues and end-of-life • Giving bad news • Grief • Healthcare providers • Hypoplastic left heart syndrome • Moral distress • Pediatric palliative care • Perinatal imaging • Prenatal diagnosis • Secondary trauma

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Introduction

Psycho-emotional Stress

Unfortunately not all patient stories have a happy ending, and some may involve a long and stressful journey affecting not only families but healthcare providers as well. Psycho-emotional stress is a broad term that encompasses a variety of negative emotions including anger, guilt, helplessness, as well as several interrelated concepts such as moral distress, compassion fatigue, secondary trauma, and burnout. Described as the cost of working in a high stress, high-acuity environment across medical subspecialties and critical-care environments, this stress is most frequently manifested when provider team members are in conflict over patient-care goals or when personal values are different from patient and family values.

Consider the following hypothetical case:

A 5-day-old term male infant presented to the emergency room at a rural hospital after 2 days at home with cyanosis, poor feeding, and floppiness. An emergency room echocardiogram revealed previously undiagnosed hypoplastic left heart syndrome (HLHS). The infant was transported to a tertiary care children’s hospital and stabilized in their cardiac intensive care unit (CICU) with prostaglandins, intravenous fluids, and vasoactive drugs. A stage one Norwood procedure was performed and was relatively uneventful. The infant returned to the CICU intubated and on moderate dose epinephrine and milrinone for poor ventricular function. During the first night, his blood pressure and tissue perfusion abruptly decreased, and despite escalating epinephrine and intensive metabolic management, he required emergent ECMO support. His function improved over several days, he was weaned off ECMO, and his chest closed after 3 days.

For the next 18 days, this infant remained in the CICU for widely varying oxygen requirements and slow advancement of feeds. His 19-year-old mother stayed at her son’s bedside as much as possible but had two other children at home, a 6-h drive from the hospital. She was aware of the serious nature of her son’s condition, but emphasized she understood the surgical plan and complications for HLHS and wanted “everything done” for her baby.

Because of his deteriorating hemodynamics, the infant was taken to the cardiac catheterization laboratory where he was diagnosed with pulmonary hypertension and placed on an oscillator and inhaled nitric oxide. He began to have pulmonary hypertensive crises requiring aggressive respiratory support, medical paralysis, and sedation. His cardiac function continued to worsen and he was found to have a stenotic pulmonary vein, possibly eliminating his eligibility for the next stage of the 3-stage surgical repairs for HLHS. A heart transplant was discussed given his tenuous hemodynamics and worsening failure to grow. He was placed on the transplant list despite lack of consensus among nurses, physicians, and surgeons about the appropriateness of continued aggressive care. His mother was rarely at his bedside now, because of her other children but called the unit frequently to obtain updates. The baby was weaned to a conventional ventilator after several weeks but continued to require vigorous resuscitation. The team found these interventions distressing, expressing concerns about causing harm to this baby, as well as voicing concerns about the infant’s apparent suffering and quality of life. At a care conference, disagreement among physicians, nurses, and other staff about the correct course of action led to heated discussions. Staff morale was said to be extremely poor, with several nurses stating, “I don’t know how much longer I can do this.”

This infant remained hospitalized in the CICU for 3 months at which time he was again placed on ECMO for another acute hemodynamic decompensation. His mother was kept informed about her son’s deteriorating condition by phone. She said she understood how serious his condition was and urged the team to do “everything.” Ten days later the infant was unable to be separated from ECMO and he died in the CICU. His mother was unable to make it to his bedside.

In spite of improved surgical techniques and medical management of infants and children with
congenital heart disease, stories like the one described above are an ongoing part of working in critical care. The medical and surgical management may lack consensus among the critical-care team, or else, even if consensual, it may be emotionally demanding, leading to psycho-emotional stress, poor morale, and possibly staff retention issues.

Several overlapping concepts are considered part of psycho-emotional stress and include burnout, compassion fatigue, secondary trauma, and moral distress. While there is considerable overlap among these concepts and they are often used interchangeably, each concept will be discussed separately in this chapter. Additionally, examples of provider stress when giving bad news and facing the death of a child will be discussed, using words from providers whenever possible.

