ChiPSS Pediatric Palliative Care Newsletter
Issue #24; August, 2011

Edited by Charles A. Corr, PhD, Christy Torkildson, RN, PHN, PhDC,
and Maureen Horgan, LICSW

Issue Topic:
Stress and Moral Distress: Identifying Stressors and Supporting Staff

Welcome to the twenty-fourth issue of the ChiPSS electronic newsletter. This issue of our e-newsletter offers a PDF collection of articles that explore some issues involving stress and moral distress in staff who work in pediatric palliative and hospice care. These are, of course, merely a limited number of the vast assortment of issues that arise in this broad subject area. Nevertheless, we hope this sampler will help to bring out some useful discussions and guidelines for readers of this issue.

This newsletter is produced by ChiPSS (the Children’s Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO’s Communications Work Group, co-chaired by Christy Torkildson and Maureen Horgan. Archived issues of this newsletter are available at www.nhpco.org/pediatrics.

Comments about the activities of ChiPSS, its Communications Work Group, or this issue of the newsletter are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues of this newsletter. Please contact Christy at torkc@sbcglobal.net or Maureen at Maureen.Horgan@providence.org.

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ChiPSS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.
Issue #24: Stress and Moral Distress: How to Identify Stressors and Support Staff
(Click on the “bookmark” tab on the left-hand side of the PDF document for links to the following articles.)

One of the Blessings in a Cancer Journey  p. 4
Kris Forth
Kris bravely shares her journey with her son Brandon and the Providence Hospice Team in Seattle. I recalled all the journeys I have shared with other children and families and how, despite our best efforts and our professionalism, the ties to the families are emotional and professional and we too must deal with loss. Kris lets us know how much this meant to her – something I believe we always need to remember.

A Brief Link from David Browning  p. 6
David Browning, MSW, BCD

Grieving after the Loss of a Patient: Nurses’ Perspectives  p. 7
Alyssa E. Erikson, PhD, RN
Alyssa relates stories voluntarily shared by nurses contributing to a better understanding of their emotional experiences. “Nurses shared incredible stories and depictions of their experiences. It is no surprise that they described a wide range of emotions associated with their work." As Alyssa states, “it is the personal connections, which define the art of healing.”

A Deficit of Care  p. 10
Florence Jennings, PhD
Florence shares with us her research, international in scope, and focused on medical students and residents’ burnout and resilience from the physician’s perspective. The following profound statement gives a hint to the depth of her findings, “…I doubt any medical education can generate sustainable patient-centred physicians, capable of procuring endless comfort and assistance to their patients, while being void of dedicated resources intended to support their own physical and mental health.”

The Cost of Caring  p. 13
Alani Esterhuyse, B.Soc.Sc (SW)
Alani tells the story of Masego, a compassionate home-care worker helping those suffering from AIDS. She shares this heartbreaking story to highlight compassion fatigue and goes on to offer questions to determine if you may be at risk and practical suggestions to help combat compassion fatigue.

Under Pressure  p. 17
Florence Jennings, PhD
In this short article, Florence briefly discusses her research on physicians’ resilience. As she states, “We have to grasp physicians’ humanity not as something to contest, wrestle with, or resist but as the underpinning for enhanced professionalism and empathetic care.”

Walking in Our Shoes: The Experiences of Caregivers and the Challenges of Differing Goals  p. 19
Lori Ives-Baine, RN, MN (CPB), Crystal Hannon, RN, BScN, and Jennie Saini, RN, BScN
All healthcare providers who work in an acute care facility caring for children will be able to relate to the case discussed here. The authors write this article “to review the Interprofessional team perspectives on caring” for a severely medically fragile premature with an extended NICU stay. They discuss how they worked through the moral distress that occurred amongst the team and with the family, and how this impacted their relationships with the family and with each other. They offer specific suggestions and a framework based on their own research and experiences.
**Moral Distress in NICU Nurses**  
P. 26  
Susan Rogers MS, BSN, RN, CHPN  
Susan starts her article with a personal experience with a NICU nurse; however, this article is applicable to all healthcare providers. As she states, “Continuing research to identify moral distress and activities to prevent, monitor and treat the problem are essential to a good working environment for the health of the healthcare community and the quality of patient care.”

**Moral Distress in Pediatric Palliative Care**  
P. 29  
Scott M. Klein, MD, MHSA  
Scott also shares a case study of an infant who started life in the neonatal intensive care unit. As he states, most of the available research is focused on the neonatal intensive care unit staff; however, moral distress can affect any healthcare provider caring for a dying patient. “… it is the very caring nature of the staff that predisposes them to moral distress. If they did not care about doing the right thing about their patients, there would be no conflict. The answer to addressing moral distress is not to stop caring; rather it is supporting each other both at the colleague level and the organizational level.”

**Transforming Moral Distress in Pediatric Palliative Care**  
P. 32  
Cynda Hylton Rushton, PhD, RN, FAAN  
Much of Cynda’s research has focused on moral distress and ethical issues in healthcare. She provides a simple overview of moral distress along with comprehensive “recommendations for expanding the professional repertoire for responding to challenging cases” that can lead to and involve moral distress.

**Strategies and Interventions for “Caring for the Caregiver” in the Presence of Compassion Fatigue and/or Moral Distress**  
P. 38  
Compiled by Ann Fitzsimons, BS, MBA  
Ann provides a comprehensive list of strategies and interventions to help with moral distress and compassion fatigue. Strategies and interventions are categorized into three areas: personal, professional and organizational.

**NICU’s Top Ten Ways Nurses Take Care of Themselves**  
P. 42  
Lori Ives-Baine, RN, MN (CPB)  
Based on a self-care survey completed by nurses April-June, 2011, Lori presents the data in a light-hearted way. Please note the methods reported are the results of a survey of one group of nurses and are not meant as a prescription for all.

**Reader’s Corner: “Changes in Medical Care at a Pediatric Oncology Referral Center after Placement of a Do-Not-Resuscitate Order”**  
P. 45  
Suzanne Toce, MD  

**Items of Interest**  
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Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its Communication Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.
ONE OF THE BLESSINGS IN A CANCER JOURNEY

Kris Forth
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As of February 2nd, 2003 I’d never heard of a brain tumor being found in children, let alone in my own. Brandon had been sick for weeks; we were told it was just a tough virus. On February 3rd, 2003 I had a bad feeling as we drove to the emergency room. My husband was driving so fast that I normally would have been worried, but at this point we could not have arrived quickly enough. Fifteen minutes after walking through the door we were told our son had a large mass at the back of the brain. I remember starting to cry, not because I realized the severity of the diagnosis, but because of the sadness, concern, and fear in the doctor’s eyes and voice.

From 2003 to 2010 my son Brandon fought so hard to battle his cancer into remission. He enjoyed a total of 4 years in a healthy remission. Although some of the side effects from his treatment were permanent and not easy to deal with, Brandon knew that he was healthy, not in the hospital, and happy. If Brandon was happy then I was happy. As his mom that’s all I wanted and all I worked to achieve. My son led me courageously through his battle with cancer and filled me with strength every day.

Brandon’s strength began to diminish as his cancer overwhelmed his body. Seven years after being diagnosed it was obvious that Brandon would not survive his brain tumor. Brandon did not have to say he could no longer fight, it was apparent in his eyes and body, he was done. I was not done, not even close; no parent could prepare themselves to be. But just as Brandon had lead me courageously in his fight he also led me to accept the battle was almost over. I could no longer rally a fighting spirit; I now needed someone to lead me to the end.

My first experience with Palliative and or Hospice care was with my grandmother. Hearing those words meant “the end” to me. Accepting this to be “the end” for my son was too much for my brain and body to accept. I turned down the opportunity to accept Palliative/Hospice care for 6 months. When I finally accepted, I felt defeated, felt like I had given up. Upon meeting Maureen and her team from Providence Hospice I learned differently, much differently.

The Palliative/Hospice care team now led us, courageously through Brandon’s battle. Although the outcome we were moving to wasn’t one of remission and health, it was one where we still worked for happiness, love, closure, and peace. Balancing the end of life for my son and the desire to still smile, live, and love was not easy. Envisioning a life without Brandon here would overwhelm my mind and push out the need to be at peace. Brandon still needed to be cared for, he still needed his medications and to be monitored, you really could not leave him alone. They helped me balance his care, quality of life, and living, living to the end. All of this was so complicated, but the Hospice team showed us how to do this.

Now I was wrestling with the fact that my child was going to die. Emotionally this left me empty at the end of every day. I really needed some help but did not want anyone else taking care of my son. Brandon needed his meds, check-ups, nursing support, and so much more I did not know about. This is where I did not understand hospice. Hospice was all of that to me and more. Not only did hospice attend to Brandon’s needs, medically and emotionally, they also took care of me. Brandon’s hospice teams filled me with confidence in taking care of Brandon and were there to listen to my concerns and questions, and there were many!

I first met Maureen in March of 2009, one year before Brandon would pass away. I was immediately comforted by her “way” with Brandon. She was so calm and patient when meeting him. Her dog,
Dresdan, was an automatic connection for the two of them as Brandon LOVES dogs. Maureen was honest and really took her time when talking with Brandon. She was not over whelming which was a welcomed pace, as life had been so over whelming for the past 7 years.

The experience with hospice became even better when we met the rest of the team. Nurses Ann, Tammy, Elise, and pal Greg were all very professional, at the same time you felt as if you had invited friends over for coffee. At this time in Brandon’s illness, he was fairly withdrawn and not especially excited about “New Visitors”. His hospice team was different. He would look forward to their visits and would plan what he would want to share with them when they arrived. They were so wonderful and patient in his “show and tell”. He would often show the same thing he had a few days prior but they still acted as if it were the first time they had seen it.

In the last year of Brandon’s life he had two very intense and terrifying episodes of seizure activity that modeled the act of dying. If this were to happen in the hospital you had a team of specialist’s right outside your door. At home all I had was me. But, that’s not entirely true. I had Maureen, Tammy, Ann, and Elise. Whether in person or by phone, Brandon’s team knew his case inside and out, talked to his doctors at Seattle Children’s daily, and knew me very well as Brandon’s care giver. They gave me the confidence to manage Brandon’s care at home versus falling back on being in the hospital. It was important to be home for Brandon and for myself. From Late January 2010 to March 20th, 2010 Brandon never went back to the hospital. This is all because of hospice; that is one of the greatest gifts they gave us, being home.

When I started writing this essay it was interesting to me the things I could immediately recall. It was not all of the visits where they took Brandon’s temperature and listened to his lungs, it was the visits where we had fun! It was the visits where we laughed, shared, and cried. To me that is the tragic beauty of hospice; they take care of the patient medically without us even realizing it. They more importantly took care of the living we needed to do during that time.

I feel it so very important to support and create awareness about pediatric hospice. I could not imagine having gone through Brandon’s last year of life without them. I pray no parent has to experience that without the support of hospice. It’s not just any hospice; it really needs to be pediatric. The end of life is not normal for a child and their family. The team, their approach, their tools, and their character need to be special, and I consider the Providence Hospice Team in Seattle to be very special people that I will thank the rest of my life.
A BRIEF LINK FROM DAVID BROWNING

"Navigating well in the swampy lowlands of palliative care means being comfortable with uncertainty and with not having answers while, simultaneously, being able to be present, compassionate, and responsive in the midst of that uncertainty. It is surely the case that having answers, being certain, and fixing problems are important components of professional competence. Nonetheless, professional caregivers who survive and prosper over time have internalized the humility that comes from realizing how imperfect their offerings are while appreciating, at the same time, how these less-than-perfect gifts can really matter in the lives of patients and families coping with life-threatening illness or the process of dying. With humility, we may allow ourselves as practitioners to make mistakes, to acknowledge them, and to keep trying. In situations where we are not at all sure what to do, we can do what we can. At the times when we are less than perfect, we can do our less-than-perfect best."

GRIEVING AFTER THE LOSS OF A PATIENT: NURSES’ PERSPECTIVES

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Pediatric nurses are usually the health-care providers working closest to children and families. Nurses are present every hour of the day and every day of the week. They typically are at the bedside for the initial diagnosis of a serious illness and for administering the first treatment. They continue being present through the child’s illness; sitting with parents during family meetings, wishing them well for discharges home, welcoming them back for another admission, celebrating victories, mourning losses, and at the end, caring for the family and child through their death. This description is often true for a nurse across any specialty, but there is an added intimacy for nurses in pediatric palliative care. These close connections can contribute to nurses’ grief and bereavement when a child dies.

