Everything Matters In

Patient Care

Empowering our
Patients and Families
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In Recognition

Pictured left: Nationwide Children’s generates parents’ ability to make decisions and be involved in their child’s care as part of the full health care team.
What is Parent Empowerment?

In previous issues of Everything Matters in Patient Care, I have written about our model of care which includes the family at the center of everything we do. In this issue, many of the topics have a theme of parent empowerment.

What is parent empowerment? Webster’s defines empowerment as “giving the right to.” As health care providers, do we really have the ability to give parents rights? No! Their rights come from legal authority to have autonomy to make the best decision for their child.

So how do we empower parents?

Health care and its terminology can be daunting for someone who has not been exposed to the complexity of terms. The navigation through this process for families, from wellness and perhaps even end of life, can be very complicated. Understanding the medical terminology regarding the types of tests and the navigation of the many roles needed to care for patients is often very challenging. Sometimes strong evidence can guide us to the best approach to achieve a balance of wellness or treatment of chronic and acute conditions. As with any decision, it is best to be armed with all the knowledge possible to make the best decision.

I heard an economic advisor, who was a patient advocate, describe her experience with the health care system. First, she asked her audience to make a decision on the best way to invest their money after espousing terms unique to the economic industry. Her point was that it was exactly what the information sounded like to her when she was given the diagnosis of Multiple Sclerosis from her health care team and asked to make decisions on her care based on those conversations. She was a college graduate and very successful business woman.

However, health care has its own unique language that must be broken down into terms the patient and family can fully understand.

In order to help parents exercise their role of being empowered, our role as nurses, doctors, social workers and other health care providers is to bring information to them in a way they understand so they can use the information to achieve a decision that works for their child and their family. In order for parents to be empowered to make the best decision, it is important to help them analyze the information they have, discern the value of the information and synthesize all of it to fit their goals, beliefs and values.

Two tools that are valuable in the assessment of parent knowledge of health care information are motivational interviewing and teach-back. Motivational interviewing is using open-ended questions to gain insight into the family’s beliefs and goals for their child as it relates to the health care situation. Teach-back is an effective tool to help assess the family’s understanding of information you or another source has provided. Many times we think of teach-back in the discharge phase of a healthcare encounter, but it is very helpful in assessing the parents understanding of any information provided without leaving the person feeling intimidated if they did not fully comprehend the medical information.

We want families to make decisions for their child as full partners in the health care team. Ensuring parents have all the knowledge in a way they understand allows them to exercise their parental right of being empowered and advocates for their children and families.
Nationwide Children’s Hospital should be a safe and healthy environment for every child. Yet it might not be unusual to walk by a hospital room or a busy clinic waiting area and witness a caregiver frustrated by a child’s behavior and shouting at, threatening to strike, or actually striking, the child. When hospital staff witness such behavior they have an obligation to intervene, interrupt the behavior and offer assistance. Staff may not feel empowered to intervene nor feel they possess the necessary tools to appropriately intervene. Nationwide Children’s has instituted a new initiative titled Hitting Harms, Hugging Helps to create a safe and healthy environment for every child, parent, visitor and staff member.

We must recognize we live in a more violent society. American children are exposed to violence in a variety of ways. This country has been embroiled in a war for more than a decade, children are bombarded with images of war via television and the internet. Tens of thousands of American children have been personally affected by war due to the deployment of a loved one. Terrorism has been a reality for American children since September 11, 2001. Mass shootings are becoming all too common in the United States. Places that should be safe havens for children, school and home, are often venues for violence exposure. School can be a site of multiple violence exposures for children: bullying, corporal punishment (CP), and even deadly shootings. Too many children experience violence in their homes, and up to 10 million children witness domestic violence each year. According to the U.S. Department of Health & Human Services (2017) more than 600,000 American children experienced child maltreatment in 2016. More than 90 percent of American parents report having used CP once, and up to 40 percent report using CP in the past six months. The more frequently a society endorses the use of CP with its children, the more it will endorse all forms of violence, and therefore violence becomes more prevalent in the society as a whole. What effect does CP use have upon children? Spanking is a very common and normative method of discipline in the United States. Yet, numerous studies have linked experiencing spanking to a variety of negative consequences for children. The more children are spanked, the more likely they are to experience physical abuse at the hands of their parents. Spanking is also associated with more aggressive behavior, anti-social behavior, slowed cognitive development, poorer mental health outcomes and negative parent-child relationships.