**Prenatal Diagnosis**

Improvements in prenatal imaging, including ultrasonography, magnetic resonance imaging (MRI), and fetal echocardiography, over the last decade have made a four-chamber view of the fetal heart and verifying if the great vessels are well positioned a standard practice. Although some cardiac lesions may develop late in pregnancy, abnormal four-chamber views may detect approximately 50% of congenital heart disease, including fetal arrhythmias and abnormal situs [1]. Care for the affected fetus requires a multidisciplinary approach, including obstetricians, perinatologists, neonatologists, cardiologists, cardiac surgeons, nurses, social workers, and others, all of whom bring a different set of experiences and perspectives to the pregnant woman and her family. In addition to providing valuable information about a fetal cardiac anomaly, when considered within an ethical framework, such information may require uncomfortable discussions and decisions about continuing the pregnancy, fetal interventions, postnatal management, and the possibility of an uncertain outcome. Results from an ultrasound or fetal echocardiogram may provide reassurance when a woman is referred for prenatal concerns.

However, when the news is bad, the healthcare provider often faces parents’ emotions including sadness, anger, or shock. Coping with such bad news impacts not only the parents but also those providers tasked with repeatedly giving the news and having to provide care for the mother and fetus. Providers may cope with delivering bad news by compartmentalizing, as one physician said during an interview (personal communication, July 2012):

“I try very hard to keep how the family responds to the information separate from everything else about my job and my personal life. I try not to think about my own healthy family and how I would deal with this bad news. Yes, it’s hard to see a woman crying because she’s “lost” her perfect baby and it’s even harder knowing my diagnosis may have led to termination of the pregnancy, but I can’t dwell on that. I go home, have a glass of wine, and try not to think about all the families I saw that day. It works for now.”

For other providers, the cumulative effect of giving bad news may lead to finding another position within the institution or leaving cardiology, neonatology, or critical care altogether. As one nurse stated:

“I’m not making a difference because the babies keep dying. All I can think about is the cost to the family and their child with single ventricle disease, the repeated hospitalizations, the strain to the marriage and the lack of available resources. I can’t take it anymore and want to go where I can fix things.

**The Case of the Hypoplastic Left Heart Syndrome**

Dramatic changes in the diagnosis, management, and outcomes for hypoplastic left heart syndrome (HLHS) over the last two decades have changed the discourse. Prenatal diagnosis of HLHS has a prenatal detection rate as high as 85% [2] in major medical centers, with up to 95% of cases of HLHS confirmed on postnatal examination. Survival rates to adulthood with the three-stage approach are close to 70% [3], although there is significant variation among centers. In spite of
improvements in surgical interventions and critical medical management, the optimal approach is still debated, with a lack of agreement on many of the management issues [3]. Of interest are the questions around comfort or palliative care, developmental outcomes, long-term survival, and quality of life.

HLHS accounts for up to 9% of congenital heart disease [2]. With current estimates of 70% infants diagnosed with HLHS surviving to adulthood with good management, comfort or palliative care may be controversial and not discussed in some centers [2]. Wernovsky [4] argued that palliative care is no longer a valid option for HLHS and not in the best interest of the child or the family, because palliative care is offered only out of frustration related to a specific challenging case where a child died with end-stage heart failure years after the third surgical intervention. Many, but not all, physicians are comfortable presenting families with management choices including the three-stage surgical procedures, a hybrid palliation, or cardiac transplantation. A survey of pediatric cardiologists and cardiac surgeons in North America showed that almost all (99.7%) physicians discussed staged surgery, 67% discussed cardiac transplantation, and 62.2% discussed comfort care or palliative care; only 14.9% included all three options in the discussion [5]. The authors stated that recommendations for nonintervention were associated with respondents’ own hypothetical choice of comfort care for their own child or fetus.

