Creating an optimal healing environment for pediatric patients and families: a medical school course on child life theory and practice

Erin Halman
Bank Street College of Education

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Creating an Optimal Healing Environment for Pediatric Patients and Families: A Medical School Course on Child Life Theory and Practice

Erin Halman

Jon Luongo, Mentor

Child Life Department

Bank Street College of Education

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Abstract

This project outlines an introductory child life course intended for medical students. The course covers salient topics from a graduate level child life curriculum, as well as skills identified as the most useful for physicians in a survey of certified child life specialists. This course aims to educate and inspire future physicians to provide better psychosocial support for children and families in the healthcare setting; to promote child and family-centered, cross-cultural care; to help reduce the psychological trauma associated with medical experiences; to improve communication skills and ability to interact with children and families in healthcare; and to innovate in the field of medical education by addressing the social, psychological, and emotional needs of all patients. By developing this course, I hope to better address the needs of patients and to promote optimal healthcare for all pediatric patients and families.
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Rationale for Course

Creating a course for medical students on the practices of child life can seem unnecessary. Medical schools already require plenty of work for their medical students, what would be gained from training doctors in these skills? These are the skills child life specialists already use, so why can’t child life specialists take care of the psychosocial care while physician take care of the physical side of care? In the medical field, child life is often seen as the “touchy-feely” topic. However, studies have shown that better psychosocial care not only leads to better health outcomes and faster recovery, but actually saves hospitals money on unnecessary treatments and readmissions (Sobel, 1995). Therefore, it is important for all healthcare professionals to also address psychosocial needs. Child life specialists in the hospital are usually assigned to entire units, which they cover alone, and many hospitals have one child life specialist covering every unit, leading to child life specialists not being able to see every patient. As child life is not a reimbursable service, hospitals have to find space in their budgets to hire more child life professionals (Myers Wilson & Cross, 2009). Therefore, it is important that physicians learn these skills, not only to boost patient satisfaction scores, but to make sure that children receive psychosocial care, regardless of a hospital’s ability to hire enough child life specialists for their patient population. Also, the curriculum guidelines for both basic medical as well as graduate medical education layout required knowledge and skills that are in the realm of child life and many medical school programs as well as hospitals have child life training in place for their students and residents.
With the changing face of healthcare, patient satisfaction is becoming more and more important for reimbursement (Caramenico, 2011). Medicaid and Medicare are starting to reimburse based on patient satisfaction scores, so hospitals need physicians that can effectively communicate and have positive bedside manner (Caramenico, 2011). Therefore, it is starting to become necessary that hospitals look at patient satisfaction when hiring new doctors, and when assessing current physicians. Are patient satisfaction scores already where they need to be? Research has shown that patient satisfaction scores have been consistently low, which is why these scores are such a big part of the new reimbursement laws (Swirsky, 1999). There is a need for doctors to be taught bedside manner, and this can be started from the ground up, by teaching up-and-coming physicians starting in their medical school training.

There are many programs throughout the country with standards that outline bedside manner, compassion, and communication skills, but this piece will focus on three: The University of Michigan in Ann Arbor, Michigan (UM); The George Washington University in Washington, DC (GW); and The University of California: San Francisco in San Francisco, California (UCSF). All three of these Universities have in-depth curriculum guidelines and competencies that are expected to be met during the medical students’ training. Many of these competencies and guidelines address compassionate patient care, cultural competency, and communication skills. For instance,

By the time of graduation, students are expected to:
Demonstrate empathic patient-centered communication. Inform the patient and his/her representatives about the status of the patient’s health and condition. Synthesize and present a coherent description of the patient’s clinical condition based upon the information obtained from the patient and other resources. Demonstrate shared decision-making with patients including discussing the risks and benefits of medical interventions and obtaining informed consent. Demonstrate skills and strategies for engaging patients and their families in difficult conversations (e.g. end-of-life, medical errors, serious diagnosis, etc.). Collaborate effectively with other health care professionals in caring for patients. Negotiate conflicts within health care teams. Consider the patient’s culture, beliefs and level of health literacy in communicating effectively (The George Washington University, 2013).