Pediatric health care providers should be at the forefront urging Americans to look to countries like Sweden for a blueprint for eliminating CP use in the United States. Thirty years ago Sweden introduced a ban on all forms of physically and emotionally abusive discipline. Sweden was the first country to do so, and subsequently 49 other countries have passed similar legislation. Public attitude in Sweden supporting CP use decreased from 55 to 9 percent (1960 & 2000) and the use of CP decreased from 95 to 12 percent. Anticipatory guidance is an essential part of pediatric health care. All health care providers working with children are in a unique position to influence a new generation of American parents and children regarding the use of CP. Parents often look to their child’s health care provider for guidance regarding discipline concerns. Pediatric health care providers must feel comfortable and confident talking with parents about discipline and the potential negative consequences of CP use. Encourage the use of non-physical methods of discipline. Stress to parents the importance of realistic developmental behavioral expectations and discipline strategies. Discipline should always include teaching. Encourage parents to talk with their child about what is acceptable behavior and why a certain behavior may not be acceptable and to explain to their child that they are still loved despite the misbehavior and discipline. Encourage parents to reward positive behavior with praise, a hug or at times a small treat. Discuss there will be times when age appropriate discipline may be necessary such as time-out, losing privileges, or grounding. It is important parents understand they teach with their actions as well as their words, and children mimic parental behavior they see, both good and bad.

There are currently organized efforts in the United States to address the concern of CP use. The No Hit Zone (NHZ) project is one such effort. The origin of the NHZ is in pediatric health care and began at Rainbow Babies and Children’s Hospital in Cleveland, Ohio. The original goal of the NHZ was to reduce the frequency
which parents administered discipline that was physically or emotionally excessive or disruptive in the hospital setting. This was achieved by providing staff with strategies to intervene when discipline seemed excessive or disruptive. Numerous pediatric hospitals have implemented their versions of the NHZ within their institutions. Information and support are available to pediatric institutions interested in NHZ implementation via the Gundersen Health System and the No Hit Zone website.

With the research on corporal punishment and understanding the responsibility of pediatric health care as a whole, Nationwide Children’s brought key stakeholders together to plan for implementation of the NHZ concept within our institution. There were many things within our current culture that were already seen as positive that the team believed would contribute to this new NHZ concept. The team focused on our Zero Hero Patient Safety program, our Treat Me with Respect initiatives and our integrated Code Violet response to protect staff and others being threatened. As we focus on quality and safety as a pre-eminent clinical institution, it only makes sense to incorporate pediatric research and a NHZ into our culture at Nationwide Children’s. The core concept of Hit Harms, Hugging Helps is “At Nationwide Children’s no adult shall hit a child and no adult shall verbally abuse a child.” When hitting or verbal abuse is observed, as Zero Heroes, we interrupt the behavior and offer assistance to diffuse the situation.

As a pre-eminent clinical institution, it only makes sense to incorporate pediatric research and a NHZ into our culture at Nationwide Children’s. The core concept of Hit Harms, Hugging Helps is “At Nationwide Children’s no adult shall hit a child and no adult shall verbally abuse a child.” When hitting or verbal abuse is observed, as Zero Heroes, we interrupt the behavior and offer assistance to diffuse the situation. Our Journey to Best Outcomes could not be accomplished without empowering our staff to role model and intervene as Zero Heroes in this very important, but sometimes difficult subject.

Pediatric Health Care Providers Should Guide Parents About Discipline By:

- Encouraging the use of non-physical methods of discipline.
- Stressing the importance of realistic developmental behavioral expectations and discipline strategies.
- Encouraging talking with their child about what is acceptable behavior and why a certain behavior may not be acceptable. They should explain to their child they are still loved despite the misbehavior and discipline. Discipline should always include teaching.
- Encouraging rewarding positive behavior with praise, a hug or at times a small treat.
- Discussing there will be times when age appropriate discipline may be necessary such as time-out, losing privileges, or grounding.
- Helping them understand they teach with their actions as well as their words, and children mimic parental behavior they see, both good and bad.

Hitting Harms, Hugging Helps is on NationwideChildrens.org with realistic expectations and tips!

We made the national concept our own; “Hitting Harms, Hugging Helps,” with a stronger focus on role-modeling and coaching positive parenting concepts.
Empowering Patients and Parents for Individualized Pain Management

Sharon Wrona, DNP, RN-BC, PNP, PMHS, AP-PMN

One of the new Joint Commission Pain Management Standards PC.01.02.07 states:

The hospital assesses and manages the patient’s pain and minimizes the risks associated with treatment.

- The hospital involves patients in the pain management treatment planning process through the following: Providing education on pain management, treatment options, and safe use of opioid and non-opioid medications when prescribed.
- The hospital educates the patient and family on discharge plans related to pain management including the following: Safe use, storage, and disposal of opioids when prescribed.

Nationwide Children’s Hospital engages in family-centered care for our patients and families, and this care goes beyond the patient bedside. Coming to the hospital, even for a planned admission or surgery, can be very stressful for both the patient and family. Studies show pre-surgical anxiety in both the patient and family can be predictors for higher post-operative pain, so educating early is important. Nurses in the clinic and preoperative settings can help educate on pain management including non-pharmacological and pharmacological treatment options. They can provide handouts on treating pain after surgery and engage patients and families in conversations to help with setting realistic goals for their pain management.

A pain rating of zero may not be a realistic expectation, keeping the focus on functional goals is imperative. But be sure to cover the menu of choices for treating pain from relaxation, deep breathing, distraction, massage, child life, hypnosis and aromatherapy; to scheduled mild analgesics if appropriate. Stronger analgesics such as opioids should be available only as needed. Use your resources to help teach patients more advanced skills to empower them to have additional control over their own pain — the mind can be a great source for analgesia.