Byrne [6] found that physicians have become more optimistic about surgical intervention outcomes with HLHS and may downplay the risks, calling the omission of offering palliative care ethically worrisome. At the same time, Johnson [7] reported that 64% of physicians and 62% of nurses reported discussing comfort care with parents. Kon [8] maintains that more educated parents with access to the Internet will find out about palliative care on their own, potentially disrupting parents’ trust in their physician if not brought up as an available option.

A decade ago, palliative care, cardiac transplant, and the three-stage surgical reconstruction were all discussed equally with families; pregnancy termination of an affected fetus was also mentioned [9]. The discussion centered around survival with an emphasis on autonomy and supporting family decisions through provision of impartial information about survival statistics and comorbidities (e.g., neurodevelopmental delays). Zeigler [9] briefly refers to the importance of providers attending to their own values and contributions to the discussion with the family, without acknowledgement of the effect of such discussions on providers. A recent study from the UK with similar responses indicates that 50% of parents with a prenatal diagnosis of HLHS before 20 weeks gestation would terminate [10] but highlights that counseling parents is difficult for the physician.

While some providers feel comfortable discussing how they would handle HLHS management for their own child [11], most prefer nondirective counseling that maintains boundaries between their personal and professional attitudes. In studies examining the choices nurses and physicians would make if their own or a family member’s pregnancy involved HLHS, 48% would terminate, 22% would continue the pregnancy, and 30% did not know what they would choose [12]. In a similar survey, 43% of pediatric residents and 50% of nurses reported they would terminate if faced with a prenatal HLHS diagnosis and 48% of residents and 68% of nurses chose or seriously considered comfort care with HLHS diagnosed postnatally, citing concerns about long-term quality of life and survival [13].

Such research suggests that while providers counsel families toward intervention, when personally facing an HLHS diagnosis, their choices become more ambiguous. Providers’ differential responses and ambiguity around decisions reflect a tension between the professional and personal arenas that surfaces in critical-care environments. Although providers operate under institutional and professional practice parameters, they bring their own values, beliefs, and expectations to critical-care cases and, consequently, to their interactions with patients, families, and other professionals. When a discrepancy exists between the professional and the personal beliefs,
providers may experience discomfort, distress, and potentially more impairing emotions that directly impact the work they are tasked with doing. The conscious efforts to suppress their own feelings and maintain composure during interactions with families [14] may further exacerbate the situation.

**Giving Bad News**

It is commonly accepted that children and their parents are physically and emotionally stressed by being in the hospital and particularly with high risk cardiac surgery or an intensive care unit stay. Receiving bad news about a child’s medical condition is also known to produce an acute stress response for family members. The consequences of delivering bad news on providers are less understood, with little information about the cumulative effect of stress on healthcare professionals. Ptacek and McIntosh [15] suggest that giving patients bad news about their medical condition is stressful for providers, especially medical students and residents early in their careers. Other authors [16] suggest that critically ill patients may elicit physicians’ own emotions and can reflect a need to rescue feelings of failure and frustration, as well as powerlessness. The tendency to distance from intense emotions may affect the physicians’ sense of well-being because unexamined emotions may lead to distress, disengagement, burnout, and poor judgment.

Physician stress appears to increase with the perception that the delivery of information did not go well, and many physicians report enduring stress beyond the patient encounter that may impact subsequent patient interactions. Cohen [17] postulated that physicians experience an acute stress response beginning with the anticipation of the actual delivery. The only study of pediatric cardiologists [18] suggests providers must be aware of parents’ feelings as well as their own emotions and know how to keep everything under control. In this study, the authors also state that some cardiologists can create a closer relationship with parents by sharing stressful news, while others prefer more distance and argue they are careful about getting too close to families. Interestingly, cardiologists were asked what caused the most distress, and most felt making an incorrect diagnosis or a breakdown in communication with the family was more distressing than actually delivering the bad news.