UCSF also expects cross-cultural communication skills as well as establishing the competency that students should be able to, “communicate effectively with diverse patients and ensure patient understanding” (The University of California, San Francisco, 2012). UM establishes additional guidelines about respect and empathy with the expectation that its students, “demonstrate compassionate, empathetic, and respectful care of patients/families... demonstrate respect for how people in diverse cultures perceive and respond to health, illness and care” (University of Michigan Medical School, 2012).

These three universities show through their guidelines an emphasis on seeing patients as human beings as well as medical patients, and an emphasis on
respect for all patients and families regardless of age, culture, or background. All of these competencies fall under the scope of child life-practice, focusing on the ability to work with all patients, as well as effective communication strategies for difficult situations. This is where child life curriculum can come in. By teaching medical students about basic child life skills, such as appropriate language, procedural preparation, family-centered care, cultural competency, and pain management, we can help these medical schools to better satisfy their curriculum guidelines.

The requirements for graduate medical education, or residencies and fellowships, also require child life related competencies. The ACGME, the governing body for medical graduate education, lays out many competencies that must be achieved by medical residents. For instance, “residents are expected to communicate effectively with patients, families and the public, as appropriate, across a broad range of socioeconomic and cultural backgrounds” (ACGME, 2012). Residents are also expected to, “advocate for quality patient care and optimal patient care systems” and “participate in the education of patients, families, students, residents and other health professionals” (ACGME, 2012). These competencies, as well as many others, show a need for basic communication skills, as well as an ability to educate patients of all ages and developmental levels. Through a child life course, these skill sets will be addressed, and these physicians will be able to implement what they have learned in a healthcare setting throughout medical school and residency.

There are many programs that are actually starting to implement training for medical students and/or residents in various areas of child life practice. At SUNY
Upstate Medical University, a child life specialist has started a resident training program for all medical residents (not just those in pediatrics) as well as a communications course for medical students (C. Baish Cameron, personal communication, February 25, 2013). The course is six weeks, and focuses solely on communicating with children and families, using appropriate language, and having tough conversations (C. Baish Cameron, personal communication, February 25, 2013). This class is co-taught by the child life specialist and an attending physician. In this way, the material has a child life focus, but is backed by a medical professional, giving it more importance and credibility in the eyes of the medical students, or the child life specialist’s “buy in” when working with medical students (C. Baish Cameron, personal communication, February 25, 2013). This course is problem-based, where the students review actual cases and scenarios they have observed or experienced and use them for critical discussions with their peers (C. Baish Cameron, personal communication, February 25, 2013). The resident training program covers what child life specialists do in the healthcare setting, as well as pediatric pain management (C. Baish Cameron, personal communication, February 25, 2013). Through these programs, the aim is to create well-rounded physicians who understand the needs of children and families in healthcare.

Maimonides Infants and Children’s Hospital of Brooklyn has a training program for all pediatric residents through the Child Life Department. This training focuses on topics such as working alongside child life specialists, procedural preparation and support, and viewing and respecting the patient as a whole child functioning within a family, as well as a hospital, system (Maimonides Infants and
Children’s Hospital of Brooklyn, 2013). This program also requires that the residents meet with and interview a family about their hospital experiences in order to understand the hospital setting from the child and family’s point of view (Maimonides Infants and Children’s Hospital of Brooklyn, 2013). Lastly, this program requires the residents to do a presentation to teach patients and families about a specific health topic. This helps the residents to both practice effective and developmentally appropriate language and communication, as well as improve their public speaking skills (Maimonides Infants and Children’s Hospital of Brooklyn, 2013). This program incorporates many aspects of learning as well as many different facets of child life theory in order to better prepare and train physicians in pediatrics.