Empower patients and families being discharged with a pain treatment plan to ask questions and speak up if they don’t feel their child needs as many opioid medications as prescribed. Emphasize everyone’s pain needs are different. Studies and Quality Improvement data collected at Nationwide Children’s have shown there is a mismatch between the amounts of opioids needed to treat pediatric acute pain and how much is prescribed. Children are using less than 50 percent of their prescribed opioids. Patients and families need to be empowered to ask if using mild analgesics such as acetaminophen and ibuprofen contraindicated as part of the individualized pain treatment plan.

Ohio is in the midst of an opioid overdose epidemic; however, safe opioid use, storage and disposal can help make a difference. Seventy percent of the opioids that are misused are received from a friend or family member. Most likely, many of them do not realize they could be considered an unintentional drug dealer by not locking up their medications.

There is an average of 32 calls a day to U.S. Poison Control Centers related to unintentional opioid overdose, with 60 percent of these occurring in children less than 5 years of age. Patients and families need to know these important factors to empower them to do their part in safe opioid storage and disposal. A Helping Hand™ on opioid safety and a new video have been created to help disseminate this important information and can be found on the Nationwide Children’s YouTube Channel. Please continue to use all of the educational resources created at Nationwide Children’s on pain management and opioid safety.
Empowered Nurses Empower Patients and Families
Sherri Watts, MSN, RN, Nurse Specialist, Magnet Program Coordinator, Department of Professional Development

Empowerment of nurses amidst the 1980s nursing shortage crisis is what prompted the American Nurses Credentialing Center (ANCC) to develop the Magnet Recognition Program. The spirit of inquiry by several nurse researchers to understand why some hospitals were able to attract and retain nurses, revealed these magnet-like hospitals had similar cultures of nursing excellence as measured by patient satisfaction, nurse satisfaction, evidenced-based practice, quality patient care outcomes and interprofessional collaboration. In response, the American Nurses Credentialing Center (ANCC) was tasked to develop a program that would facilitate enculturation of those identified magnet-like characteristics for other hospitals subsiding to the staffing challenges.

Today, more than 470 national and international health care organizations have received ANCC Magnet Recognition.

To be re-designated Magnet, health care organizations are required every four years to demonstrate ongoing nursing excellence through submission of a document which includes story exemplars and outcome data pertaining to the four components; Transformational Leadership, Exemplary Professional Practice, New Knowledge & Innovation, and Structural Empowerment. Structural Empowerment was not only recognized by ANCC as essential in creating environments that support professional nursing practice, but by the National Academy of Medicine (formerly the Institute of Medicine) who directly associate quality of patient care to the degree which hospital nurses are empowered. Because everyone at some point in their life will need a nurse for a loved one or themselves, empowering nurses so they can empower patients and families, makes sense. Nurses provide their patients and families with knowledge, skills and attitudes necessary for the patient and family to influence their own healthy behaviors and live healthier lives.

As one of the largest pediatric hospitals serving more than 1.4 million patient visits, having strong structures in place to ensure employees are inspired to empower patients and families is essential. Nationwide Children’s empowers all employees, including nurses at all levels, through a multitude of programs such as Zero Hero, Safety Coach, I Will Commitment, teach-back and See Something and Say Something. Guided by our patient- and family-centered model of care and vision to create best outcomes for children everywhere, Nationwide Children’s is committed to remaining part of the elite two percent of hospitals that strive for a fourth Magnet designation.

In October 2018, Nationwide Children’s will submit our fourth Magnet document highlighting more than 50 stories of how nurses, individually or as part of an interprofessional team, empowered patients and families toward better health outcomes, along with eight quarters of our most recent patient care outcome data demonstrating outperformance of a national benchmark a majority of the time. Attaining Magnet recognition is no doubt an honor, but small in comparison to knowing we remain committed to instilling structures that will support our more than 120 year vision to provide best outcomes for patients everywhere.

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Good Death: free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural and ethical standards. Institute of Medicine (2003)

I t could be said that there is no such thing as a “good” death when an infant dies. Death at the beginning of life is unnatural, unexpected and tragic. For families, the trauma of the experience may have lasting effects, including long-term negative health outcomes for a subset of parents. Parents of infants who die in the neonatal intensive care unit (NICU) face unique challenges when the end of life (EOL) comes so closely to the beginning of life. For example, opportunities for bonding are limited because mothers must often stay at the birthing hospital to recover and parents are not able to fully participate in care activities because of the infant’s fragile state. Defining and maintaining the parents’ role while making difficult treatment decisions can be extremely stressful for them during this time. Parents may be further distressed by their infant’s appearance, physical symptoms or perceptions their infant is suffering. Parent perceptions of infant suffering at EOL have been associated with prolonged grief at three years post-death. Some health care providers also report high levels of distress and compassion fatigue in caring for infants and families at the EOL.

Important research led by co-investigators at the Ohio State University College of Nursing and the Center for Biobehavioral Health at Nationwide Children’s Research Institute highlights a constellation of factors that contribute to the quality of the EOL experience for infants, families and health care providers. While the loss of an infant may be unavoidable, patient and family-centered care may ease distress and help those who are bereaved to move forward in a healthier, more positive way.