**Death of a Child**

Nurse and physician experiences of the death of an infant or child they have cared for are possibly the most distressing aspect of working in the healthcare field. With death commonly described as a physician’s personal failure or failure of the team [19–21], the impact of a patient’s death can be long-lasting and associated with compassion fatigue, moral distress, or burnout. Jackson et al. [19] reference physicians’ descriptions of a particular patient’s death as a critical incident in their career, with lasting implications for how physicians care for other patients. In this study, physicians were most distressed when they had a recent personal experience with loss, identified with a patient or family, had a close relationship with the patient or family and the death was unexpected or traumatic, and finally if they had a sense of accountability for the death. As one physician stated when pronouncing death for a patient she does not know:

...I did as all of us have done, have had to do: I stopped thinking about her life, her hopes, her dreams, even her family, and did my job...I went home [afterwards] and tried to never think about this patient again. And when my husband kissed me and asked how my day was, I just answered, ‘Fine,’ with a smile. [22]

This response is seen as the only possible response in a busy day – to shut off emotions quickly and keep all negative feelings in check so they never get in the way of doing your job. The tendency to suppress feelings because of the need to take care of the next patient may result in the accumulation of unresolved grief. In the USA, approximately 15% of physicians are thought to experience clinical impairment at
some point in their careers with rates of anxiety, depression, and suicide higher than in the general population [14].

Physicians and nurses often suffer after the death of an infant or child yet frequently work in clinical settings where grief is inadequately acknowledged or even denied. Unit culture may have unwritten, unspoken rules about appropriate behavior when a child dies [20]:

It was expected that grief responses would never be so intense as to impair clinical judgment or lead to emotional breakdown. Suffering should never be apparent to other sick or dying children.

Suffering and grief may be seen as a sign of weakness, with the expectation that a good nurse or physician is invulnerable, strong, in control, and able to effectively cope with painful or distressing experiences [20].

Some physicians became emotionally shut-down and reported little emotional reaction at the time of the patient’s death, only to have “unexplained” problems later. Unprocessed emotions and grief responses may manifest in ways that are not immediately evidenced or understood by the individual. As one physician stated (unpublished data), reflecting on the death of a patient many years previously, “I will never find a resting place for that one.”

Findings from Papadatou’s work suggest that physicians’ and nurses’ grief is a dynamic interpersonal and interpersonal process for those working with critically ill infants and children where pain, suffering, and death are expected events and part of being a provider. Responses to grief may include recurrence of both positive and negative thoughts about the patient, sadness, depression, anger, and crying. Some providers seek peer support, while others prefer coping privately. Expressions of grief may come close to the patient’s death or long after and may be different for physicians than for nurses [23–25].

The lingering sequelae of distress and unresolved grief can be manifested in compassion fatigue, burnout, and moral distress. Many providers are able to recall distressing events years and even decades later. Some are able to process the experience and learn from their experience, while others become distraught with the continuing suffering, repeated hospitalizations, and death of the child. It is important to understand the cost of working in pediatric critical care with infants and children diagnosed with congenital heart disease.

### Burnout

Physician distress has received increased attention in the last decade with stress and burnout considered so pervasive to be called a public health issue [26] and linked to increased rates of self-medication, alcoholism, depression, and anxiety as well as poor patient care [27–29]. It has become part of the everyday vocabulary as when a healthcare provider says he or she needs a break or that he or she is “burned out.” Burnout is not unique to a particular specialty area, affecting surgeons [30], oncologists [31], intensivists, obstetricians [32], and emergency or trauma physicians. Nurses are by no means immune to stress and burnout, which increases the risk of nurses leaving critical care or the nursing profession altogether. Additionally, burnout is not a US phenomenon with studies from Italy [33], Canada, the UK, and Germany [34] reproducing similar findings.