As a pediatric nurse, I experienced loss and, at times, grieved for patients and families. I wanted to understand more about this area—for myself—but also to expose more light on nurses’ experiences. I entered the PhD program in 2005 and under the direction of Dr. Betty Davies (a seasoned researcher and pediatric palliative care expert), I studied how nurses describe working with families and children with life-limiting illnesses. Specifically, how they view professional and personal boundaries in their work. Eighteen nurses from a children’s hospital (intensive care units and the oncology unit) and an end-of-life facility (i.e. children’s hospice) participated in the study. The study was qualitative, whereas I interviewed and observed nurses, and then interpreted the data using grounded theory methodology.

Nurses shared incredible stories and depictions of their experiences. It is no surprise that they described a wide range of emotions associated with their work (e.g., anger, distress, happiness, and pleasure) and some nurses specifically described feelings of grief and bereavement from a patient’s death. A nurse’s job is complicated and variable; it can be stimulating and draining, joyous and depressing, heartwarming and heartbreaking. What interested me is the process of how nurses manage these extremes while still providing meaningful care. The following case is a composite from the study participants to highlight some key findings. Any identifying information was changed or removed. The quotations are directly pulled from the transcripts.

Case Example

Martha (a pseudonym) began her years of nursing in the pediatric intensive care unit. Like many of the nurses in the study, she vividly remembers her first death of a patient and can quickly recount the day and time even though it happened many years ago. *I just remember everything about that kid.* She admitted the patient and their family and became their primary nurse. The child was in the hospital for many months and she cared for them every shift. At the time, she was married with a toddler and pregnant with her second. She was drawn to this family for known and unknown reasons. *I poured myself in a little too much.* The parents were east coast transplants, like her, and the patient was the same age of her daughter. *It’s true what they say, that if they’re at your kids’ age, it could be your kid.*

The night the child died, she had worked an extra shift to be with the family. As she consoled the family and allowed them time to be with their child’s body, she began to feel like breaking down. Tears blurred her vision. She consciously chose to put her emotions aside and focus on the tasks of post-mortem care.
I have things to do. I have a family to be there for. I can’t be there for myself, just yet. I will be, but not yet. After cleansing and preparing the body, she then transported it to the morgue. Going to the morgue is always freaky...you want them to be comfortable, even though they’re dead, you still want the little bodies to have some respect. Days later, she and few others from the medical team attended the funeral, which was her first. I kind of felt that I needed to be there. To show the family that their daughter really mattered to me. Immediately following the funeral, she went to work and could not stop crying through the first hours of her shift. Her colleagues told her to go home.

Over the next few days and weeks, she found herself uncontrollably crying from small reminders in her daily life of the child and their family, such as a song on the radio, their favorite color, or a child the same age. She woke up from dreams about them. I knew that I was grieving by crying by association. I knew that I was feeling empathy for the parents and the family. I knew I was feeling how I would feel if my children died. She withdrew from her own family, friends, and colleagues. Where she once derived fulfillment and reward from her job, she started to not want to come to work and struggled during her shifts. She strictly focused on required nursing tasks and avoided connecting or engaging with families. I just don’t want to deal with a family today, can I please have the kid who’s intubated and sedated and has no family?

Personal and Professional Boundaries

As this case illustrates, nurses are profoundly affected from their work with dying children and their families. Every person had their own individual response and coping strategies, however, a common thread was that nurses must continuously balance between connecting personally and maintaining a professional distance. The core values of nursing, or any health-care professional, are care and compassion. It is the personal connections which define the art of healing. Moreover, connections benefit families because they make them feel secure in the care their child receives and that their child matters (Heller & Solomon, 2005; Macdonald et al., 2005). It follows Maya Angelou’s reflection that, “People will forget what you said, people will forget what you did, but people will never forget how you made them feel.” Personal connections, however, heighten nurses’ emotional responses. They can grow close to families and patients over long hospitalizations and form attachments, which in turn affect them on a deeply personal level.

Although nurses knew that connecting personally with families and patients was an important piece of their work, they questioned if their emotional responses were in some ways unprofessional. For example, the professionalism of crying in front of families was often discussed. Every nurse in the study felt that showing tears was an expected response from witnessing and being part of tragic human situations. But they also questioned if it reflected incompetence from lacking control. Ultimately, nurses felt most comfortable with their emotions when the culture of their unit expected, accepted, and supported grief and sadness, such as when Martha’s colleagues allowed her to go home.

Attending Funerals

Many contributing factors emerged that intensified nurses’ grief experience. For many nurses, their first patient’s death was the hardest and they were much more mindful of their personal boundaries in an attempt to protect themselves. Moral distress, which occurs when one feels they are acting against their own moral or ethical values, also seemed to compound nurses’ grief. In these cases, nurses described the experience as unresolved and an issue they were still processing some time later. Additionally, nurses had a more difficult time in cases where they shared commonalities with the family or patient and closely identified with them.

Like the above case, attending funerals presents its own set of emotional consequences. A child’s funeral is painful for anyone and nurses in the study varied on the issue of whether they go to them. For some, it
provided closure and was their professional obligation in supporting the bereaved families. For others, it was too distressing, disruptive, and taxing. At the center of their decision was how each nurse drew their personal and professional boundaries. Nurses attend funerals outside of work, which was challenging for some nurses who clearly separated their professional and personal selves. Building these strict boundaries helped protect them for becoming overwhelmed with emotions, which would then impede their ability to practice effectively or compassionately.

Supporting Nurses

Caring for dying children can be isolating. People in the community uncomfortably turn away or change the subject when a child’s terminal illness or death—taboo topics—are brought up. No one can truly understand except for other colleagues, so nurses find themselves confiding in and supporting one another. The question of how best to support health-care providers in palliative care is still unanswered. Developing support resources is a need recognized by others in their field (Institute of Medicine, 2003; Liben, Papadatou, & Wolfe, 2008). Nurses in this study did not want to feel forced to debrief about their experiences and emotions; they wanted the space and acceptance to be able to when/if needed. Nurses felt support from seemingly small gestures in their working environment, such as being allowed to go home after a patient’s death, not assigned quickly to another child at the end-of-life, or being open to time off to recover from a loss. Or, as mentioned above, feeling accepted in appropriately displaying emotions (e.g. crying).

Conclusion

Working in pediatric palliative care brings its own set of rewards and fulfillment. As many nurses in the study proudly said, it is an honor and privilege. I am eternally indebted to the nurses who voluntarily shared their stories and contributed to a better understanding their emotional experiences. More research is needed to understand how best to support nurses and other healthcare providers in this intimate and sensitive specialty, and consequently serve patients and families with the highest compassionate and meaningful care.

References


A DEFICIT OF CARE

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She entered the interviewing room with an unassuming and quiet demeanour, sitting promptly. Her motions were restrained, yet not wasteful. I sensed she was used to being efficient. She murmured: “I’m sorry, I’ve to keep track of time” while unloading her pocket on the table. From the way she performed this gesture, I understood these two objects, her phone and her pager, had inexplicably morphed into vital organs, foreign extensions of her slender self, vehicles of much work responsibilities, flashing, vibrating and occasionally ringing.

“I’m doctor L,” she added softly, “I think I’m your next one.” I pondered if that remark implied some cynicism about her participation in my research. The next hour would poignantly demonstrate that she was void of sarcasm, irony or rancour, void of expressions to articulate her pain, void of a voice to convey how she felt.

I began researching medical burnout and resilience almost five years ago. I’d been studying factors affecting resilience and burnout in medical officers undergoing their residency rotations in various specialties, as well as more broadly researching the functioning of hospital physicians. This research had taken me to many hospitals and medical schools around the world, from South Africa to Europe and the U.S. and eventually to Singapore, where I met Dr L.

Academic medicine has become justifiably concerned with burnout among medical students and physicians. Hence, a vast amount of medical literature already exists pertaining to various parameters of physicians’ stress, symptoms, and remedial interventions for burnout, effects on health care systems, on patients’ adherence to treatments, costs of physicians’ turnover, attrition rates in medical school, professional satisfaction, quality of care, etc. However, while this isn’t an exhaustive list, research on medical resilience is much scarcer, particularly from the physicians’ own standpoint.

After my first set of professionally related questions, I reached the more personal part of the interview. Participants were invited to share with me two events that had profoundly affected them, positively and negatively. After over 40 prior interviews, all sorts of issues had been raised: clinical events, exposure to death and suffering, errors, doubts, and shame, along with inspiring tales of mentoring, guidance, passion, and altruism through medical training and practice. Dr. L had experienced challenges like the rest of the participants. Sleep deprivation, deplorable nutrition, and a near complete absence of exercise.

These were the all too ordinary outcomes of a drought of personal time and a preoccupation with self so minimized that health was assimilated with getting by, making do, and surviving. Emotional wounds were there too, invisible to the eyes, and perhaps, more worrisomely for what this conviction implies about our perceptions of such trained professionals, implausible to assign to an individual formed to weather illnesses, pain, and death in others.

By then, I had already passed the stage of questioning the reality of burnout and erosion in medicine. I had heard compelling evidence, interviews after interviews, of the slow burn of physicians’ anguish, and the silent breeding of long-term consequences sanctioned only by oblivion or denial. What I had yet to encounter was the dilapidation caused by dismissed pain.

“Well yes this posting was particularly challenging, I had to move fast through different wards, patients’ load was really… you know…plus we didn’t have enough doctors that might have contributed to how physically taxing it was. I guess that’s how I lost my pregnancy.” There were no warnings to buffer the
blow. No inflexion of tone, no shifts in her posture, no emotional banner I had missed. As I stopped writing, I looked up, hoping for a semantic error, wishing for something lost in translation. "I had help from my family and friends of course, but nothing from the hospital I was in when it happened... no time to... you know... nothing."

As a psychiatrist in training she wasn’t short of descriptiveness or clinical insight to account for what had happened two years ago, in a different hospital than the one where she was now working. Yet, the absence of support, a dedicated structure for help, time, or perhaps simply human comfort had left a sinister void in this young physician’s emotional health. “The irony,” she added, “is that often as a trainee psychiatrist I deal with women who have gone through a similar event... well to an extent. The real kick was the line of the resident at the time... he said I could take a few days to get over “it”... then he went back to his paperwork.”

“To cure sometimes. To relieve often. To comfort and support always.” In this aphorism pertaining to patients’ care, I wonder if Edward Trudeau implied a unilateral empathetic duty of care? I doubt any medical education can generate sustainable patient-centred physicians, capable of procuring endless comfort and assistance to their patients, while being void of dedicated resources intended to support their own physical and mental health.

Physicians are neither numb nor oblivious human beings. They are not inherently better able at dealing with personal assaults and injuries. Their medical competence doesn’t make them vicariously more immune to personal needs or inherently accomplished at addressing them. These are enduring and convincing convictions for us all, and sometimes for physicians too. Disconcerting thoughts and problematological truths can often leave systems paralyzed, stuck in the seeming permanence of a problem, reinforced by the apparent intractability of a situation. Denying, concealing, refuting, eventually avoiding, masking, and numbing can become second nature on the path taken by the protocol of silence, where physicians’ pains fester. Silencing or denying remain the incoherent parts of tradition, paradoxically and unjustifiably embedded in medical culture, and passed on as a laudable inheritance. There is an implicit dissociation inferred here between who is deserving of empathy, comfort and care and who isn’t. A system that denies its practitioners that which it demands they must provide ad infinitum to their patients, is both perverse and bound to fail in several painful ways. The failures have already taken many forms—burnout, attrition, depersonalization, dissatisfaction—and have engendered considerable costs, such as suicide, addictions, family traumas, etc.

I’m not implying that all physicians are bound to become hospital statistics or mental health patients. Neither am I suggesting that there is a total dearth of help or support within the profession for physicians in trouble. However, I believe that neither medical education nor medical practice have even begun to declaratively acknowledge this internal dichotomy, let alone systematically allocate resources to reform training and practice.

The baffling chasm between our requirements of physicians’ aptitude at connectedness and empathy in the treatment of our failing health and the negation of their personal state of being is ethically deplorable and pragmatically unwise. 21st century medicine is requiring much of its physicians—business efficiency, medico-legal aptitudes, and financial sustainability—in addition to clinical skills and patient-centred care.