Advances in the management of high-risk deliveries and the delivery of care in the NICU have significantly contributed to an increased number of infants who confront prematurity, congenital anomalies or other life-limiting and life-threatening syndromes and survive against the odds. However, each year in the United States, 23,000 infants die, with more than two thirds of these deaths occurring in the NICU. Infant deaths constitute the highest percentage of deaths for any age group in pediatric institutions and most occur following the withdrawal or withholding of medical therapy, primarily mechanical ventilation. Death is never the desired outcome for an infant, but when the situation becomes futile, a death free of pain and suffering becomes the new goal. Both the American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care (2000) and the Institute of Medicine (2003) have called for greater attention to improving palliative and EOL care in pediatrics. Further, an increasing number of research studies have highlighted the importance of examining the quality of EOL care for infants.

Each year in the United States, 23,000 infants die with more than two thirds of these deaths occurring in the NICU.

One way the quality of a neonatal death can be evaluated is through the use of an evidence-based framework that has been adapted from the adult literature. Fortney & Steward’s Framework for a Good Neonatal Death (2014) identifies key variables across three domains (infant, parent, nurse) that interact within the changing NICU environment and may contribute to a “good death,” defined by the Institute of Medicine (2003) as “free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural and ethical standards.” The interaction of these variables may influence whether the death experience will be more positive or more negative.

The framework includes parent and nurse perceptions of infant symptoms and suffering, which are particularly important given the infants are not yet verbal. These are considered to be modifiable characteristics we should be able to change through adequate assessment and appropriate interventions that may be pharmacological, non-pharmacological or both. However, methodological issues, particularly the lack of standardized measures for use in assessing infants, have limited our understanding of symptom manifestation and how to optimize care for infants. Perceptions of symptoms and suffering by parents and nurses can be influenced by a variety of factors, such as life experience, social support, family dynamics, education level, clinical experience, and familiarity with the infant. Often perceptions between parents and health care providers differ and can lead to issues with communication and trust.

The presence of infant symptoms and perceptions of suffering are noticed by parents and can be extremely distressing for them, as well as influential factors in their decision making. Parents have reported choosing to withdraw or withhold life-sustaining therapy in order to relieve suffering in their infant. Recent research found mothers and fathers reported seeing an average of six different symptoms in their infant during their last week of life. Respiratory distress, agitation, pain and lethargy were described as being the most distressing. Both mothers and fathers tended to report moderate levels of suffering for their infant during the last week of life, though the association between the number of symptoms and the amount of suffering was weaker for mothers than for fathers. Collaboration between the medical team and parents in recording symptoms and making medical decisions continues to be a highly important and impactful area of the course of treatment.

Recently, the original Framework for a Good Neonatal Death was expanded to incorporate research results that provide a deeper understanding of bereaved parents’ experiences with their infants at EOL and highlight opportunities for enhanced care. Parents as partners in care, communication with the health care team, relationships with staff, and bereavement support were added to the model as influential processes in the determination of quality of the EOL experience. Parents generally felt positive about their role in treatment decisions, relationships with staff, and memory-making activities. However, parents noted areas for improvement, including team communication, anticipatory guidance, family inclusion at bedside and bereavement care. Another modification to the model extended the work of NICU nurses to include other types of health care providers, including physicians, psychologists, chaplains and social workers. While more research is needed to determine if the nurse factors identified in the original model also pertain to other NICU personnel, parents have strongly identified these staff members as being valuable resources.

Parents as partners in care, communication with the health care team, relationships with staff, and bereavement support were added to the model as influential processes in the determination of quality of the end of life.
Parents have reported often feeling alone and abandoned after leaving the hospital. They want to maintain connections to the staff members who were intimately involved in their infant’s short life and witnessed the family’s journey because they may be the only ones who knew their child. However, ongoing contact can be difficult in terms of balancing professional boundaries and staff burnout and needs to be examined further.

NICU teams should provide information on community grief resources and consider initiatives which designated staff may reach out via phone calls or mailings at significant milestones to communicate to families their infant is not forgotten. Hospital bereavement programs can provide services and encourage parents to reintegrate into their own community and support network; customizing the information to serve the needs of individuals within families and recognizing differences in grieving and required levels of support.

Continued research can provide answers to what comes next for bereaved families. A recent study found associations between parent perceptions of infant symptoms/suffering and parent distress affected decision making about having additional children after an infant’s death in the NICU. Parents who have another child after an infant loss endorsed fewer symptoms of prolonged grief and posttraumatic stress. Although further prospective research is necessary to distinguish directional associations, as this suggests having another child after infant loss may promote resilience or serve as an indicator of positive adjustment among parentsbereaved by infant death in the NICU.

The search for the best possible death experience continues to unfold through research with parents and health care providers throughout the infant’s journey and after death. Ongoing prospective research is assessing views of infant well-being from multiple sources and identifying associations between parents’ perceptions of infant symptom experiences and their decision-making around goals of care, as well as their distress and coping. This research will inform the development of interventions aimed at improving symptom assessment, as well as outcomes among infants and their families in the NICU.