The University of Michigan started a course a decade ago where first and second year medical students are paired with a family dealing with chronic illness (University of Michigan Medical School, 2012). Through this course, they meet with the patient and/or family for five interviews, as well as accompany the patient on one doctor’s visit (H. Wagenshutz, personal communication, March 1, 2013). This course aims to give students a perspective on how chronic illness affects patients and their families during their daily lives. This program hopes to showcase the “human side of medicine” by giving future physicians first-hand experience of a patient’s world outside the hospital (University of Michigan Medical School, 2012). This program consists of the interviews, as well as small group meetings where peer groups are led by physician facilitators to discuss complex or upsetting issues that come up with their families (H. Wagenshutz, personal communication, March 1,
Through this peer support, the students learn to cope with the secondary stress of working with patients with chronic illness, as well as gain more insight into what these families go through in their lives outside the hospital. This course was based on the approach of various medical schools, however, the University of Michigan chose to make this class a requirement, whereas it was only an elective at other schools (H. Wagenshutz, personal communication, March 1, 2013). This is one of the first programs in the country with such a requirement, though in many other countries throughout the world these types of courses are a national standard (H. Wagenshutz, personal communication, March 1, 2013). Hopefully, courses like these will lead to a standard of practice that will elevate the overall optimal healthcare of all patients and families.

By introducing a full-semester course on child life themes and skills, medical schools can better prepare physicians for the changing healthcare environment. In this way, schools will be training well-rounded physicians with high patient satisfaction scores that hospitals want to hire.
Class Structure

This course will be a full semester, 14-week course that expects the students to complete readings, watch videos, write papers, as well as think critically about the course content. Each class will be two-hours long, and will consist of a mixture of teaching techniques such as PowerPoint presentations, class discussions, role-playing, and the use of video excerpts related to course content. The course will be co-taught by a child life specialist and a physician. This way, medical students can gain the perspective of someone using these skills in their everyday work with patients both from a child life professional and a medical professional. This will also lead the students to better see the benefits of this course to their future careers by seeing how practicing physicians are implementing these theories and ideas.

The textbooks used in this course will be Meeting Children's Psychosocial Needs Across the Healthcare Continuum by Rollins, Bolig and Mahan (2005); Helping Children and Adolescents with Chronic and Serious Medical Conditions by Nancy Boyd Webb (2009); The Handbook of Child Life by Richard H. Thompson (2005); Grief and Loss by Katherine Walsh (2012); and Psychosocial Care of Children in Hospitals by Gaynard et al (1998). These texts cover the basics of child life theory as well as more detailed information about procedural preparation and support, cultural competence, bereavement, applied child development, and family-centered care. Selected readings will be chosen from each text for the various topics, and students will be expected to read the assignments and come to class prepared to discuss the skills and theory learned.
The goal of this course is to create competent, compassionate physicians with knowledge of child life practice and theory. Therefore, the course is based on the competencies set out by the Child Life Council as well as the gaps in knowledge noted in a survey done by the author. The aim is not to train physicians to be child life specialists, but to train physicians that also have a base knowledge in working with children using a child life skill set. The Child Life Council sets out multiple competencies for child life specialists, and many of these transfer to competencies for well-rounded doctors. One child life competency that also applies to medical practitioners is, “the ability to provide a safe, therapeutic and healing environment for infants, children, youth and families” (Child Life Council, 2010). This competency states that all persons within the healthcare setting have the right to feel safe and cared for. Though doctors are expected to care for patients physically, total care also applies to the patient’s emotional well-being.

For this course, a survey was given to child life specialists through the Child Life Council’s online forum. This survey addressed where these professionals saw gaps in the knowledge of physicians working with pediatric patients and their families. Responses came from 32 child life specialists, and there were many themes in the responses. Because the field of child life is widespread, it was important to choose only the most pertinent topics for physicians in order to make the course efficient. One of the major gaps cited in the survey results was applied child development. Though medical students are taught child development, a hole was seen in the application of these theories to working with ill and hospitalized children. Another issue seen was the use of developmentally appropriate, or “soft”
language use with children and families. For example, telling a child, “this will burn” as opposed to saying, “this might feel warm.” This lack of appropriate language use was seen during explanations of procedures, diagnosis education, during tests and procedures, as well as during basic communication with pediatric patients and families. The respondents came from a variety of hospitals, ranging from freestanding children’s hospitals to pediatric floors within adult hospitals. The respondents also worked in a variety of areas of the hospital, from inpatient to outpatient, acute care to chronic care. Almost every respondent cited the need for physicians to recognize and respect the whole child, and believed in the ideals of teaching physicians child life theory and practice. Therefore, these ideas were also taken into account when designing course content.