Burnout has been best described by Maslach and colleagues, developers of the Maslach Burnout Inventory (MBI) [35]. Burnout is defined as a “prolonged response to job stressors and measured by three dimensions: sense of overwhelming exhaustion, feelings of cynicism and detachment, and a sense of ineffectiveness at work or lack of accomplishment” [36]. Often used interchangeably with compassion fatigue, secondary trauma, or the more global distress term, subtle differences distinguish burnout from these other concepts. Maslach et al. describe exhaustion as the central quality of burnout and the most commonly reported but explain that exhaustion alone is not sufficient to portray the experience. Exhaustion frequently leads people to distance themselves, emotionally and
cognitively, from the source of the exhaustion, the healthcare providers, and the patient or family. Additionally, there seems to be a strong relationship between exhaustion and cynicism, or depersonalization. The association of the third dimension of burnout, inefficacy, or a sense of lack of accomplishment, to the other two is less clear. Burnout is important to identify and address in healthcare providers, especially those working in critical-care, oncology, and trauma units.

Many studies have focused on medical students and residents with concerns over serious potential consequences for student’s health, professionalism, and patient care [28, 30, 37–39]. Additionally, burnout has been related to the quality of care physicians provide, affecting empathy and compassion, prescribing habits, depression, and the likelihood of making medical errors [40, 41].

Thought to be more common among nurses than physicians, many studies focus on the emotional exhaustion associated with burnout. In a large, six-country study of 54,000 nurses from the International Hospital Outcomes group, higher levels of burnout were associated with the provision of lower ratings of quality of care [34]. Pardoe [42] talks about the pediatric intensive care nurse emotionally devastated when her patient attempts suicide and her struggle to return to work. While some studies have focused on burnout rates among oncology, hospice, emergency department, and intensive care nurses and their association with increased use of alcohol and drugs, increased anxiety, and depression, others report that critical-care nurses are at no higher risk than other nurses [31, 43–45]. In a study comparing burnout across provider types (i.e., nurses, physicians, and residents), Hyman et al. [46] found global burnout scores higher in perioperative physicians than nurses and highest among residents suggesting that this phenomenon is by no means unique to nursing and perhaps may impact physicians more profoundly. Other studies have not found differences between physicians and nurses but found higher rates of burnout among providers with fewer years of experience [47].

Compassion Fatigue

Often used interchangeably with secondary trauma and described most frequently with emergency or trauma care providers, compassion fatigue is now thought to be a growing problem among all healthcare providers. It has been referred to as a “routine occupational hazard of exposure to working with the critically ill child” [48]. According to Meadors [49], there are nuanced differences between the symptoms of compassion fatigue, post-traumatic stress disorder (PTSD), secondary traumatic stress (STS), and burnout. Overlapping symptoms, interchangeable usage, and the lack of conceptual clarity make it difficult to distinguish among these constructs.

Figley [50, 51] attributes symptoms of compassion fatigue to the consequence of the empathic individual working with traumatized people, saying “those who work with the suffering suffer themselves because of the work.” Hallmark signs of compassion fatigue have included sadness and grief, nightmares, avoidance, addiction, increased psychological arousal, detachment, and witness guilt [52]. Some attribute compassion fatigue as caring too much [53], as losing the capacity for compassion [54], or as a result of being good at empathizing [55]. In spite of the difficulties in identifying differences between compassion fatigue, secondary trauma, and burnout, there does seem to be a negative effect on providers, physicians, and nurses alike, resulting in decreased productivity, more sick days, and a higher rate of turnover [56]. Oncology nurses are thought to be at high risk of compassion fatigue because of the constant exposure to suffering [57] and the exposure to children’s death [58]. Pediatric emergency department nurses [45] are also thought to suffer from compassion fatigue because of the societal value of protecting and caring for children [48, 49].

Several scales used to measure compassion fatigue and secondary trauma include the Secondary Traumatic Stress Scale, the Compassion Fatigue Self Test for Helpers, the Compassion Fatigue Scale-Revised [59], the
Compassion Satisfaction and Fatigue Test, and the Interpersonal Reactivity Index [48]. Compassion fatigue or secondary trauma may be difficult to measure because of the “culture of silence” often seen in critical care with admission of suffering seen as a professional weakness [48]. Study results of prevalence and specificity of compassion fatigue are mixed [60], and many using these scales are difficult to interpret because of limited sample sizes and inconsistent use of such scales. However, because of the negative impact on providers as well as patients, it is important to address provider suffering and to develop appropriate interventions.