The hope is this research will help to reduce symptom burden and suffering for infants and families, help families honor their child’s legacy, and lay a positive foundation for life after loss.

Regional Catheters for Post-Operative Pain Management

Lauren Renner, NP, APRN, Clinical Leader, Comprehensive Pain and Palliative Care Services

A PNC is the infusion of local anesthetic that can be used for post-operative pain control. A PNC is a flexible tube placed directly around the nerve innervating the surgical site. PNC placements are common with orthopedic surgeries and significantly decrease the amount of opioids that a patient requires post-operatively. Common placements of PNCs are the brachial, femoral, sciatic and lumbar nerves for upper or lower extremity surgeries. If a patient has abdominal surgery, the anesthesiologist may place a transversus abdominis plane (tap) catheter or an intercostal nerve catheter to help with pain relief post-operatively.

Peripheral nerve catheters continuously infuse local anesthetic. While in the hospital, patients and caregivers are educated on PNC care and removal which allows the patient to be discharged with the catheter in place if their care no longer requires hospitalization. The home PNC pumps are disposable and can be discarded after the catheter is moved at home. There is ongoing communication between the patient/caregiver and the pain service while the patient is at home with the PNC. Typically the PNC is removed three to five days after placement.

One of the newer techniques for post-operative pain management is a wound catheter. Similar to a PNC, the catheter is placed directly into a post-operative wound to directly infuse local anesthetic into the wound area. The wound catheter has more holes at the distal end of the catheter to allow for the local anesthetic to infiltrate the wound at various locations. The wound catheter is typically removed by the surgeon 3 to 5 days after surgery.

Providing various options for regional post-operative pain management can help with empowering patients to have even more options than opioids and other analgesics to treat their pain. A multimodal treatment plan to treating pain is the best approach.
National Nurses Week 2018
Nurses: Inspire, Innovate, Influence

Kim Kelly, BSN, RN, CPN, Nursing Student Education Coordinator, Professional Development
Vickie Bennett, MSN, RN-BC, Clinical Informatics Nurse Educator, Professional Development

The 2018 American Nurses Association’s (ANA) theme for Nurses Week, “Nurses: Inspire, Innovate, Influence” evoked the roots of nursing. Florence Nightingale’s nursing pledge, “I will do all in my power to maintain and elevate the standard of my profession… and as a ‘missioner of health’ I will dedicate myself to devoted service to human welfare” led the week-long celebration of the nursing profession. Nurses Week was celebrated May 6 to May 12. Activities at Nationwide Children’s Hospital highlighted our nurses’ devotion to our community, patients and elevation of the nursing profession.

Highlights included:

• Linda Stoverock, RN, DNP, NEA-BC hosted several sessions on nursing’s role in Nationwide Children’s Journey to Best Outcomes.
• Linda presented various inpatient units and ambulatory clinics with sweet treats provided by The Edward and Sally Kosnik Scholarship for Advanced Practice Nurses.
• Staff honored an inspiring, innovative or influential nurse by sending stories to the Nurse’s Week Committee for display at Fun Day and on ANCHOR.
• Nationwide Children’s Pastoral Care staff provided “Blessing of the Hands” ceremonies on each end of the hospital. Two locations made it easier for staff to partake in this important spiritual nourishment.
• The Schools of Nursing Expo hosted multiple nursing programs offering information on a variety of nursing degrees from baccalaureate to doctorate.

• Three one-hour presentations with continuing nursing education highlighted nurses’ contributions to pediatric behavioral health, genomics and the opioid crisis.

• Night Shift staff enjoyed food trucks, pancake flipping, continuing education presentations, coloring pages, a snack cart and a fun night celebration with ice cream.

The week ended with a fun day celebration in Galaxy Lounge. More than 600 staff enjoyed a variety of activities throughout the day. Breakfast items, popcorn, chilidogs, cupcakes and ice cream were available. A visit with Nationwide Children’s therapy dog Piper, games, coloring pages and relaxation techniques from Urban Zen offered staff a short respite.

Special recognition goes to the following individuals for making our 2018 Nurse’s Week celebration exceptional:

• Department of Professional Development: planning and supporting Nurse’s Week programs
• Managers: donating $1,300 for prizes and gifts
• Dr. Edward and Sally Kosnik: providing “The Edward and Sally Kosnik Scholarship for Advanced Practice Nurses” and treats recognizing our nurse’s dedication to advancing quality patient care
• Thirty-One Gifts: generous donation of lunch bags to acknowledge our nurses’ devotion to improving patients and families lives
• Panera Bread: providing nurses with a coffee and bagel coupon to celebrate their dedication and commitment
• Urban Zen, Piper, and her handler, Sheila Gottron: contributing to the overwhelming success of fun day
Patient Empowerment through Psychosocial Services and Programming

Tammi Young-Saleme, PhD, Director, Psychosocial Services and Program Development, Division of Hematology/Oncology/BMT
Claire Russell, PhD, Pediatric Psychologist, Department of Pediatric Psychology and Neuropsychology

The moment children and teenagers are diagnosed with cancer, their world changes. Instead of going to school, spending time with friends and focusing on developmentally-appropriate growth, they must cope with hospital admissions, treatment and managing side-effects. The diagnosis of cancer brings emotional experiences of uncertainty, anxiety and distress. It often leaves patients feeling a loss of control.