Students will be given readings and assignments addressing many of the course learning objectives. For instance, to address the theme of culture, the medical students will be asked to read the novel *The Spirit Catches You and You Fall Down* by Anne Fadiman (1997) which addresses the issues of culture clashes in the healthcare system. The students will be asked to think critically about this text and discuss strengths and weaknesses in the physicians dealing with this family from a minority culture within small groups during class time.

For the class on procedure preparation, the students will prepare a preparation tool using non-medical items. For instance, a student might use a child’s toy ring and a tongue depressor to make an MRI; or cookies, icing and candy to explain bone marrow. By creating these unconventional preparation materials, the students will use their creativity, as well as be better able to use non-medical
language to explain medical procedures, which is beneficial when working with preverbal or nonverbal children as well as younger children in a developmentally appropriate way (Gaynard et al, 1998).

During the second-to-last class, the students will be put in groups and given scenarios. They will have to act out these scenarios, with one student playing the role of the physician, while the remaining students act as patient and family. The students will act out these scenarios (which range from procedure preparations, procedural supports, cultural issues, etc.) and the other students in the group will critique their language usage, as well as their grasp on course topics covered. In this session, self-reflection surveys will be given to the students to determine what they took away from the course in order to better the course each time it is taught and to show its efficacy.

The final assignment for this course will be a presentation on what daily life is like for families and children with chronic health conditions. In preparation for this assignment, families interested in volunteering to help teach medical students will be identified through family support groups and the health system. Each pair of students will be assigned to a family of a child receiving care for a chronic illness. They will be asked to interview the family about how illness and hospitalization has affected both patient and family, and will then give a presentation, or create a project, to show what they have gained from speaking to this family. This idea is based on the Family-Centered Experience course given to University of Michigan medical students, and is a way to humanize patients and families for these future medical practitioners.
The aim of this course is to better prepare future physicians to better work with pediatric patients and families, even physicians not planning on practicing pediatrics. Because most physicians work with children in some aspect of their day (whether children of patients, covering pediatric patient units on off-hours, or working in adult hospitals that see pediatric patients) it is important that all physicians have an understanding of how best to work with this population, and the family as a whole. Hopefully, this course, through education in child life skills, will lead to a future of medicine that is based on respect, whole-person wellness, and an understanding of the impact of illness and hospitalization on lifespan development.
Course Content

Class One: Child Life Specialists

Learning Objectives

• History of the child life profession
• What child life specialists can do for patients
• When to call child life

Teaching Modalities

• PowerPoint slides
• Class Discussion
• Video
  
  o All Children’s Hospital (June 29, 2009). Courtney: Helping kids cope. Retrieved April 30, 2013 from:
    
    http://www.youtube.com/watch?v=qTcklclPAsI&list=PLCCEC3D9DA657BBDF&index=4

History of the child life profession

The profession of Child Life started not as a career, but as the promotion of play within children’s hospitals (Wojtasik & White, 2009). Once play became a more regular part of hospital care for children, Emma Plank was asked to create a program addressing the socioemotional needs of hospitalized children in 1955 (T. Pinkney-Ragsdale, Child Life Lecture, September 20, 2011). What would later be called the Association for the Care of Children in Hospitals was established in 1966, and in 1992, what is now the Child Life Council broke from the ACCH to form a
separate governing body (T. Pinkney-Ragsdale, Child Life Lecture, September 20, 2011). Soon, there became certification measures, as well as other training protocols, pushing the Child Life career ahead to be seen as more professional and not just “play ladies” (Wojtasik & White, 2009).