These demands have grown in quantity and nature and yet our healthcare systems and our medical schools, for the most part, continue to ignore the alarming implications of an implicit yet patent double standard of care and allocation of support. It seems that most, with the power to reform such an irreconcilable state within the medical profession, are more resigned to the inevitable than committed to the current and future health and satisfaction of the physicians we will all need. Indifference, apathy, and acceptance can, given a sufficient amount of time, amount to incompetence or negligence.
As for Dr. L, she and I both knew that damage was done. There were no structure, time, or resources dedicated to mending her. As she left the room to catch up with her beeper, her patients, her duties, I faltered to find the right words to convey all the empathy she was owed. I couldn’t but fail to close the deficit of care. The time for reforming the training and management of our physicians is overdue. We have to restore health and satisfaction to the healers if we expect them to retain not just their sanity but also their humanity through all the challenges and sacrifices of a medical career.
Masego* grew up in a happy home. Her home was in a small rural community and she knew everybody in her village. She grew up in times when children were children and had no worries, except for passing the next exam. The family was a churchgoing family, living a life of involvement with neighbours and friends. In those days her mother would take food to families in times of illness or would stay with sick children during the night to give the mothers a rest.

The clinic was the meeting place of mothers with babies – happy, fat-cheeked, wide-eyed, and healthy babies. The clinic sister was well respected and trusted by all; she always had time to listen to the people’s concerns, answer their questions, and take their hands in hers in times of illness. She always had a bit of advice and some medication for all illnesses.

After finishing school, Masego left her village to find work in the big city. Upon her return to her village a lot of years later, everything has changed. Her poor mother was taking care of 7 small children; all left orphaned after their mothers died. Their mothers were sisters and cousins of Masego’s and they died of HIV/AIDS. The graveyard was more than double the size Masego remembered from her previous visits.

Very soon after her return to the village, she was recruited by a community organisation and started working as a home based care giver. She did very well and was driven by her passion to help people in need and her compassion for her people at war with the HIV-monster. Since she loved children, she was transferred to the children’s programme of her organisation and she loved working with the children. She would respond to calls for help at all hours of the day and night. But that was initially…

The longer she worked in her community, the more changes she saw. The friendly, ready-to-help professional nurse at the clinic was gone and in her place a younger lady not-so-friendly and not-so-ready to help. The community organisation struggled to refer patients to the clinic and also got no referrals from the clinic, despite the fact that they offered their services to the nurse. She was shocked when she took a very sick child to the clinic and the sister refused to see the child, because it was almost closing time on a Friday afternoon. Her pleas to get assistance for the child she had to carry on her back for 2 kilometers fell on deaf ears. The child did not make it through the weekend and was buried the next weekend.

As time passed, Masego witnessed horrible things. She witnessed children and thin women with no food to eat. She saw the HIV-monster tear families and communities apart because of stigmatization. She saw how the HIV-monster ate away the flesh of its victims and how people she once knew and loved became shadows of whom they were. She witnessed men coming home from where they worked and infecting even more families with the dragon. She witnessed children being born ill and she was present when they died. Young babies and toddlers and teenagers and adults and old people alike, dying after their encounter with the HIV-monster.

Later on, hope came in the form of anti-retro viral treatment and people started living longer, being healthy again, and being able to live fairly normal lives again. Masego also started hoping again. But then people started getting horrible diseases again. The doctor explained that it was because people did not drink their medicine as often and as regularly as they should. She also saw grandmothers refusing their grandchildren being treated, because they did not believed the tests that showed the HIV-monster at work.
or feared the shame. She saw young people who became pregnant in spite of all the education to use condoms. She witnessed young people, really only children, who became overwhelmed by the HIV-monster. Steadily all hope drained out of Masego and one day she looked in the mirror to discover that she has changed. She became a stranger in her own body.

She no longer responded to calls for help outside her hours of work, she no longer jumped out of bed each morning exited to go to work, she struggled with high blood pressure and a constant headache, she withdrew from her friends and never went to church any more. Masego experienced no joy anymore; she existed and no longer lived!

If you can identify with this story of Masego, chances are that you need information on compassion fatigue.

**Compassion fatigue**

*Only people who are capable of loving strongly can suffer great sorrow, but this same necessity of loving serves to counteract their grief and heals them.*

Tolstoy

We must acknowledge that all jobs have some component of stress and in actual fact some degree of stress is good for one. But when we work under constant stress, that stress can lead to burnout. Burnout is a state of physical, emotional, and mental exhaustion caused by long term involvement in emotionally demanding situations. It leads to emotional exhaustion, depersonalization, and experiencing less personal accomplishment.

Masego’s story is, however, not a story of burnout, it is more than that. To understand Masego’s story better, we need to have a look at trauma. A lot of people use the word trauma, but it actually only refers to severe events where people died, could have died, or were injured very badly. People who experienced or were directly impacted upon by these severe events often report that they are re-experiencing the traumatic event and live in a constant state of arousal. They often avoid any reminders of the traumatic event or feel numb when thinking about the event. This is called post-traumatic stress disorder.

The Greek word for trauma is wound and we can say that a person who experienced trauma is psychologically wounded. Usually people have the ability to cope with crisis and other challenges, but trauma causes a malfunction of a person’s coping mechanisms. Working with the trauma of other people, causes its own trauma known as secondary traumatic stress or compassion fatigue.

The dictionary says that compassion is a feeling of deep sympathy and sorrow for another who is stricken by suffering or misfortune, accompanied by a strong desire to alleviate the pain or remove its cause. Compassion fatigue refers to a phase of emotional and spiritual fatigue or exhaustion that takes over a person and can cause a decline in his ability to experience joy or to feel and care for others. Compassion fatigue is the emotional residue of exposure to working with people who are constantly suffering.

**Compassion fatigue could be caused by:**

- The type of work we do
- The specific dilemmas of our clients, e.g., poverty, stigmatization, symptoms
- Numbers of clients we deliver services to
- Working conditions, e.g., transport, staff shortages, poor logistical support
- Poor remuneration
- Poor supervision & support
Certain personality factors make some people more susceptible to compassion fatigue:
- Female
- Being sensitive
- Being introverted
- Continued exposure to suffering
- Pre-existing form of mental ill health e.g., depression, etc.
- Having a tendency to withdraw

The following symptoms may be signs of compassion fatigue:

<table>
<thead>
<tr>
<th>Cognitive indicators</th>
<th>Emotional indicators</th>
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<tbody>
<tr>
<td>Lowered concentration</td>
<td>Powerlessness</td>
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<tr>
<td>Lowered self-esteem</td>
<td>Guilt</td>
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<tr>
<td>Apathy</td>
<td>Anger / rage</td>
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<tr>
<td>Rigidity</td>
<td>Shutdown / numbness</td>
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<tr>
<td>Disorientation</td>
<td>Fear</td>
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<tr>
<td>Perfectionism</td>
<td>Helplessness</td>
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<tr>
<td>Preoccupation with patients and dying</td>
<td>Sadness</td>
</tr>
<tr>
<td>Thoughts of self-harm or harm to others</td>
<td>Depression</td>
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<tr>
<th>Spiritual indicators</th>
<th>Personal relationship indicators</th>
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<tbody>
<tr>
<td>Question the meaning of life</td>
<td>Withdrawal</td>
</tr>
<tr>
<td>Loss of purpose</td>
<td>Decreased interest in intimacy &amp; sex</td>
</tr>
<tr>
<td>Decreased self-appraisal</td>
<td>Mistrust</td>
</tr>
<tr>
<td>Pervasive hopelessness</td>
<td>Isolation from others</td>
</tr>
<tr>
<td>Anger at God</td>
<td>Overprotective as parent / spouse</td>
</tr>
<tr>
<td>Question religious beliefs</td>
<td>Projective anger or blame</td>
</tr>
<tr>
<td>↓ faith in Higher Power</td>
<td>Intolerance</td>
</tr>
<tr>
<td>↑ degree of skepticism</td>
<td>Loneliness</td>
</tr>
<tr>
<td>Question the meaning of life</td>
<td>Increase in interpersonal conflicts</td>
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<tr>
<th>Behavioral indicators</th>
<th>Physical or somatic indicators</th>
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<tbody>
<tr>
<td>Impatient</td>
<td>Shock</td>
</tr>
<tr>
<td>Withdrawn</td>
<td>Sweating</td>
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<tr>
<td>Moody</td>
<td>Rapid breathing</td>
</tr>
<tr>
<td>Regression</td>
<td>Increased heart rate</td>
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<tr>
<td>Sleep disturbances</td>
<td>Dizziness and disorientation</td>
</tr>
<tr>
<td>Nightmares</td>
<td>Increase in number and severity of medical concerns</td>
</tr>
<tr>
<td>Appetite changes</td>
<td>Impaired immune system</td>
</tr>
<tr>
<td>Hyper-vigilance</td>
<td>Other somatic complaints</td>
</tr>
<tr>
<td>Elevated startle response</td>
<td>Joint and muscle aches</td>
</tr>
<tr>
<td>Accident prone</td>
<td>Breathing difficulty</td>
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<tr>
<td>Easily loses things</td>
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<th>Work performance indicators</th>
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<tr>
<td>Low morale</td>
<td>Lack of appreciation</td>
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<tr>
<td>Low motivation</td>
<td>Detachment</td>
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<tr>
<td>Task avoidance</td>
<td>Poor work quality and communication</td>
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<tr>
<td>Obsession about details</td>
<td>Staff conflicts</td>
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<tr>
<td>Dichotomous thinking</td>
<td>Absenteeism</td>
</tr>
<tr>
<td>Apathy</td>
<td>Exhaustion and irritability</td>
</tr>
<tr>
<td>Negativity</td>
<td>Withdrawal from colleagues</td>
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Develop your own self-care plan

The lifestyle changes you choose to make will depend on your unique circumstances, but three things can speed your recovery.

1. **Take time out.** Learning meditation, visualization, and relaxation exercises is an excellent way to ground yourself in the moment and to enable yourself to “escape” from your daily routine and stresses.

2. **Commit to your own health.** Commit yourself to eat healthier and taking a break while eating can have benefits for both your psyche and your physical body. A regular exercise regimen can reduce stress, help you achieve outer balance, and re-energize you for time with family and friends. Sleep enough and go for regular health check-ups.

3. **Re-connect with family and friends.** Time with family and close friends feeds the soul like nothing else and sadly seems to be the first thing to go when time is scarce.

4. **Make time for fun.** Make a list of things that used to give you enjoyment. Then make time to do it, even if it’s just taking a bath, listening to music, reading a book, watching a movie, etc.

5. **Start a support group at your work.** If you are struggling, there will be some of your colleagues who are struggling as well. Discuss it with your superior and establish a support group for staff members.

Please take care of yourself, you are precious!
Literature has shown that several factors seem to enhance or decrease physicians’ ability to cope with the multiple stressors they will encounter during their medical career, influencing thereafter their own physical and psychological health, their motivation, satisfaction, and, at times, their willingness to remain in practice.

An oncologist I interviewed for my research on physicians’ resilience made a notable comment about the intricacy of the subject of doctors becoming patients: “All our training, culture, and identity bring us to fight diseases, that’s our purpose, our mission if you will. How can they turn on us? How can we become ill and remain who we are…” It was an identity declaration, striking, logically impeccable, and thus, hard to challenge or refute.

The practice of medicine goes beyond the requirements of any profession; it becomes a blueprint for the role physicians are expected to play. The white coat becomes an emblem of health provision making them the implicit gatekeepers of wellbeing. The change of role to that of a patient is therefore often irreconcilable with their mandate, self-perception, and training, as well as incompatible with the intransience of their entire identity. Despite a now-significant recognition of the serious effects of stress, burnout, and compassion fatigue in physicians, the changes necessary to address these consequences seem disproportionally small and slow in regards to the tasks at end.

Physicians’ Health Programs (PHP) and Health Enhancing Programs (HEP) for medical students have selectively been created in order to respectively redress dysfunctions such as alcoholism, drug addiction, unprofessional behaviors, burnout, and mental illnesses and improve functioning. These programs have had significant success rates in regards to the treatment of various addictions, as well as in diminishing the levels of emotional exhaustion. PHPs offer physiological assessments and testing, as well as remediation in the form of psychological counseling or medication. Interventions aimed at preventing burnout have used medical findings pertaining to the physiological and psychological sequelae of stress to promote better nutrition and physical fitness along with the regulation of sleep.