Moral Distress

Moral distress, experienced by healthcare providers, has received increased attention in the past 5 years in both the popular and medical literature with the growing recognition of the physical and emotional toll on providers as well as on institutions with retention and medical errors. Originally defined by Andrew Jameton in 1984 to describe critical-care nurses’ experience of knowing the right thing to do but prevented by institutional constraints [61], the concept has grown to include physicians, social workers, and other healthcare providers. The focus is on both physicians and nurses. While the patient-care experience may be different between these two groups of caregivers, the two disciplines have more in common than previously thought. Based on principles of moral theory, understanding moral distress in critical care is essential because it influences how patient-care decisions are made and how the unit functions as a team.

In the broadest sense, personal moral theory refers to how providers evaluate choices and decisions in the critical-care environment as “right” or “wrong.” Timmons [62] posits that the purpose of moral theory is to examine the underlying features of actions that make them right or wrong, good or bad. Finally, role expectations refer to what one “should” do as a professional in a given situation [63]. For example, a nurse may say “my job is to support the family and to be a patient advocate,” while a physician may define his or her role as making the best decisions about care for this family using his or her clinical expertise and judgment. Oberle and Hughes state that both physicians and nurses experience institutional constraints on moral agency while remaining ignorant of each others’ limitations [63]. Other factors including age, gender, religious affiliations, or cultural background may contribute to how providers respond to critical-care situations.

Jameton expanded his definition to differentiate initial moral distress, where the nurse confronts a disturbing situation and experiences feelings of discomfort, frustration, anger, and anxiety, from reactive distress with reflection on the inability to act on the initial distress [61]. Reactive distress may have longer-lasting consequences, including physical symptoms such as heart palpitations, loss of self-worth, and depression, ultimately leading to job dissatisfaction and nurses leaving the profession entirely [64]. Fry et al. identified symptoms such as crying, loss of sleep, loss of appetite, nightmares, feelings of worthlessness, loss of confidence, heart palpitations, changes in body functions, and headaches when unresolved moral distress occurs over time [65].

Growing from approximately 35 articles identified in PubMed in the 1990s to over 200 between 2000 and 2010, nursing moral distress has been associated with powerlessness in hospital settings [66–69], failure to uphold patient autonomy [70], witnessing patient harm or suffering [67, 71], poor ethical climate [72], and end-of-life issues with overly aggressive care or the perception of futile care [73]. Increasingly, nurses attribute symptoms of physical, emotional, and social problems to moral distress [65, 68, 74], including feelings of sadness, anger, and frustration; physical symptoms such as headache, neck pain, and muscle pain; and reluctance to come to work, emotional or physical withdrawal from others, or reluctance to take on patients with complex ethical issues. Paradoxically, moral distress among nurses has also been reported to enhance relationships with other nurses and an increased desire to advocate for patients [74].
Experiences of moral distress involve complex patient-care issues, are not easily measured, and are rarely resolved. Moral distress has been identified as a grave area of concern particularly among critical-care nurses because of high patient acuity and high levels of stress, often leading to high turnover rates. The American Association of Critical-Care Nurses’ position statement on moral distress challenged nurses and their employers to address the consequences of moral distress [75]. Intensive and critical-care nurses experience high levels of moral distress; new and inexperienced nurses may experience tremendous stress because of patient situations or communication and collaboration failures among nurses and physicians [70]. These new nurses may experience secondary trauma witnessing or participating in distressing situations such as aggressive futile care of patients, with feelings of guilt or incompetence. Acknowledging the negative effects of unresolved moral distress, some institutions have developed educational programs and debriefing sessions to try and mitigate nurses’ experiences of moral distress [76, 77].

Corley conducted rigorous and systematic work on moral distress and developed the Moral Distress Scale (MDS) [78, 79] that measured levels of distress as well as intensity. Corley found that inadequate staffing causing the most distress with 15–26% of nurses reporting they had resigned a position because of intolerable levels of moral distress. The MDS has been used extensively in studies examining nursing moral distress. Moral distress increases with years of nursing experience, futile care situations, and inadequate pain management situations, as well as experience caring for oncology and transplant patients [80], inappropriate aggressive care associated with the highest intensity of moral distress, high rates of job dissatisfaction, and interestingly, nurses’ reluctance to participate in blood and organ donation [81].