What child life specialists can do for patients

The American Academy of Pediatrics, in their Policy Statement on Child Life Services states that, “the provision of such services [Child Life Services] is a quality benchmark of an integrated child health delivery system and an indicator of excellence in pediatric care” (Wilson et al., p. 1757, 2006). Child Life Services are now seen as essential to the hospital care of children and families. From a purely psychological perspective, the benefits of Child Life are numerous. The play that Child Life provides is essential to the mental health of children, especially those in the hospital, helping them work through their stress and trauma (Gaynard et al., 1998; Boyd Webb, 2009; Bolig, 2005). Gaynard et al. went on to describe how medical play using real medical equipment helped make children less stressed during medical procedures and around medical equipment, as well as more relaxed in the general hospital setting (1998). Also, the coping techniques that child life specialists give patients and families help children to get through more painful procedures, as well as cope in the future when child life is not available (T. Pinkney-Ragsdale, Child Life Lecture, October 25, 2011). From a more global, institution-based perspective, Child Life Services can also save a hospital money on pain medications through procedural support, as well as reducing time children spend
hospitalized through developmentally appropriate education (Wilson et al., p. 1760, 2006). Because of this, it has become integral for hospitals to employ child life specialists for psychosocial care of patients and families.

Child life specialists bring many skills to the multidisciplinary hospital care team. Child life specialists have a large skill set, such as an expertise in child development and the effects of trauma on normative development, coping techniques, therapeutic play, education of parents and professionals, and creativity (Hicks, 2005). Child life specialists not only use their skills one-on-one with families, but they also bring these skills to the multidisciplinary team through going on rounds, attending case meetings, and discussing patients needs with the nursing staff (Vilas, 2009). Another important factor that the child life specialist brings to the healthcare team is their work with siblings, whose needs may be neglected during the illness of another sibling (Bell, Johnson, Desai, & McLeod, 2009). Family-Centered Care is an important element of healthcare that many hospitals feel is important to implement. As experts in family-centered care, child life specialists bring a wealth of knowledge about working with families within the context of healthcare, as well as advocacy for their needs and educating them to be better able to navigate the hospital and healthcare system at large (Julian & Julian, 2005; Bell et al., 2009). With all of these skills (plus many unique to each individual child life specialist) child life specialists create a healthy environment for healing in children's healthcare.
When to call child life

When possible, child life should be called before procedures or treatments take place. Child life specialists use preparation techniques in order to prepare children and their families for procedures and treatments, and this preparation can help children better cope with the impending procedure and can often save the medical team time when a patient is calm and ready for a procedure (Yun-ping, Zhen-hua, Finley, & Yun-xia, 2012). Child life should also be called if an assessment of coping is needed, for instance for a patient who has never been hospitalized before, or conversely, for a patient who has repeated hospitalizations. If physicians feel that a patient or family is having difficulty coping, or could use developmentally appropriate assessments, play, or preparation, child life should be called in to work with these patients.
Class Two: Applying child development to the healthcare setting

Learning Objectives

- Effects of hospitalization on each stage of development
- Ways to mitigate these effects
- Theory in action (case examples)

Teaching Modalities

- PowerPoint presentation
- Class discussion
- Case examples

Effects of hospitalization on each stage of development

In each stage of development, there are different cognitive, physical, and psychosocial tasks that must be met. Hospitalization can disrupt this progression, and therefore have lasting impacts on life-span development. Since cognitive development will be covered in the class session on language and communication, this session will instead focus on psychosocial development.

Infants are in Erikson’s developmental stage of trust vs. mistrust (Erikson, 1960). In this stage, the infant is learning whether or not his or her needs will be met. Will his diaper be changed when he is uncomfortable? Will she be fed when she is hungry? Will he be held when he is scared? Will she be kept warm and comfortable? Through having their needs meet, infants learn to trust their caregivers and to feel a sense of comfort and safety in the world (Erikson, 1960). The biggest issues that hospitalized infants face is separation from caregivers and
inconsistent care (Pearson, 2005a). Other issues that infants face are lack of appropriate stimulation, and pain (Pearson, 2005a). Historically, it has been thought that infants didn’t feel pain, and that anything that happened during infancy would be forgotten, and therefore not affect later development (Turner, 2009). However, we now know that this is not the case, and hospitalization during infancy is seen as a huge factor in later development.