Monitoring, maintaining, and improving physicians’ health and wellbeing is in the best interest of healthcare organizations, in regards to their concerns for medico-legal issues, medical error rates, and ultimately cost control. The literature has shown evidence of a relation between physicians’ health and enhanced patient satisfaction, as well as improved physicians’ retention and recruitment. Organizational stress is another contributor to burnout and dissatisfaction with the profession. The lack of business skills among physicians can hinder their ability to manage their personal finances through adequate financial planning. Developing managerial skills for physicians might assist the occasionally strained communication between hospital managers and doctors. Exposing physicians to managerial strategies, language, and purposes may diminish their own ethical and financial exposure to the marketing maneuvers of the pharmaceutical industries. Other interventions have been in the domain of team building, peer support, and enhanced education in communication and listening skills.

There are few opportunities, either during medical training or practice for self-reflection, introspection, and a discovery of meaning through narrative approaches. Self-awareness is neither actively taught nor reinforced by role modeling in seniors and academic medicine staff. What is clear is that a single approach to address such a complex spectrum of issues is unlikely to be sufficient. Multiple modalities involving education, stress assessments, counseling, social and peer support, and organizational engagement are more likely to lead to the active promotion and protection of physicians’ wellbeing.
However, the cornerstone of change lies in the need for the culture of medicine to address some of its tacit tenets, as well as the values it imparts and exalts, from medical schools to hospitals.

Professionalism extends to being able to practice what physicians advocate for their patients. Professional satisfaction can’t sensibly coexist or strive with either physical and mental deprivation, let alone burnout. Medicine is under strain internally from the metamorphosis implicitly established by a crisis of meaning about what defines good medicine and good doctoring in the enduring and emotive dualistic debate contrasting profit and altruism. The profession is also under pressure externally as it prepares physicians for the conflicting demands of 21st century medicine. In principle, medicine holds much promise of meaningfulness, significant attainments, and long-lasting fulfillment. However, the day-to-day erosion engendered by its practice and the compounding effects of an obsolete tradition of self-abnegation and denial transform aspirations and promises into parables and allegories, consolations for a bleak reality. The expectations of near perfection and alleged mechanistic performance which society and the medical culture impart on physicians are akin to a constitutional folly. Healthcare organizations and medical schools have a responsibility in restoring physicians’ status and satisfaction through actively investing in the safeguarding and promotion of their wellbeing. The critical endeavor lies in not forgetting that behind each evidenced-based, scientifically apt physician is a human being with frailties, flaws, fears, and doubts alongside astounding proficiency and skillfulness. We have to grasp physicians’ humanity not as something to contest, wrestle with, or resist but as the underpinning for enhanced professionalism and empathetic care.
WALKING IN OUR SHOES: THE EXPERIENCES OF CAREGIVERS AND THE CHALLENGES OF DIFFERING GOALS

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Baby Girl Kalesh was born at 23+3 weeks to a family who desperately had been trying to have a baby for many years. She was the “last chance” pregnancy for this couple and they wanted everything done, no matter what. Not only was she born too soon, she also had an antenatally diagnosed gastroschisis (large) which required surgical intervention, but not until much later in her course of care. Over her short life, she had significant lung disease, Grade 3 and 4 intraventricular hemorrhages causing cystic Periventricular Leukomalacia, multiple infections, several bouts of Necrotizing Enterocolitis, causing Short Gut Syndrome and TPN dependence, and multiple cardiac arrests.

Her parents, from the time of the antenatal diagnosis through to the day of her death, were adamant that EVERYTHING BE DONE for their child. They were not going to allow her to die, and if we removed her from the ventilator, they identified that they would take us to court. From a few days after her birth until her eventual death 9 months later, discussions were held frequently with her parents about issues including: quality of life; futility; extreme prematurity and its complications; surgical interventions and their benefits/challenges; withdrawal of life-sustaining medical therapy; CPR and the list went on.

As might be expected, this family and their story caused some angst amongst the care giving team in the NICU at our outborn tertiary/quaternary care hospital. The intent of this paper is to review the Interprofessional team perspectives on caring for Jasinka (she was named a few weeks after her birth), how we worked through the moral distress that occurred amongst the team and with the family, and how this impacted our relationships with the family and with each other.

The Neonatal Intensive Care Unit (NICU) at our hospital experiences between 60-90 deaths per year, of infants from hours old to those who have spent months. This equates to between 8-10% of the population who come through our NICU, an outborn tertiary/quaternary care centre (Simpson, Hellmann, & Tomlinson, 2010). There is another population of infants who may survive their NICU stay, but will go home with life-limiting conditions, either congenital or acquired. Often the support the family requires leads them to stay connected to our program, either through the NICU Palliative Care and Bereavement Coordinator’s role or through our hospital-wide Palliative and Bereavement Care Service that helps with...
community supports as well as pain and symptom management and advance-care planning with families of infants, children, and teens with life-limiting conditions.

The case above relates to issues of moral distress and caregiver anguish which occur in our NICU on a frequent basis. In this context, moral distress or compassion fatigue (Figley, 1995) is described as the inevitable experience of the emotional exhaustion that comes from continuous compassion directed toward those in crisis. These descriptors are felt by this group to be similar enough to be used synonymously. Some of us look at moral distress as the "yuck factor" when clinical issues come up that make us uncomfortable and there is no specific action that can ameliorate it that would be acceptable to all, including family.

Struggles surrounding diagnosis and prognosis, long-term benefit of intensive care treatments, staff having differing opinions about what is "best" for the infant, caregiver grief, how the family is processing information, and changes in most responsible physician may each lead to changes in plans or differing concerns, based on each person's own moral compass. These issues have been considered in the literature (Saunders & Valente, 1994; Swanson, 1993), and our group decided to look at how we might support those who care for the dying infant and family. In order to do that, we had to understand what it was like to "walk in our shoes."

Our Research

Over the past two years, our nursing group has been participating in narrative inquiry-based research (Newman, 1994) to gain a perspective on the experiences of nurses. This study had been approved by our hospital's Research Ethics Board. Our main question in the study focused on the "most meaningful experience related to end-of-life care for babies and families." This work is currently awaiting publication in the Journal of Neonatal Nursing (Lindsay, Cross and Ives-Baine), and works with the experience in a research-grounded methodology.

What we learned in this study was that nurses were intimately involved in the experience of families in end-of-life care, as they were the primary caregiver for these tiny patients and their families, caring for them 24/7. One of the descriptors used by this group was a "call to presence" between nurse and infant, where nurses were interpreting a combination of vital sign cues, as well as a non-numeric perception of changes in their patients. Reading their cues, their waxing and waning, as death approached, and attempting to communicate these subtle but powerful cues to others, both parents and other professionals, was challenging, especially when it might not have been numbers-oriented data. Within this understanding of the infant and this intimate relationship, the nurse is often called to cause pain, as the team tries to ascertain if the changes were fixable or not. This knowledge that we cannot always fix what is happening is very powerful.

Nurses also described the challenge of the "knowing and unknowing" this constantly changing feeling of not knowing the "right" thing to do or say, and it was related to "walking on glass"—a feeling that was very strong for many nurses. Nurses often had to develop a relationship with families in a very short period of time, and may not have known their story before their child was in the nurses' care, so may have felt uneasy about the "right thing to say." While this was often interpreted as a negative, our group identified that it provided openness to the specifics of this child in front of us, and that there wasn’t one "right thing to say" but it was about being present, and listening. This is validated in the relationship-based work of Rana Limbo and Kathi Kobler (2010). In this work they look at the development of a therapeutic relationship with the family as being emphasized by good communication and presence with those we are caring for and about.

We took this research knowledge and shared the results with a larger group of NICU nurses, as well as our leadership and medical director. These thoughts and perspectives resonated with them as well.
here, as part of our ongoing support of the whole health care team, we have continued to provide ongoing education to staff, as well as gaining their perspectives on the type of scenario that was described at the beginning of this article.

When we considered writing this article, we recognized that there was a great wealth of knowledge and perspective we wanted to seek from our interprofessional team. As part of our study and its dissemination, our nurses had provided their perspectives on self-care and needs for support from colleagues and management, and many of these practices were discussed with our colleagues.

Taking it Beyond Nursing

Our group decided to talk more with our colleagues, and we shared this case with them, asking their perceptions, with the knowledge that we would be sharing a compilation of their responses in this paper. This was not a research focus, but an opportunity to share perspectives informally. We asked respiratory therapists, social workers, and clinical fellows, as well as our information clerks, to think about this scenario and respond. These conversations were not recorded but were reviewed with the individuals, and anonymously summarized. While we also had perspectives of our Neonatal Fellows, we chose not to include the staff physicians, as their challenges, as most responsible physician, were different from ours, as we did not have that intense level of responsibility.

We asked three questions:

1. What is it like to care for a baby like this day in and day out?
2. When the goals are different for the team and family, what is it like for you?
3. How do you deal with this personally and professionally?

When we considered all perspectives, we recognized a large number of similarities in how people saw these types of ethical and morally distressing scenarios. The following is a summarization of our perspectives, and is responsive to these three questions.

Emotional Impact

All involved in these informal discussions described how it was emotionally taxing being involved with these complex situations day in and day out, balancing the parental issues and the infant’s best interests. Consistent commentary from all groups related to perspectives by the staff that the parents were thinking of their own interests above those of their tiny child and this played out in increased physical tension, illness, and moral angst among many of the team members.

Maintaining a therapeutic relationship with the family when we were potentially on opposite sides about what was best took its toll on the team, but all members of the team were continually brought back to the best interests of the infant—and the perspective of how much suffering (Carnevale, 2009) this baby was undergoing for little benefit. There was acknowledgement from the respiratory therapists, fellows, and social workers that this presence was often the most taxing on the NICU nurse, who could not leave the bedside as they could to collect themselves or access informal support away from the bedside should they need it. The nurses and the other health care professionals together recognized that being in that tension could have physical and emotional tolls that may not be able to be quantified.

How did we respond to this? Communication—amongst the team who may all be seeing things in a similar vein, or may not, and just being there for each other. Many staff described the need to have another colleague listen as they unravel their emotional response to these difficult stories, whether it was during shift or in the days to weeks after a specific trigger hit, the need to debrief (formally or informally), and be heard was strong. As well, using self-care modalities like vacations, taking a break from a clinical
case when needed, healthy lifestyles, and other modes were constantly reinforced (Rourke, 2007). As a result of our work, we have created the “Top 10 Ways NICU Nurses Take Care of Themselves” which we have made available to the NICU staff based on our research work and the work of many others.

Communication with the family is also part of how we need to walk through this journey. Sometimes parents are needing to feel heard, and may not be able to hear themselves until their story is unraveled. When we actually listen to the stories of these families, which are admittedly often very overwhelming, we learn that parents are doing what parents should do—advocating for their child. In a paper by Gillis (2008), he reminded us that often parents are equating “wanting everything done” with care for their child and for them, and they are relating withdrawal of life-sustaining medical therapy, which they do understand won’t cure the underlying damage done, as abandonment (p. 192). This concept needs to be thought about by all involved, in language, as well as in our approach to families and each other.

**Differing Perspectives/Plans**

We acknowledged the challenges of being in a team of more than 300 professionals just in our NICU (and this didn’t include the perspectives of the many consultants we worked with) and that all perspectives may not have been the same, as each other or as the parents. However, part of being on the team reinforced that the individual and community need to be respectful in communication with each other and with the family. An openness to listening was highlighted, but this also took its toll on the individuals involved as it required intense emotional energy.

Open communication took many forms. This included the request to have staff not involved in the challenging cases refrain from “lounge discussions” about these situations. Those caring for the child and family didn’t need the additional stress of hearing about “their case” when they were on a break; rather, they needed a chance not to talk about the specifics. What they identified as even more difficult was hearing the misinformation wandering through the unit and they struggled confidentially to clear that up.

We learned that even within the team, the tensions that occurred with changes in plans, lack of documented orders or family meeting discussions, and differing perspectives made it much more challenging to support themselves and each other in these complicated situations. There was recognition about the need to acknowledge differing opinions and to value them, not dismiss them. Members of our discussions talked about the need for open communication, frequently updated documentation, and revisiting of plans for all patients, but especially when there is ongoing disagreement between parents and staff and amongst staff. Isaac and colleagues (2006) described that the nursing staff were often in the best position to judge whether or not the baby was suffering, as they were with the baby the most time, and this would mean that they need to be part of those discussions (p. 312).