While the MDS is the most frequently used scale in studies of moral distress, the scale was normed with both adult and pediatric nurses and physicians were not included in the development. Long thought to be a nursing issue because of the power differential between nurses and physicians, physician experiences have not been discussed until relatively recently. Davis, a physician, recognizes that doctors feel as powerless and frustrated as do nurses when they do not have the ability to make clinical decisions they feel are most appropriate [82] or with institutional constraints on physician authority [83]. Davis states that the physician most typically expresses moral distress with anger, with caustic attitudes or verbal abuse of residents and nurses. Interest in moral distress has reached the popular press as well with a column in The New York Times [84] by Pauline Chen, a surgeon, where she notices moral distress in conversations with nurse and physician colleagues who are caught between competing obligations to patients, insurance companies, and families.

Medical students and residents are often “caught between” competing interests and medical hierarchy [85] but also experience moral distress when witnessing poor patient care, when placed in situations without adequate supervision or training, or when seeing disrespect for colleagues [86–88]. Hamric and Davis [82] discuss that while nurses are particularly vulnerable because of the hierarchy of hospital structure, both nurses and physicians feel powerless in many situations and say that speaking out arouses their fears of criticism. In one of the few studies to include physicians, a survey of perspectives on caring for dying patients in an adult ICU setting showed that physicians did experience moral distress but had higher satisfaction with quality of care perception and of institutional ethical environment and higher perceptions of collaboration [89].

The discussion on moral distress has shifted in recent years from studies describing the nursing experience to examining the range of experiences and the development of moral distress as an umbrella concept [90], while others question whether moral distress can accurately identify a wrong being done to patients [91]. Epstein and Hamric [92] see the definition of moral distress becoming blurred, minimizing the experience to emotional distress over a tragic patient-care situation rather than identifying the issue as an
ethically challenging situation. Moral distress is increasingly described in professions other than nurses or physicians and includes rehabilitation professionals [93], podiatrists [94], genetics professionals [95], respiratory therapists [96], childbirth educators [97], and psychiatric professionals [98]. Recently, specific aspects of moral distress have been examined such as “inappropriate care.” As defined by Piers et al. [99] inappropriateness of care involves specific patient-care situations where the provider acts in a manner that is contrary to personal or professional beliefs, with the most common reasons given by providers as excessive or aggressive care, feeling care was disproportionately provided, and end-of-life decisions being made too late.

Moral distress is variably experienced by healthcare providers. Gaps still remain in the understanding of moral distress in experienced physicians rather than in medical students or residents where moral distress is attributed to their lack of power and position in the hospital hierarchy. There is also a need to better identify differences and similarities in the nurse and physician experience of moral distress in order to develop strategies to support providers in caring for critically ill children.

Conclusion

Providing medical care to critically ill children in pediatric cardiac units can be rewarding and challenging, with opportunities for healthcare providers to make a difference in the lives of these children and their families. For some healthcare providers, the challenges may become stressful, and for a few, it may become overwhelming, leading to psycho-emotional stress. This stress may be manifested at work or involve changes in providers’ personal lives. Constructs including burnout, compassion fatigue, secondary trauma, and moral distress have gained recognition as important issues that need to be openly addressed to improve healthcare providers’ job satisfaction as well as the safe, compassionate, and effective provision of patient care. While it is probably not possible to prevent all psycho-emotional stress, some institutions have implemented programs to address aspects of this stress, including multidisciplinary debriefing sessions, workshops, and conferences. Psycho-emotional stress has also increased visibility in medical school and residency training programs as our understanding of the long-term consequences of stresses such as burnout has grown. Acknowledging psycho-emotional stress among healthcare providers is as important as providing excellent patient care in pediatric cardiac units.

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