For toddlers, Erikson’s second stage of autonomy vs. shame and doubt is the main task at hand (Erikson, 1960). Children at this age are trying to learn to do things on their own: walk, feed themselves, dress themselves, and use the potty (Erikson, 1960). Because of this, hospitalization can pose a challenge to their growing autonomy (Pearson, 2005a). A child who is recently potty-trained may be asked to urinate on a table during a VCUG; a post-op patient may be in a SPICA cast for weeks after learning to walk; a child in the hospital is unable to decide what they wear, when they eat, or what happens to them. Children of this age are also greatly effected by separation from caregivers, and have more fears and worries than before (Pearson, 2005a). Because they can now remember images, doctors’ coats may remind them of previous, possibly traumatic, doctor visits. They will also remember those who performed painful or scary procedures, so this can lead to more difficult relationship building for doctors and nurses (Pearson, 2005a). Lastly, children of this age rely on schedules. This can be difficult to maintain in a hospital setting, and can throw-off a child’s homeostasis, leading to emotional and/or sleep issues (Pearson, 2005a).
Preschoolers are in the stage of initiative vs. guilt (Erikson, 1960). These children want to try new things, such as pouring a large jug of milk or picking out their outfits (Erikson, 1960). When children of this age are hospitalized, they may see it as a punishment (Pearson, 2005a). Because of magical thinking, a preschooler may feel they are being punished for thinking or doing something wrong, and this is why they are in the hospital (Pearson, 2005a). This can also apply to preschool siblings of patients, therefore, it is important to address this misconception to prevent psychological trauma (Pearson, 2005a). Preschool children also fear body mutilation, as they are becoming more aware of their body parts, and understand the idea of injury (Pearson, 2005a).

The school-aged child is in the stage of industry vs. inferiority (Erikson, 1960). These children thrive on completion of tasks, and are very curious about everything (Erikson, 1960). This can cause an issue with school-aged patients feeling a loss of mastery and industry (Pearson, 2005a). Children in this developmental stage have a fear of bodily injury, and more understanding and fear about illness (Pearson, 2005a). Therefore, school-aged children show more fear of hospitalization, and may withdraw during their hospital stay.

Adolescents are in Erikson's stage of identity vs. role confusion (Erikson, 1960). In this stage, the teen is trying to decide who they are, what they believe, and who they want to be in the future (Erikson, 1960). Illness and hospitalization can pose an identity crisis for the teen, who now has to incorporate an illness into their identity (Pearson, 2005a). The teen may fear that the illness will become a defining part of their identity, or may start to over identify with being a “sick kid” (Pearson,
Teens may also become frustrated with having to rely on adults again, as well as a lack of privacy if they need help bathing, eating, or using the bathroom (Pearson, 2005a). Teens may act out or withdraw during hospitalizations, and many have issues reconciling their illness with their own feelings of invincibility (Pearson, 2005a).

Ways to mitigate these effects

Though there are many possible issues for children of all ages stemming from illness and hospitalization, there are many interventions that can help minimize or alleviate these difficulties.

For infants, it is important to limit the amount of medical personnel they interact with in order to maintain consistency. “Such consistency, continuity, and sameness of experience provide a rudimentary sense of ego identity” (Erikson, 1963, p. 247). Keeping consistency is important to the infant’s sense of trust in the caregivers he or she interacts with. It can also be beneficial for parents and siblings to bring in clothing items that they have worn in order to give the infant the scent of family members in their crib, and therefore a sense of comfort (Turner, 2009). Another important factor is to make sure that infants get as much appropriate stimulation as possible. Letting them be held when possible, giving them toys or teething rings, and making sure they are spoken to, sung to, and played with will all make sure that these infants don’t fall behind developmentally during their hospital stays (Pearson, 2005a).
Toddlers need to be given as much opportunity for autonomy as possible. Letting them try out the stethoscope, or put on their own band-aid can help give them a sense of autonomy, even if they are unable to walk or use the restroom on their own (Pearson, 2005a). Another intervention to use with toddlers is parental involvement; by letting a child sit in a parent’s lap during a procedure, or allowing parents to be present during stressful moments, a toddler will be better able to cope with hospitalization (Pearson, 2005a). Play is also especially important for this age group, so allowing for play and playfulness is beneficial (Pearson, 2005a).