This leads to the need for staff to bring up issues before they become explosions. We realize that many have not been comfortable with asking some of the difficult questions (“Who are we helping in providing this therapy?” or “Why are we not taking a stand in this situation?” are some examples that occur frequently). Staff need to feel empowered to speak to the staff neonatologist, clinical support nurses, and other members of the team as a proactive response to the clinical situation, rather than letting things brew. This will continue to require organizational and personal support, but is thought to be a growth opportunity for all involved.

Another way that we have attempted to improve our communication amongst the team has been our “Voicing Space.” This is an open-door environment that was used several times during one of the more intense clinical challenges earlier this year. The space was open for a couple of hours in the afternoon, and the facilitators (RN and chaplain) had brought in treats to provide a relaxing environment. The room had three basic rules: What is said in Voicing Space stays in Voicing Space; Respect what others say; Please be respectful of the family stories. This idea has been used in many other environments.
recognizing that having the ability to set a "Voicing Space" up in a short time-period was necessary, as it provided a safe space to talk about the tough stuff, without fear of reprisal, and with colleagues, to share the burden outside the patient rooms but still within the work place. These meetings did not have management present, which is different from our more formal debriefing sessions that occur in some of these complex situations. Participants identified that there different needs are met by the Voicing Space and by debriefings/formal staff meetings.

We also encourage the team and family to access external resources (to the NICU) to help with understanding perspectives and looking at issues like “best interests.” Our Bioethics department offers independent consultations with families and with teams, and this can be helpful—having a non-involved professional review the case to help each party to make sense of the issue, and assist with language about the problem, as well as keeping the infant as the centre of the story. As well, our hospital previously had a Patient Representative department, which was recently redesigned to become the Child and Family Relations Department. This group assists in building positive experiences for both families and staff and will respond to concerns expressed by all.

Acknowledgement of Parental Perspectives

We also recognized the value of acknowledging that this was not “our child” and that we may not have made the same decision as the family. We valued that the parents were the primary decision-makers for this infant, and understood that they would have to live with the outcomes of whatever decisions they had made. This recognition came with the need that parents truly understood the long-term implications of their decisions.

Some nurses and other health care providers found value in taking time away from a clinical case where their moral distress was high, but this was not always possible. As social workers, our colleagues are there each day and can’t just have a family switch over to the other social worker’s caseload without a very strong reason. The same goes for staff neonatologists, fellows, and residents, who may have primary responsibility for specific patients and can’t abandon them.

As a team, we have found some ways to help parents to better understand the world that they may be living in when they take their child home with a complex medical condition or who has a high potential of death in the first few weeks. With parental participation, we have linked them up with the resources and community providers to help families understand the burden of care for their child and the resource and funding-intense world that will exist, even in a system that is publicly funded, should the child survive the NICU stay. Opportunities to introduce families to other families with similar diagnosis and probable outcome has also been helpful for some. However, this may not be the right way to ensure that parents understand what they are signing up for, as some parents are so desperate to have their child survive that they are unable/unwilling to consider what it might look like for them to have an intensive care unit in their home. In those circumstances, we do all that we can to help them manage this need, with discussion about the potential for death at home and how they might handle it. This is met with mixed response, but we believe that it is important to be transparent about our concerns and support the family in the journey that they are taking.

In these circumstances, staff who have been able to develop a relationship with the parents use that connection to provide gentle guidance and support, and to empower parents to provide as much of the care as they can, as they learn the intricacies of their own child. Some do this after a great deal of self-reflection about the issue that this is not their child, and others do it as it is their job. However, it still leaves some significant moral residue when staff hear that the child has died soon after transfer home, or that parents have not coped well with the transition and that the infant has been readmitted to hospital soon after discharge.
Validation in Literature

Breuner and Moreno (2010) provided a good review of the challenges of difficult encounters with families. The cases they discussed were not ones related to crisis and end-of-life but they were focused on communication and how good communication techniques can reduce the differences in perceptions and difficult encounters. They described the many components of these challenges and each reinforced some of the experiences of the members of our team. They state that these situations may be even more challenging because of "the complexity of dealing with a parent who may be both desperate and dedicated to his or her child with major needs" (p. 164). In the NICU, these parents are often experiencing additional stressors, including guilt, possible previous pregnancy-related losses, and the feeling that they MUST advocate for their baby, as no one else is. They remind us that physicians (and we would extend this to all health care professionals) who experience this type of job stress continuously are at a much higher risk for burnout and dissatisfaction as well as physical health concerns (p. 166).

When reviewing Rourke's (2007) paper on compassion fatigue, the validation of the clinician as a trauma responder, whether it is in a chronic situation or an acute one, we recognized that this issue has physical, emotional, and social responses that need to be acknowledged. Lack of recognition of this impact leads to longer term impacts on all involved.

The issue of burnout or compassion fatigue always sat as a result no one wanted to experience. This was validated in a paper by Altun (2002), who identified that nurses needed to understand their own values and beliefs as they cared for others. Those with the highest levels of emotional distress struggled more with issues of equality and altruism than did those who described a lower level of emotional distress.

Summary

From our research we have learned that nurses often internalize the conflict—their role during their shift is to care physically for the infant, and often to cause pain in order to “fix” or ameliorate a problem that can be reduced or fixed. When they see that the issue is either not fixable or is causing more harm than good, these nurses struggle. We also understand that these struggles are experienced as well by the other members of the health care team, even the Information Workers who work at the unit’s main desk, as they experience the tensions that the parents exude, hear the distress by stressed staff, and take some of that on.

When we compare this compiled case with “the real world,” things are not that different for the health care team. We all struggle with opposing perspectives of “best interest,” we feel angst at the pain we cause, without necessarily knowing the benefit it will provide and we worry about the suffering of the baby—our primary focus.

We know that there are ways that we can support ourselves and each other, from the personal care needs, to improved communication and opportunities for group discussion and problem solving.

However, we do acknowledge fully that each of these experiences, while very difficult, is not that of our own child. One individual described that they might also become one of those “nightmare” parents if it was their own child in that overbed warmer, needing significant medical intervention to survive. We all hoped that we might know when enough is enough but we couldn’t be certain. After all, we have walked in the shoes of a professional many times, but we haven’t walked in the shoes of those parents in that specific situation.
References


Note: The"case" described in this article is a compilation of several challenging clinical situations and the events and details have been changed to protect patient, family, and staff confidentiality.

The authors thank the NICU EOL Team and the staff in the NICU at SickKids for sharing their insights for this article—we couldn’t have done it without you!!!
MORAL DISTRESS IN NICU NURSES

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“I don’t not feed babies. But every time I feed this baby I feel like I’m hurting her.”

Then this NICU nurse, eyes brimming with tears, went on to describe the positioning and procedure she followed to tube feed the child. This included holding the child while inserting the feeding into the PEG-tube with one hand while suctioning the bubbling liquid from the baby’s mouth with the other … and so began the author’s interest and concern in regard to the moral distress experienced by some staff working with infants/children who were dying, with their vulnerability, their need for support, and at times their inability to seek help. This incident became the first of a series of events I would experience which signified the stress and anxiety pediatric staff were having as they struggled to resolve the conflict(s) they were experiencing between their personal, religious, spiritual, and organizational ethic.

Moral distress is described in the American Association of Critical Care Nurses (AACN) "Moral Distress Position Paper" as occurring “when you know the ethically appropriate action to take, but are unable to act on it,” and/or “You act in a manner contrary to your own personal and professional values, which undermines your integrity and authenticity.” The AACN cites the evidence that "I in 3 nurses have experienced moral distress, nearly 50% of nurses studied left their units or nursing field because of moral distress," and “approximately 50% of nurses have acted against their consciences when providing care to terminally ill patients.”

Moral distress causes suffering. Suffering occurs when a person’s integrity and sense of self are threatened. Some sources of moral distress include, but are not limited to: end-of-life challenges, nurse-physician conflict, disrespectful interactions, workplace violence, and ethical dilemmas. The consequences of moral distress include anxiety, guilt, and discomfort, as well as factors adversely affecting job satisfaction, retention, psychological and physical well being, self image, and spirituality.

Health care professionals caring for children with life-limiting illness not only care for the physical needs of the patient and family but also the psychosocial, emotional, and spiritual needs of these patients. Decision making in regard to the children’s treatment or non-treatment was presented extensively in the CHIPPS May E-Newsletter. This article may touch on some of those ethical decisions but it is more a reflection of the emotional toll and significant impact that decision-making regarding care of these children and families, has on the patient and family but also on the healthcare providers caring for them.

The attending physician and family usually make decisions pertaining to the care of these children after multiple conversations regarding benefits and burdens in regard to the choices. Parents share with the physician what they believe is best for their child. Many express what they absolutely want and the physician provides the best recommendations based on the history and physical condition of the individual patient and family, scientific evidence, and the wishes of the child/family. At times, these recommendations may conflict with the physician’s own personal, spiritual, and organizational ethic as well as the values of the healthcare providers (nurses, social workers, etc) who must carry out the orders. “It is clear that physicians feel the burden of responsibility for ordering the withdrawal of treatment and the attendant possibility that such withdrawal could end … life prematurely.” Nurses may disagree with written orders and may voice such opinions, but if their opinions are not valued and respected or are
ignored, the nurse will feel that his/her moral obligation and personal integrity have been compromised and this is at the heart of moral distress.

Nurses are the frontline caregivers for these infants and children and their families. Nurses caring for them regularly experience the moral distress arising from the collision of the competing principles of their personal, organization and spiritual ethics. “Moral distress doesn’t go away. You don’t get desensitized to moral distress”.3

A physician colleague said to me “I cannot take care of one more dying child alone” and gave an account of children dying in his arms or in the arms of their parents and the agony parents and family experienced … “and there was no one else in town caring for these children.”4 No one to share the emotional pain with who understood.

Yam and colleagues found 8 recurring themes regarding the experience of being a NICU nurse in Hong Kong. The themes were disbelieving, feeling ambivalent and helpless, protecting emotional self, providing physical care to the infant, providing emotional support to the family, expressing empathy, a lack of knowledge and counseling skills, and conflicting values in care, all of which contribute to NICU nurses’ moral distress.5 (See also Rogers et al.6)

The patterns of response to moral distress were described by Hamric in 2010.7 Three patterns of response are described in the literature: 1) the numbing of moral sensitivity and withdrawal from involvement in ethically challenging situations; 2) nurses leave their position or leave the profession itself; and 3) nurses resort to conscientious objection and advocate for their patients. So then, moral distress affects the workplace environment, causes emotional suffering among staff, in some cases leads to loss of healthcare workers, and threatens the quality of patient care. It therefore becomes essential to provide education and tools to manage workplace distress and in so doing preserve the workforce and improve patient care.

Hamric suggested that ethics consultants would agree that in cases of moral distress analyzing single cases is not effective.7 Rather she states that recent work describes three levels of intervention. “A patient–level of intervention to bring team members together for frank discussion; a unit-level intervention to identify changes needed to prevent or minimize such situations in the future; and an organizational-level intervention to examine policies and modes of operation that compromise healthcare professionals' moral integrity.

It is the responsibility of every healthcare worker and every employer to do something about moral distress. The American Association of Critical Care Nurses (AACN) developed a handbook: The 4A's to Rise Above Moral Distress. This handbook states that “addressing moral distress requires making changes” and the change process happens in stages and cycles. The 4A's or stages include: ASK or identify the source of your distress; AFFIRM your distress and commitment to take care of yourself; ASSESS or identify sources of your distress; and ACT when you are ready.8

AACN has also suggested action steps for employers and organizations. Among these are the creation of support systems (EPA programs, end-of-life protocols, ethics committees, critical stress debriefings, grief counseling), creating interdisciplinary forums, providing education, and finding tools to decrease moral distress. Continuing research to identify moral distress and activities to prevent, monitor and treat the problem are essential to a good working environment for the health of the healthcare community and the quality of patient care.