Empowerment results from the utilization of support and coping strategies that help patients increase their perception of control and independence despite their difficult circumstances. Integrative care models with psychosocial and medical providers working closely together helps to engage patients as active participants in their treatment.

The Hematology/Oncology/BMT division at Nationwide Children’s Hospital utilizes an integrative care model. From the time of diagnosis and throughout treatment, a primary psychosocial team, including social work, child life, psychology, pastoral care, school liaison, therapeutic recreation and massage therapy, help to support and empower the patient and family. Evidence shows a sense of personal control, empowerment and self determination are associated with positive mental health and adjustment within the context of managing a chronic illness. The psychosocial team promotes these self-determination skills in a number of ways, including individual intervention, group-based interventions, and specific programs.

Our social workers and psychologists help address patient and parental concerns with one-on-one education regarding diagnosis, treatment plan and potential side effects, as well as providing emotional and social support directed at increasing self-confidence. Self-efficacy can be gained through psychosocial interventions such as teaching patient’s coping skills to manage symptoms, including nausea and pain, with the use of guided imagery, biofeedback, and hypnosis. Other supportive therapies, including therapeutic recreation, art and music therapy, provide psychoeducation and opportunities to share, as they offer a sense of hope to empower the patient and family.

As children and teens are removed from their typical social environments during treatment, opportunities to engage with other patients helps promote a sense of normalcy and increase peer support. Recreation therapy and child life work together to offer group activities on the inpatient unit which allow patients to gather together, share their stories, express emotions, and build positive coping skills.

Empowerment is also promoted through several programs within the Hem/Onc/BMT division. The Adolescent and Young Adult (AYA) program has been developed to meet the unique needs of this patient population. An AYA mentorship program is available to link current AYA patients with past AYA patients. This program promotes shared experiences which improves self efficacy and social support as it enables patients to take control of their response to their illness.

Another program is offered by our child life team to foster independence and choices in the context of a common and difficult side effect—hair loss. The loss of hair for a child or teen can be a traumatic experience that may result in lack of self confidence and worry. Our child life team has developed a hair loss kit which includes psychoeducation around hair loss and offers choices to children and teens about different ways to cope with their hair loss. The kit also includes a developmentally appropriate book that normalizes hair loss, a hair loss journal and either a Barbie named Ella who has no hair or a Mr. Potato Head. This intervention reminds patients they have control over certain decisions with hair loss (e.g. they can decide to shave their head, cut their hair short to allow for less of an impact once it starts to fall out or allow hair to fall out naturally).

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With the assistance of an integrated care model, the Hem/Onc/BMT divisions’ psychosocial program empowers patients with cancer and their families to participate in their own care by learning coping strategies, accessing support, normalizing challenges and increasing opportunities for growth and independence to improve quality of life.
Learning Through Play
Tabbetha L. Greco, MAEd, MSEd, Manager, Early Childhood Development and School Program, Family and Volunteer Services
Kaleigh Paul, MA, EIS, Early Childhood Specialist, Early Childhood Development, Family and Volunteer Services

The Sensory Room on H10A is the first of its kind at Nationwide Children’s Hospital. The Family and Volunteer Services Department, which includes Early Childhood Specialists, Child Life Specialists, Columbus City School teachers, Music Therapists, Sibling Clubhouse and Volunteer Program staff spearheaded the project. The team pulled together their collective strengths in child development and family support, and along with families, planned a multipurpose room for use by disciplines and families across the enterprise. It was evident patients with sensory processing disorder, including those with Autism, did not have a safe place to move, rock, swing or receive tactile stimulation in the typical playroom settings. Recognizing that sensory exploration supports the regulation of our patients and they use these experiences to calm and ground themselves in their spaces, a plan was developed to turn the existing play space on H10A into a sensory play space.

All the equipment in the room is child and family centered. A highlight is the infant-adapted therapy swing, allowing families to swing and move together with their child. There is an interactive motion sensed computer, which turns the floor into a variety of games patients and families play together for educational or recreational fun. To accommodate other sensory modalities, light tubes, a textured wall, bubble machines and magna tiles allow patients to experiment with sound, light and force.

The room is accessible to families and patients of all ages. However, they must be accompanied by a staff member, to assure safe interactions with the equipment. Every Tuesday from 10:30 to 11:30 a.m., the Early Childhood Development (ECD) team coordinates playgroup in the space for children age birth to 5 years old. The ECD team facilitates play and encourages parents and family members to be an active participant in their child’s learning. During this time, children are free to actively explore the environment, while discussing feelings, colors, textures and sounds.