1. http://www.aacn.org/WD/Practice/Content/Publicpolicy/publicpolicypositionstatementcontent?menu=Practice


4. Personal discussion.


MORAL DISTRESS IN PEDIATRIC PALLIATIVE CARE

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Baby G was born with a severe brain abnormality that left him unable to communicate or interact with his environment. Although he was able to suck from a bottle normally, he did not make eye contact or make any sounds other than when he would cry. He was very floppy and as he grew in size, he never made any progress in his development. When he was born, the staff in the Neonatal Intensive Care Unit met with his 16-year-old mother to explain that he would likely die within months of his birth. His mother, alone in this country except for an older sister, decided that she would like to take him home on Hospice. She cared for Baby G lovingly in a small room in her sister’s apartment. When he would become ill, Baby G’s mother would call an ambulance and ask that the hospital staff use all life-saving measures.

Over time, the hospital staff became more and more concerned that despite the seemingly hopeless future for Baby G, his mother continued to demand repetitive resuscitations, Intensive Care Unit stays, and prolongation of what the staff considered inevitable—his death. The staff struggled with the decisions made by the mother to have life-prolonging efforts performed repeatedly and they became increasingly frustrated by their own inability to convince his mother to allow him to die in peace. The staff believed Baby G was suffering and that his mother was not acting in his best interest. His mother, on the other hand, felt she was acting, as any mother should—to protect the life of her child. This inherent conflict led to many heated discussions during staff and team meetings. In the end, Baby G died in the Pediatric Intensive Care Unit with his mother at his side.

Moral distress is the result of believing you know the right thing to do, but you are prevented from doing so. The “right” thing to do is quite subjective and therefore moral distress can be felt by some staff while not by others in each situation. This has little to do with staff being right or wrong, rather it is their own moral barometer that controls their feelings in these difficult situations. In Baby G’s case, there were several staff members that were clearly struggling, whereas others in the staff were supportive of the mother’s decision-making. There are several common triggers for moral distress and, for each of us, the cause and effect may be very different. As a healthcare provider, there is a responsibility to self and others such that suffering should be acknowledged and managed. As a healthcare organization, the well being of the patients, families, and employees is affected by the differences in beliefs and actions taken by each of us.

For the staff, the day-to-day experience of caring for patients and families who are suffering can certainly take a toll emotionally. Nurses, physicians and other providers must be careful to not take in too much of others’ pain, as the long-term effects can be burnout, depression, and somatic health issues. Yet, part of the qualities of an excellent health care provider is empathy—the ability to share the feelings of others. Empathy is critical in the caring for those in pain, and nurses in particular are adept at healing through listening and “being” with others. In fact, for many nurses, the ability to connect with patients who are facing a dark time is a critical factor in job satisfaction. For some, this is why they fell in love with nursing.

However, when a nurse, or other provider, has beliefs that are at odds with those making the decisions for a patient, there is an inherent struggle over wanting to do the “right” thing as well as honor the rules and laws that bind the profession. Few would argue that an adult patient does not have the right to
choose to forgo curative therapy or elect to have resuscitation performed even in a futile situation. A nurse may try to counsel a patient, provide education, and discuss options, but ultimately the nurse will respect the patient’s wishes. That same nurse may go home and talk to family members about the sadness of the situation, but in the end the adult patient with capacity can make his or her own decisions.

Where moral distress tends to occur is in situations when others are decision-makers for a patient. Much of the academic research in moral distress has focused on nurses in Neonatal Intensive Care Units (NICU). That environment, in particular, seems particularly ripe for the development of conflict between staff and parents over the care of a newborn. Infants in the NICU are unique in that they do not have a voice of their own, their parents have had little time to bond, and the NICU nurses sometimes feel as though they are surrogate parents. The nurses spend 12-hour shifts at the bedside—touching, holding, feeding, and talking to the infants—sometimes many more hours than the parents. As a result, the nurses feel they know the likes and dislikes of the infants as well or better than the parents.

Whereas this bonding of the staff to an infant can be a wonderful asset to the parents—knowing that loving arms are holding their baby when they are not around—there can be conflict when the staff and the parents differ in what is “best” for the infant. By law, the parents have the decision-making authority to decide for their child. However, the law also expects healthcare providers to ensure that the child is protected from undue harm. This inherent conflict in the law between parental decision-making rights and healthcare provider obligation can create a layer of mistrust.

In the case of Baby G, the staff of the NICU had been caring for him for most of his life. He would have brief stretches of time at home, but otherwise most of his life was in the hospital. Several of the nurses became the “primary” caretakers for Baby G and would request to be assigned to his care. Conversely, several nurses made every effort to take other assignments in order to avoid caring for Baby G. His mother, also, had “favorite” nurses. She would petition the charge nurse at the beginning of each shift to try to manage the nursing assignment for her son. As time went on, the job of the charge nurse became more challenging, as fewer nurses were interested in being assigned to Baby G and his mother.

The avoidance by some of the nurses to care for Baby G is typical in cases of moral distress. The staff suffering from moral distress frequently feels powerless and copes by avoiding meaningful relations with the patient and family. In the event the staff member is assigned, they will often limit their contact to the physical acts needed to care for a patient with minimal emotional interaction. As described above, this emotional vacuum can be devastating to the nurse who values empathy highly. Much of this displaced emotion can spill over into other areas of a nurse’s life and manifest as depression, anger, and somatic complaints.

The strategy to combating moral distress starts with first recognizing the signs it is present, such as nurses avoiding assignments, becoming withdrawn from contact with a patient or family, depressed affect, frequent absences, and uncharacteristic emotional outbursts. Moral distress is often difficult to self-assess but can be easier to identify in someone else. Taking a moment to regroup as a team and assess each other’s distress can go a long way to prevent future conflict and suffering.

At the organizational level, the leadership needs to be aware of the risk factors for moral distress as described previously. The morale of a unit or department can be greatly damaged by a particularly difficult case. Open, honest, safe team discussions are very important. Sometimes an outside facilitator can help tease out the issues and quell the rising tension. Ethics committees and other administrative bodies can be useful to support the staff, patient, and family. The key is to make sure that each member of the team has a voice. The role of the facilitator is often to level the field so the nurses can speak openly to both the other members of the team as well as senior leadership within the organization.
The story of Baby G is fortunately a less common story in the NICU. Most patients who spend time in the NICU find caring, empathetic staff that collaborate well with parents. In fact, it is the very caring nature of the staff that predisposes them to moral distress. If they did not care about doing the right thing about their patients, there would be no conflict. The answer to addressing moral distress is not to stop caring; rather it is supporting each other both at the colleague level and the organizational level.
TRANSFORMING MORAL DISTRESS IN PEDIATRIC PALLIATIVE CARE

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What is moral distress?

Palliative care clinicians regularly confront suffering in their work with people living with life-threatening or life-limiting conditions. Embedded in these cases are ethical conflicts that can result in moral distress. “Moral distress is the pain or anguish affecting the mind, body or relationships in response to a situation in which the person is aware of a moral problem, acknowledges moral responsibility, and makes a moral judgment about the correct action; yet, as a result of real or perceived constraints, participates in perceived moral wrongdoing” (ANA, 2002).

When clinicians perceive that their actions are causing the patient unjustified pain and suffering, their participation in implementing this treatment plan violates ethical values central to their role (ANA, 2001). In such instances, acting in a manner contrary to personal or professional values undermines the individual's sense of integrity (Jameton, 1993). When clinicians cannot live up to their personal and professional values by acting in an ethical manner or their conscience is violated, they experience moral distress (Solomon et al., 2005; Hamric & Blackhall, 2007).

The impact of moral distress

Moral distress affects the whole person—physically, emotionally, behaviorally, and spiritually. Symptoms may range from musculoskeletal complaints, headaches, or GI upset to depression, cynicism, anger, sadness or emotional outbursts, addictive behaviors, or boundary violations, to name a few. Relationships can be disrupted, sense of meaning eroded, and the quality of care undermined (AACN, 2004).

For people with repeated exposures to moral distress that are not adequately healed, a “moral residue” can begin to accumulate (Webster & Baylis, 2000). The moral residue reflects an emotional response to the inability to act with integrity and the sadness, regret, shame, or anger about unmet ethical claims or obligations. These memories can be activated in future cases and can obliterate the relevant features of the current case and risk projecting past experiences into the current situation. Similarly if the intensity of the moral distress is severe, it can undermine team functioning.

How can we address moral distress?

The antecedents and consequences of moral distress are complex and require both individual and system level interventions. Methods for dealing with moral distress have focused primarily on developing skills in moral reasoning, communication and conflict resolution, interdisciplinary collaboration, system reforms, ethics consultation, and policy development (Fine & Mayo, 2003; Gutierrez, 2005; Hamric & Blackhall, 2007; Rushton, 2006). A promising body of work that heretofore has not been applied to instances of moral distress involves a variety of contemplative practices aimed at supporting principled, compassionate responses. Recommendations for expanding the professional repertoire for responding to challenging cases involving moral distress are offered.
Engage in contemplative practices

Developing a consistent routine in one’s life to intentionally cultivate stillness, insight, reflection, and focused attention can support clinicians as they navigate through morally distressing situations. Contemplative practices and processes, such as prayer, body practices such as yoga or Tai Chi, meditation, or mindfulness, can help to stabilize mind and emotions, particularly during ethically charged situations. Regardless of which one is chosen, each of these practices can be a doorway for individual nourishment, insight, and support. One of the most widely used meditation techniques, Mindfulness-Based Stress Reduction (MBSR) (Kabat-Zinn, 2003), has been found to support overall well-being, strengthen resiliency, and increase self compassion among healthcare professionals (Shapiro, Astin, Bishop, & Cordova, 2005). Qualities cultivated by mindfulness practice include self reflection, deep listening, acting with awareness, observing, describing, and moment-to-moment presence (Baer et al, 2006; Carmody & Baer, 2008), qualities which are foundational for compassionate end-of-life care.

Cultivate moral sensitivity

The way that we respond to an ethical conflict is informed by our values, intentions, and character. A crucial element of our responses involves moral sensitivity as an antecedent for discernment and action. Moral sensitivity is the ability to: 1) empathize with the distress of others; 2) discern the morally salient dimensions of the situation; 3) be aware of ethically justified options for addressing the ethical issue; 4) appreciate how one’s actions affect self and others; and 5) respond in an emotionally balanced, ethically grounded manner (Rushton & Penticuff, 2007). If one’s moral sensitivity is not well developed, one may not accurately identify an occasion for moral action or may inappropriately tolerate morally objectionable acts. Similarly one may overlook the impact of certain behaviors on patients, families, or caregivers and this lack of moral sensitivity can lead to tolerating inappropriate behavior or decisions. Conceptually, moral sensitivity is related to the development of conscience—that aspect of oneself that evaluates one’s own actions and engenders emotions of pride or shame. Moral sensitivity is a key element in aligning intentions, character, and principled action.

Modulate emotions

People may experience myriad feelings in response to perceived conflicts in values, interpersonal disagreement, and institutional constraints related to moral distress. Concurrently, emotions may be ignited by the perceived violation of a moral value, principle, or standard. Feelings such as generalized discomfort, anxiety, confusion, uncertainty, or anger can arise, instigating a process of moral appraisal and reasoning as one determines the morally correct response. Once recognized as a situation where action is needed, the initial distress associated with the event can either be relieved by taking the morally correct action or may be intensified because the person is unable to act upon his or her reasoned choice. This process involves an appraisal of how the situation and the actions taken or not taken promote or undermine integrity or result in participation in actions that are viewed as justified, permissible, or unsupportable (Jameton, 1993).

When feelings in response to the distress (both related to the moral conflict and one’s ability to take the correct moral action) are modulated, the emotional connection to the patient and his or her predicament contribute to one’s moral sensitivity to the situation by engaging one’s empathic concern. If this arousal is regulated, and self and other are distinguished, then the aroused state can give rise to compassion with the manifestation of other-focused pro-social behaviors and integrity preserving moral action (Halifax, 2011). If the arousal that produces empathic concern is unregulated, the boundaries between self and other are not distinguished, moral distress or outrage ensues shifting the focus to self-focused behaviors aimed at consciously or unconsciously relieving the personal distress (Halifax, 2011). Moral outrage has been described broadly as anger provoked by a perceived violation of an ethical standard such as...
fairness, respect, or beneficence (Batson et al., 2007). Pike (1991) describes moral outrage as “characterized by energy-draining frustration, anger, disgust, and powerlessness” that can fuel one’s motivation to uphold the violated moral value, principle, or standard. This suggests that developing skills through focused attention, the cultivation of stability of mind and emotion, and differentiation of self and other are essential for modulating the emotional responses to ethically challenging situations.

Create a pause in the process

When conflicts and challenges arise, connection to purpose, meaning, altruism, and compassion may be abandoned—consciously or unconsciously. As a form of mindfulness, the “Art of Pause” is a powerful strategy in the process of ethical discernment and action (Rushton, 2009). Spaciousness can be cultivated in myriad ways. Table 1 offers suggestions for how to create the necessary pauses when challenging situations arise in clinical practice.

Table 1: Creating Pause (adapted, Rushton, 2009)

1. Anchor yourself in your breath: Bringing awareness to the inhale and exhale of breathing can help to focus attention and help to stabilize the nervous systems and help to neutralize emotions.
2. Pause: Intentionally creating spaciousness in conversations, processes, and decision-making can support insight, reflection, understanding, and principled action.
3. Be transparent: Acknowledge your own assumptions, biases, confusion, or ambiguity.
4. Monitor your mindset: Assess the prevailing feeling tone and mindset of self and others involved in the situation that is causing moral distress. If a negative, judging tone is present, notice it and consciously shift to inquiry, dialogue, and understanding.
5. Explore personal responses: When there are strong reactions to the behaviors, choices, or perspectives of others, notice it and consider what might be being activated within you. Noticing such responses can be an invitation to bring yourself back to a place of stability and reflection.
6. Ask questions: Create an environment of inquiry by being humbly curious. Asking questions can help to shift from telling or convincing to learning and respectful exploration. Seek to understand the other person’s perspective rather than convince them of your own.
7. Get clarification: Good decisions are based on good facts. Clarify what you know and what you don’t; identify areas of confusion or dispute.
8. Be open to new possibilities: Intentionally step back from the acute situation to discern the patterns and perspectives that may be converging in the conflict. In doing so, new possibilities for how to respond may emerge. Intentionally cultivating a space for being changed by the situation or learning something new fosters connection and understanding.
9. Let go of outcomes: When people are attached to a particular outcome or process that they judge as right or wrong, possibilities become limited. Attachment often breeds constriction in self and others. For example, when people decide that the only ethically appropriate outcome is the discontinuation of life-sustaining therapies, it can close off our willingness to consider information or options that may be relevant to an alternative view. Allowing ourselves to let go of things that we have no control over, such as the mystery of life and death, the behaviors and decisions of others, the course of disease or injury can create more space for exploration. This is particularly true when ethical conflicts arise.
10. Become a witness rather than an actor: Re-framing the situation from an opportunity to fix or control the outcome to adopting a stance of witnessing, deep listening, and understanding can release energy for creating new possibilities. Relinquishing control over oneself, others, and the situation allows one to be with oneself in the presence of another and can support everyone involved to discover the most ethically justifiable response.
Caring for yourself so you can care for others

In order for clinicians to provide compassionate end-of-life care, it is necessary for them to be self aware, recognize their own difficulties, and make a commitment to address their own suffering by nurturing physical, emotional, mental, spiritual, and social dimensions of their own lives and relationships to others. (Halifax, 2008). Cultivating harmonious interconnection among mind, body, and spirit can provide the needed foundation for care of self and others. Yet without sufficient nourishing of their own wholeness, it is impossible to sustain the ability to be fully present and engaged with patients and their families, as well as to witness suffering and remain connected with a sense of meaning and purpose. Clinicians cannot give what they do not possess within themselves. Compassionate care requires that aspirations for others are balanced with commitments to one's own well-being, integrity, meaning, and purpose (Rushton, Halifax, & Dossey, 2007). Committing to a disciplined, ongoing plan to support one's resilience and integrity is foundational for sustainability and resilience in the face of ethical dilemmas.

Reconnect to meaning

Rachel Naomi Remen states: “Meaning is a function of the heart” (Remen, 2001). Meaning is the capacity to be inspired by our work and lives; it allows us to see things in new ways and connect with ourselves, our aspirations, the people we serve, and the world around us. Meaning can provide the fuel to navigate challenging circumstances. It can help us to focus our attention on the essential values of living, service, and compassion, as well as give strength in the midst of crisis. For many clinicians, rediscovering meaning and commitment in their professional lives can provide an antidote to burnout and provide the means for sustainability and renewal (Fillion et al., 2006; Hatem, 2006; Shanafelt, 2005). Meaning can be cultivated through activities that connect clinicians to something greater than themselves. These may include spiritual or religious practices, connection to God or divinity, the natural world, or connections to their sense of calling (Catlin et al, 2001; Catlin et al, 2008).

Develop institutional systems

Create and use ongoing mechanisms to review problematic cases, address conflicts, and to design system-wide responses. Mechanisms such as root cause analysis processes (Rushton, 2006) can help to illuminate system structures and processes that contribute to the incidence and patterns that create moral distress. Ethics committees and clinical ethics consultation processes, in addition to individual and group support sessions such as debriefings (Keene, Hutton, Hall, & Rushton, 2010; Rushton et al., 2006), can be viewed as resources as both a preventive and responsive measure. Policies that define the morally permissible boundaries of treatment and processes to guide decision-making can be helpful but are generally ineffective in dissolving the moral angst that accompany ethical dilemmas and conflicts.

Summary

Moral distress is a reality of clinical practice, particularly pediatric palliative care. Policies designed to legislate behavior and define possibilities have had limited success in reducing the incidence or intensity of moral distress by clinicians. Alternatives, such as those described in this article, expand the repertoire of clinicians to respond with greater resilience, clarity, and stability without becoming overwhelmed with the conflicts or the emotions that accompany them. These methods offer promising strategies to help modulate empathic concern so that compassionate action can arise.

References


STRATEGIES AND INTERVENTIONS FOR “CARING FOR THE CAREGIVER” IN THE PRESENCE OF COMPASSION FATIGUE AND/OR MORAL DISTRESS

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This issue has highlighted some of the causes of and symptoms related to conditions like compassion fatigue and moral distress in a healthcare setting. While the articles have drawn distinctions between these terms, the end result, in many cases, is the same—healthcare professionals who have or do suffer physical, mental, and/or emotional symptoms or pain as a result of experiencing these conditions. Compassion fatigue and/or moral distress are seemingly evident in all specialties of healthcare, and pediatric palliative/hospice care has not been spared.

It stands to reason that if the “caregiver” is feeling the effects of compassion fatigue or moral distress (and is not being cared for), then how can we expect him/her to be able to care for others, and especially for children with life-limiting or life-threatening conditions. When compassion fatigue or moral distress exist in healthcare professionals and the workplace, they take a toll on the caregivers, and the entire system suffers, including the patients. The organization, fellow colleagues, and/or family and friends need to recognize the signs and also know how to offer help.

To further provide direction as to “What to do” if you or a colleague appears to be experiencing/showing some signs of compassion fatigue or moral distress, the following compilation of potential strategies and interventions is offered as a place to start.

Using a framework of personal, professional, and organizational categories, a variety of strategies/interventions will now be classified into one of these three areas:

Personal

- Maintain one’s own physical well-being…get proper/Enough sleep/rest, good nutrition, and regular exercise
- Build relaxation techniques into one’s daily routine…cleansing breaths/deep breathing, visual imagery, massage therapy, acupuncture, reiki, etc.
- Look for ways to create balance in your life and be aware of tendencies to overwork. Engage in non-work related activities to help provide some of this balance between work and personal life. Find a hobby or passion to devote time to outside of work.
- Acknowledge personal and patient losses and grieve for them
- Meditate—take up a practice of doing yoga or personal reflection to help cope with the stressors of the job
- Spirituality—Be aware of and attend to one’s own spiritual care needs to build a system that aids in meaning-making of one’s personal experiences; confide in the hospital chaplain or find your own spiritual care advisor
- Religious activities/outlets—Pray, seek out religious services, join a church or other religious/spiritual group
- Maintain healthy boundaries: Create and be protective of one’s “Me” time; take a break from caring for others and just care for oneself. Avoid over involvement in patient cases
- Call friends to “come out and play” often
• Learn to recognize and accept that children dying is part of the reality of working in pediatric palliative/hospice care and that as a healthcare provider, there are limits to what one can do to help alleviate the pain and suffering of the child and/or his/her family.2
• If the symptoms or emotions become very strong/overwhelming or one does not have a strong confidante to share one's feelings/emotions with, take a break from work (vacation days/sick days, etc.) and also seek out professional help via counseling/psychotherapy.3

**Professional**

• Avail oneself of peer consultation/Discuss cases with peers or colleagues in person, via email or professional listserves, etc.
• Identify the difficult situations that potentially trigger feelings associated with compassion fatigue or moral distress and role-play with a colleague on better handling of the trigger; seek advice from a peer as to how to deal with some of these trigger situations in preparation for the next time.4
• Set personal boundaries and limits/Learn to say “No” to professional requests when appropriate or needed for peace of mind
• Seek out other activities in the work environment that may reduce the hours spent in direct patient care (e.g., teaching, research, other clinical service activities, etc.)).2,3,5
• Look for the “silver lining”—spend time each day thinking about what's good about the job and about the positive experiences that one has helped contribute to. Remember (and remind oneself) what you/they love about your/their work.1
• Have fun…at work…and at home! Pediatric palliative/hospice care is a tough field to work in, but it doesn’t mean fun can’t be had on the job despite the seriousness of the care provided to the children and their families
• Attend bereavement debriefing sessions, staff support groups, or regular peer support meetings (alone or with a trusted colleague)
• Join a professional organization to be part of a like-minded group in one’s field; seek out resources they may have which can help
• Take all your vacation time to give body/mind/spirit a rest from the job and the heavy responsibilities that come with it
• Build caring relationships with colleagues/peers, leading to the creation of an empathic, open, trustful, respectful work environment that recognizes and gives praise for good work, and supports each other through the deaths/difficulties of the job
• Empower one another and give everyone a voice in briefings/debriefings/discussions on patient care in the spirit of a warm, respectful atmosphere that makes room for all the feelings to be voiced…and heard
• Establish an Ethics Committee (if not already set-up) and encourage usage of it by the healthcare providers for issues of moral/ethical dilemma
• Speak with administrators regarding appropriate resources for staffing and workload; voice through appropriate channels issues/concerns with a case, the work environment, patient care, etc.. Schedule 1-on-1 time with supervisors on a regular basis to discuss issues of concern and just “how it’s going”

**Organizational**

The articles in this issue underscore the need for healthcare institutions to provide structures, processes, and resources for addressing compassion fatigue/moral distress, and the like. While this may take time, the institutions can begin to focus on strategies/interventions to help prevent or reduce these conditions from occurring by:
• Acknowledging these conditions exist in professionals in each healthcare organization and provide avenues for those professionals affected to speak about them safely and without recourse from the institution; increasing awareness of the problem and strategies/interventions to help prevent and/or resolve if a professional needs help
• Providing physical settings/environments/workspaces that are comforting and calming/soothing. In non-patient areas, by allowing for staff to have personal items/pictures/mementos which are a tie for them to their life outside of the workplace.
• Establishing a positive work climate through honoring scheduling/day off requests without stress, offering appropriate benefits, setting schedules to allow for a work/personal life balance for the professionals, etc.
• Creating a work atmosphere that respects the role of pediatric palliative care as “on par” with other specialties through education around how it supports the larger mission of the institution
• Developing connective, supportive, working teams
• Formalizing a system for enabling the staff to process/debrief after a patient’s death; this should allow for team members to speak up about their feelings and the potential needs/support desired from the other team members. Periodically scheduling debriefings conducted by outside experts to bring some neutrality to the discussion.
• Diversifying the workload between acute vs. less acute cases so that no one healthcare professional is caring for all the acute cases
• Providing a system of peer consultation that is available on a regular basis, in a safe, confidential, and nonjudgmental environment
• Printing up small cards (could be business card size) to have staff carry with them to remind them of good “self-care” practices when on/off duty (as listed in this article); card could also list phone numbers on the reverse side to call for help if needed
• Do a yearly/semi-annual check-in with staff to ensure they have a list of self-care activities and that they have a partner in the organization to support them in these activities (the “buddy system”)
• Establishing a “formalized” conflict/resolution process for issues of any kind (workload, moral dilemmas, etc., to be resolved
• Generally supporting staff personally and professionally in their work
• Encouraging professional development; providing opportunities for further education and workshops on pertinent topics like coping with compassion fatigue or moral distress in the workplace
• Offering staff bereavement services/debriefs/remembrance services during lunch (and possibly offering a free lunch when they attend so they don’t have to choose lunch vs. attending the service)
• Conducting/offering staff retreats
• Offering classes and/or workshops for staff in yoga, meditation, dance, sports, relaxation techniques, aromatherapy, etc.
• Encouraging a mutually supportive work environment that provides optimal care for patients and their caregivers (i.e., the healthcare staff)

In the end, it all comes down to being more self-aware and providing ourselves, and encouraging and supporting our colleagues, with better self-care. We do not want to wonder, nor do we want our colleagues to wonder…“Does anyone out there or in here care?” The answer should always be yes. We need to take care of ourselves and our own; giving “lip service” to staff support is not enough to combat the signs/symptoms/ramifications of compassion fatigue and/or moral distress on our healthcare colleagues…or on the system in general.