The goals of the Sensory Room are shared with families while engaging them and are carried out through playgroup activities. Suggestions on how to support children in their play-based investigations are posted to guide families while interacting with their children. Children learn through play, regardless of age or ability. For younger children, the Sensory Room facilitates the development of an interest in people and objects, and challenges children to work with a variety of materials. Young children are able to explore their impulses and work to respond to multiple choices. The Sensory Room incorporates soft spaces for those unable to sit or ambulate independently. Materials on the shelves are sanitized regularly and the selection is rotated to maintain child interest. Older children may explore the environment with more purpose and ask questions when curious or prompted. This age group may demonstrate an awareness of their emotions and an understanding that their actions may have consequences. Mirrors, cause and effect toys, and calming spaces such as a block-out tent provide such stimulation. Ultimately, the Early Childhood Development team has a goal to empower families in the education of their child through play and learning in the Sensory Room.
Education and Skills for Parents of Preterm Babies and Critically Ill Children: Evidence to Support Action in Clinical Practice

Bernadette Mazurek Melnyk, PhD, RN, CPNP/PMHNP, FAANP, FNAP, FAAN

Multiple stressors face parents of critically ill children and preterm infants in the neonatal intensive care unit (NICU), including fear, uncertainty about their child’s condition and their future, and loss of parental role. These stressors often lead to heightened anxiety, depression and post-traumatic stress disorder in parents, which then negatively impacts their children.

Findings from several research studies, including two randomized controlled clinical trials funded by the National Institutes of Health/National Institute of Nursing Research, have supported when parents receive an educational and skills-building intervention entitled COPE (Creating Opportunities for Parent Empowerment), their anxiety, depressive and post-traumatic symptoms decline and their children’s outcomes improve.

COPE is a manualized intervention that prepares parents for what to expect and how best to parent their children while in the pediatric intensive care unit (PICU) and NICU. In the case of parents of critically ill children, COPE is a three-phase program beginning in the first 24 hours after admission to the PICU. The program teaches parents about the common emotional and behavioral responses critically ill young children exhibit as a result of their illness and how best to emotionally support their children and assist them in coping with their situation while in the PICU and following hospitalization. For parents of preterm infants in the NICU, COPE is a four-phase educational-behavioral intervention that teaches parents about the typical appearance and behavioral characteristics of premature infants and how they can participate in their infants’ care, meet their infants’ needs, enhance quality of interaction with their infant, and facilitate their infants’ development. Research on the COPE program has supported the intervention strengthens parental beliefs about what to expect in their children and how best to parent them, which then leads to improved parent and child outcomes up to three years following hospitalization. In the NICU randomized controlled trial with 260 families with preterm infants, COPE reduced length of stay for the preemies in the NICU by 3.8 days, eight days for preterms under 32 weeks in comparison to an attention control program. In another study conducted by a team at Nationwide Children’s Hospital, research supported that neonates whose parents received COPE had significantly reduced lengths of stay than control neonates (127.1 days compared to 139.6 days) and significantly lower readmission rates (13.2 percent versus 23.9 percent), resulting in lower hospital costs.

The physical care of critically ill children and preterm infants is of paramount importance but, the psychosocial care of both the children and parents also must be a high priority. Evidence from rigorous studies strongly supports the benefits of educating parents about what to expect in the case of a critically ill child or preterm infant and building their skills in how best to support and parent them while in the NICU and PICU leads to improved parent and child outcomes and reduced hospital costs.

What is a Personal Health Record and Why Should You Use One?

Julie Apathorpe, RN, BSN, CRRN, H9B Program Manager
Cindy Iske, MSOTR/L, H9B Rehab Coordinator

In today’s changing health care environment, consumers are taking a more active role in managing their own care. Individuals are not only responsible for their own needs, but often find they are managing the care of their children and aging family members too. As new health technology tools are available, it is important to understand their value to both the consumer and health care provider.

A personal health record (PHR) is an electronic tool used to collect, track and share health information from a variety of providers. This information is compiled into one collective environment and may contain information about diagnoses, medical history, medications, tests and procedures. The consumer is the owner of the document and is responsible for updating information as their healthcare changes. They also have control over when and where to share their health care information with providers.

Personal health record tools are available in a variety of ways and can be chosen based on the desires of the consumer. Some prefer a handwritten journal or notebook, while others reach for technology such as an electronic document or even an application to manage information.

Where can you find personal health records?

Personal health records are web-based and accessed via your personal computer or electronic device such as a smart phone or tablet. There are a variety of templates to meet individual needs, and they are filled out online. The American Health Information Management Association (AHIMA) website has information regarding various PHR tools, in a variety of languages.

What are the benefits of a PHR?

1. Chronic disease management – PHRs provide a consistent way to monitor and record test results, blood pressure, blood sugar or signs and symptoms of various conditions over a period of time.
2. Family health management – Developing a family PHR is a great way to manage all family members’ health in one location and readily available when needed.
3. Emergency care while traveling – Having an organized personal health record is valuable while traveling, in the event medical care may be needed, whether in the country or outside of the United States.
4. Relocation and identifying new providers – Having a complete and thorough record in the instance you move, retire or relocate is essential.