NICU’s TOP TEN WAYS NURSES TAKE CARE OF THEMSELVES

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(Based on a self-care survey completed by nurses April-June, 2011)

**Number 10:**
Imbibing important liquids, with friends!
(please note that this is not recommended on a regular basis as it can lead to complications, but an occasional beverage can be enjoyed!)

**Number 9:**
Get distracted: Watch TV or Movies, look at photo albums, be busy or distracted

**Number 8:**
Vacation, cottage, using personal days to care for self, including spa days (massage)
Number 7:
Music, singing, hobbies like baking and reading

Number 6:
Sleeping, taking breaks during work, relaxing

Number 5:
Think, reflect, feel the emotions (alone, with coworkers, with family) and/or cry

Number 4:
Shower or bath, treat myself, comfort food or healthy eating

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.
Number 3:  
Exercise (walking, running, yoga, bike, or any other physical way to work it out)

Number 2:  
Spending time with friends including hugs and holding

And the Number 1 Way that NICU Nurses Take Care of Themselves

Talk about the day (friends, family, coworkers, Bereavement Coordinator, debrief, update on how the family is doing) [with respect to confidentiality, of course]
Abstract

Objective: Parents may fear that a do-not-resuscitate (DNR) order will result in reduction of the level, quality, and priority of their child’s medical care. We therefore assessed medical care that was continued, added, and discontinued after a DNR order was placed in the medical record.

Patients/methods: Retrospective review of the charts of 200 pediatric oncology patients at St. Jude Children’s Research Hospital who died between July 1, 2001 and February 28, 2005, were younger than 22 years old at death, and had a documented DNR order. Medical interventions that were added (between the DNR order and death), continued (not discontinued between 24 hours before and 72 hours after DNR), and discontinued (within 72 hours after DNR) were identified and compared by using binomial proportions.

Results: With the exception of chemotherapy, the studied medical interventions that patients were receiving at the time of the DNR order were continued in 66.7% to 99.3% of cases. Chemotherapy was continued in 33.3%. The most frequently added interventions were oxygen, steroids, and pain medicine. The most frequently discontinued interventions were laboratory draws, chemotherapy, antibiotics, and parenteral nutrition.

Conclusions: In this cohort of pediatric oncology patients, the medical interventions being received were continued with a high frequency after placement of a DNR order. Chemotherapy was continued only in a minority of patients, possibly signifying a shift in goals. These findings may help to reassure families that a DNR order need not result in a change in any of their child’s medical therapies which appropriately advance the defined goals of care.

Who is the audience for this information? All pediatric healthcare providers, parents, policy makers.

What is special about this article? These data counter the misperception that palliative care for children is somehow a lower acuity treatment plan with fewer medical treatments included. In fact, in this article there is confirmation that a DNR order in conjunction with an advance care plan specifying treatments concordant with the child and family’s goals and preferences is consistent with those treatments that further the goals of care. Comfort measures were frequently among those treatments added. After the institution of the DNR order, the goals changed but many life prolonging measures were continued.

Where and how can I apply this information? I would recommend including this information in advance care planning discussions with the child and family, including those where resuscitation is being discussed. I also think that policy makers should be educated that shifting goals to exclusive palliative care does not mean withdrawal of care. It means redirecting care to those treatments that further the goals.
Items of Interest: In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. Conference Announcement. The District of Columbia Pediatric Palliative Care Collaboration is sponsoring a "Quality of Life for the Children Conference" to be held on November 4-5, 2011, at the Renaissance Washington DC Downtown Hotel. This two-day conference will explore care for pediatric patients and their families across the care continuum. Presentations will be made by leading national experts on pediatric palliative care. Confirmed speakers include: Timothy Culbert, MD, Ridgeview Medical Center, Minnesota; Christopher Feudtner, MD, PhD, MPH, Children's Hospital of Philadelphia; Sarah Friebert, MD, FAAP, FAAHPM, Akron Children's Hospital; The Fred Rogers Company, Pittsburgh; and Stefan Friedrichsdorf, MD, Children's Hospitals & Clinics of Minnesota.

Registrants may apply for CME, continuing nursing education and social work contact hours. For more information, contact: Alisha Baptiste, Program Manager, 202-821-1914 or abaptiste@dccancerconsortium.org.

2. Pediatric Intensive at 2011 Clinical Team Conference. Register now for NHPCO's 12th Clinical Team Conference and Pediatric Intensive! The theme of the conference is "The Hospice IDT: Leading and Innovating Quality Throughout the Care Continuum". The conference will be held October 4-8th in San Diego, California. To preview sessions and register, visit http://www.nhpco.org.

3. NHPCO Position Statement. Despite the fact that issues specific to pediatrics are not addressed, the NHPCO position statement "Hospice and Palliative Care: Ethical Marketing Practices" has valuable information especially for managers of hospice and palliative care organizations. The statement is available on the NHPCO website under position statements (linked on the News Room page).

4. New Video. Nurses Grieve Too: Insights into Experiences with Perinatal Loss is a ground-breaking documentary that shares what grief is for nurses who care for bereaved families with perinatal loss. This research-based documentary answers the research question: What is the experience of grieving for obstetrical and neonatal nurses caring for families who experience perinatal loss? Nurses describe the professional and personal impact of grieving, what helps them, and how the experience has changed them and help them to grow. The documentary makes the invisible grief of nurses visible. It aspires to support nurses so they no longer feel alone or isolated in their experiences of grieving, as many nurses can carry the pain and memories of the families' loss and experiences with them for years. This video was made by nurses at Mount Sinai Hospital in Toronto. Its authors are Christine Jonas-Simpson, Cindy MacDonald, Eileen McMahon, and Beryl Pilkkington. Available from the York Space Institutional Repository.

5. Pediatric Palliative Care Online Courses Available. NHPCO's Pediatric Palliative Care Online Training Series provides instant access to educational resources for pediatric care providers. The series offers 10 online educational modules written by leading pediatric palliative/hospice care experts across the country and will be available through NHPCO’s E-Online in 2011. Two of the ten modules are now available – Pediatric Palliative Care Principles and Standards, and Pediatric Palliative Care Delivery Models. Each module offers valuable content, case studies and practical examples to help your organization deliver quality care for children with life-threatening conditions and their families. Learn more and access the online modules at nhpco.org/pediatrics.

6. ICPCN Call for Case Studies from Children's Palliative Care. World Hospice and Palliative Care Day is a unified day of action to celebrate and support hospice and palliative care around the world. The theme for World Day 2011, which takes place on 8 October, is "Many diseases, many lives, many voices - palliative care for non-communicable conditions." Voices for Hospices takes place on World Hospice and Palliative Care Day on 8 October 2011. Hospices and palliative care organizations are encouraged to share their stories about successful palliative care cases by submitting case studies to the ICPCN. Case studies should be about children and their families and should include information about the care provided, the outcomes for the children, and the impact on the families. Case studies will be compiled and disseminated to all ICPCN members and other relevant organizations. Please submit your case studies by 1 October 2011 to icp@icp-nhpcn.org.
Hospice and Palliative Care Day every two years. The objective of the event is to raise awareness for hospice and palliative care around the world by using the voice.

The ICPCN would like to raise our voice for children with palliative care needs around the world on this day. To do so we are putting together a book on true stories, thoughts, poems, and reflections of children and their family members from across the globe receiving palliative care. The focus of this book will not be academic, but will be the lived experience of children, siblings, and family members from a variety of ages, diseases and nationalities.

If possible, we would like these stories, poems, and reflections in the child’s own words but we do understand that it may be that the child is not well enough or able to write something down, in which case it would be great if they can tell you what they would like to say and you write it down – but in doing this please do not lose the child’s voice. We want to hear their experience of receiving palliative care, how it has helped them, what they have found difficult or challenging, how the team has supported them, what is their favorite aspect of the palliative care service, and how they think the service has helped their parents, brothers, sisters, etc., i.e. anything to do with their experience. We do not want the book to be just words – pictures speak louder than words – so if the child would like to draw a picture to go in the book that would be great. We would also like to have some photographs in the book and would like at least one if not two or three photos for each case.

If you feel you are working with a child or family who would be interested in having their story told in this way, please send an email to Sue Boucher at Sue@icpcn.co.za for further information on the project. Guidelines for authors can be downloaded from the ICPCN website under the heading World Hospice and Palliative Care Day.

Dr. Julia Downing      Sue Boucher
ICPCN Education and Research Consultant   CPCN International Information Officer

7. Subjects and Contributors for Future Issues of This Newsletter. In past issues of this newsletter, we have addressed a wide range of subjects, including bereavement, sibling bereavement, self care, ill and dying teens, perinatal loss, neonatal loss, spirituality, unsung heroes in the circle of care, pain and symptom management for children with life-threatening illnesses and their families, families experiencing transitions associated with pediatric palliative care, complementary therapies, examples of programs illustrating the current status of pediatric palliative and hospice care in the United States, memory building and legacy making in pediatric palliative and hospice care, examples of many programs offering this type of care in various parts of the world outside the United States, ethical issues related to pediatric palliative and hospice care, and help and healing in relationship to bereavement perspectives. (Please note that you can visit archived issues of this newsletter at www.nhpco.org/pediatrics.) For future issues, we are thinking about addressing subjects such as uses of social networking in relationship to pediatric palliative and hospice care. If you know of good topics and/or contributors (including yourself) for any of these and/or other future issues of this newsletter, please do not be shy! Step right up and contact any of the following: Christy Torkildson at torkc@sbcglobal.net; Maureen Horgan at Maureen.Horgan@providence.org; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

8. Reader’s Corner. Our Reader’s Corner column provides brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric palliative care, but that may not be known to all readers of this newsletter. Contributions to the Reader’s Corner, like the one in this issue, include an abstract of the publication, a description of the audience for this information, comments on what is special about the publication, and suggestions as to where and how this information can be applied. We welcome suggestions for publications to include in our Reader’s Corner and/or summaries and comments on such
9. Concurrent Care for Children Implementation Toolkit. The Patient Protection and Affordable Care Act (PPACA) signed into law March 2010, includes a provision, Section 2302, termed the “Concurrent Care for Children” Requirement (CCCR) which requires that every state Medicaid program pay for both curative treatment and hospice services for children under age 21 who qualify.

The District of Columbia Pediatric Palliative Care Collaboration (DCPPCC) asked for help from NHPCO in implementing this law in D.C. The organizations decided that it would be valuable to share the process with others. Thus, the Concurrent Care for Children Implementation Toolkit was born, providing detailed information on the options available to states that are implementing Section 2302 or are considering expansion of pediatric palliative care services to children. This toolkit can be used as a guide to: understand the impact of the CCCR on state Medicaid programs; consider the different Medicaid state plan amendment and waiver options available to states; review examples of existing comprehensive palliative care programs for children in states that have implemented such programs; and learn how to develop a coordinated, collaborative state-wide approach for advocating for children with life-threatening conditions through a comprehensive array of services. Download this toolkit at www.nhpco.org/pediatrics and/or www.dcppcc.org.

10. Calendar of Events. As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, www.nhpco.org/pediatrics. Please e-mail Christy Torkildson at torkc@sbcglobal.net to have your pediatric palliative care educational offering listed.

Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its Communication Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work. If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to CHIPPS2@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the Communications Preferences tab in your individual member record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the ChiPPS Web page at www.nhpco.org/pediatrics for further materials and resources of interest.

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