Do you have a PHR for yourself? What about for your family? If you there was an emergency tomorrow, would you be able to provide the information you needed to on short notice? Taking the time now to organize the health of yourself and your family can lead to decreased stress and more comprehensive medical care by providers.

Please visit www.myphr.com to get yours started today.
In Recognition

Presentations

Anderson, J., Corbin, S. “Why Does Neonatal/Pediatric Transports Have to be so Difficult to Dispatch?” Air Medical Transport Conference, October 2017

Becks, C., Selhorst, M. “The Effects of Fear-Avoidance Beliefs on Anterior Knee Pain and Physical Therapy Visit Count for Pediatric Patients: A Retrospective Review,” APTA Combined Sections Meeting, February 2018


Cary, H., Ferrante, R. “Goal Attainment Scaling to Measure Activity and Participation Level Changes in Young Children with Cerebral Palsy (CP),” APTA Combined Sections Meeting, February 2018


Donegan, A. “Differentiation and Treatment of Irritable Bowel vs Colitis vs Crohn’s Disease Part 2,” Nationwide Children’s Hospital, December 2017

Haynes, A. “Urology Case Studies, Urodynamics and GYN,” Nationwide Children’s Hospital, November 2017


Humston, C. “Synthetic Hallucinogenic Drug Use - Let the Nightmare Begin,” Annual Advanced Provider Conference, November 2017

Justice, L., Coleman-Casto, S. “The Unique Role of OT in Infant Failure to Thrive (FTT),” Ohio Occupational Therapy Association, November 2017


Lazara Mould, V., Hamilton, J. “Working With Patients With Developmental Delays: Behavioral Approaches and How to Apply to Therapeutic Recreation Interventions,” TR Fall Conference at Nationwide Children’s Hospital, October 2017


McMillen, M., CTRS, Kreuer, R., CTRS, & Stuck-Simone, S. “Animal Assisted Therapy: A Therapeutic Recreation Treatment Modality,” TR Fall Conference at Nationwide Children’s Hospital, October 2017

McMilan, M., Sinclair, C., Dudley, S. “Therapeutic Recreation - Growing and Expanding Your Program: The Practitioner, Physician, and Patient Perspective,” TR Fall Conference at Nationwide Children’s Hospital, October 2017

Miller, T. “Perception and Unconscious Bias Common in Therapeutic Recreation,” TR Fall Conference at Nationwide Children’s Hospital, October 2017

Miller, T. “Unconscious Bias In Therapeutic Recreation,” Utah Recreational Therapy Conference, March 2018

Morris, P. “Linking Therapy & Adapted Recreation to Improve Mobility & Independence: Adapted Cycling,” ASC Cycling Training, March 2018


Selhorst, M., Rice, W., Degenhart, T., Jackowski, M., Coffman, S. “Evaluation of a Sequential Cognitive and Physical Treatment Approach for Patients with Parotidobiliary Pain: A Randomized Controlled Trial,” APTA Combined Sections Meeting, February 2018

Tanner, K. “Treatment Strategies for ASD: What Does the Evidence Say?,” Occupational Therapy Association Annual Conference, November 2017


Tisdale, A. “Evidence Based Practice: Evaluating individual moods pre and post various Therapeutic Recreation intervention,” TR Fall Conference at Nationwide Children’s Hospital, Columbus, October 2017

Vicary, M., Selhorst, M. “Menstrual Function Not Related to Clinical Outcomes in Females after Acute Spondylolisthesis: An Observational Analysis,” APTA Combined Sections Meeting, February 2018

Wagner, A., Bohrer, A. “Bowel Management of the Colorectal Patient, and Colorectal Nursing Care of the Patient with Hirschsprung Disease,” Workshop De Malformaciones Ano Rectales Enfermedad de Hirschsprung, October 2017

Williams, C. “Instruction and Guidance provided to Social Workers as well as service project in recovery room,” Workshop De Malformaciones Ano Rectales Enfermedad de Hirschsprung, October 2017


Rosenberg, R., MacDonald, J. “Safe Interfacility Transport of Pediatric Patients: Medical Control Training, and Interdisciplinary Approach,” Ohio Medical Journal, February 2018

Justice, L., Coleman-Casto, S. “The Unique Role of OT in Infant Failure to Thrive (FTT),” Ohio Occupational Therapy Association, November 2017


Daisy Award

Rachel Trautman, BSN, RN, CCRN

The 21st Annual Nationwide Children’s Hospital Daisy Award was presented to Rachel Trautman, BSN, RN, CCRN of CTICU. The Daisy Award is given in appreciation of the important difference our nurses make in the lives of our patients and families at Nationwide Children’s.

Rachel was nominated by a mother whose daughter was brought to Nationwide Children’s shortly after birth. The mother commended Rachel for her dedication and encouragement. Says her nominator; “Rachel was there no matter what to answer any questions I had, she was there for me when I cried, she helped me hold my daughter here for the first time! The genuine love for her career is truly incredible and the care she gave my daughter is forever appreciated.”

To learn more about our Daisy winners, and read their full nomination, visit NationwideChildrens.org/Daisy-Award