Children of preschool age need to be given choices (Pearson, 2005a; Turner, 2009). Giving available choices, such as what color band-aid, or which arm she would prefer the phlebotomist try her IV in first gives the child a sense of initiative and feelings of mastery and control over a stressful situation (Pearson, 2005a; Gaynard et al, 1998). Medical play can be especially beneficial in this age group, and should be encouraged and utilized through child life.

For the school-aged child, information is very important, but not too much overwhelming information (Pearson, 2005a; Gaynard et al, 1998). They should also be given opportunities to show mastery and competence. By giving long-term projects, or giving them “assignments” such as teaching the physician about a new trend, or getting the signature of every nurse on the unit, we can make the child feel accomplished (Pearson, 2005a). Peer support is also important for this age group, so having the child communicate through letters or the internet with their classmates is also beneficial (Pearson, 2005a).
Teens need to feel their privacy is being respected as much as possible. Making sure to knock before entering, allowing teens to cover up when they can, and allowing them to speak to you without a parent present can all lend themselves to the teen feeling more confident and comfortable (Pearson, 2005a). Peer support is also important for teens, so allowing visitors and peer interactions is beneficial (Pearson, 2005a). Another helpful skill to use with teens is allowing teens to be the expert. By asking a teen to explain their own medical status to the professional, the teen not only shows their understanding, but also starts to take ownership of their medical situation (Pearson, 2005a).

Theory in action (case examples)

These case examples are from the author’s own experiences working with hospitalized children from a child life perspective, however, the case studies would be based on the experiences of the child life specialist and physician teaching the course.

Case Example 1: Developmentally appropriate stimulation for infants

A five-month old male patient was hospitalized following neurological symptoms of concern. The child’s parents were very concerned about his continued development, as he had stopped reaching for items they put in his crib, and had become withdrawn. In addition, they were concerned about the emotional effect of his separation from his twin brother. The author suggested that the parents bring in a onesie worn by the brother to leave in the patient’s crib. Then, the author brought a mobile, large brightly colored toys, and a musical aquarium for the parents to use
with the infant during hospitalization. Parents noted that their son was again starting to reach for toys, and would consistently turn towards the onesie in his crib.

Case Example 2: Parental involvement with toddlers

An eighteen-month old male patient was brought into the outpatient hematology/oncology clinic for intrathecal chemotherapy. Patient required a port access before the procedure, and was showing signs of anxiety. Both parents were present and showing signs of anxiety for his first access, so the author brought them into the room with the patient during the access. Author asked mom to hold patient in her lap while dad held an iPad in front of the patient so he could watch his favorite movie. Parents' anxiety lessened once they were given roles, and the patient was able to sit still and continue to watch his film during the access. After the procedure, the parents expressed their relief and gratitude for having gotten through the procedure together.

Case Example 3: Choice with preschoolers

A four-year old female patient was brought into the outpatient clinic for a blood draw. Parents noted that patient had never had blood drawn before, and were nervous as to how she would react. The author gave the patient a choice of sitting on her mom or dad’s lap, or just holding their hands. Patient chose to sit on mom’s lap during the blood draw. The author also gave her the choice of playing a game on the iPad or reading a book during her blood draw. The patient chose to play a game on the iPad. During the blood draw, the patient was told that her only job was to keep her arm still, but that she could watch or look away if she wanted. The patient chose to look away, and sat on mom’s lap while playing a princess matching game on the
iPad. Patient was able to stay still for blood draw, and parents were extremely relieved and grateful.

Case Example 4: Task-completion for a school-aged child

An eleven-year old female patient was admitted for a pericardial effusion stemming from a pericardial mass removal the week prior. The patient was withdrawn and showed fears of having chest tubes removed. The author asked the patient to create a photo-scrapbook of her time in the hospital, after learning that she enjoyed art and photography. The author checked in daily to see what pictures she had added to her book. The patient took pictures of her IV pole, nurses, doctors, hospital room, gown, and parts of her chest tubes. Through this, the patient started to talk more about her fears surrounding her chest tube removal, and parents reported less anxiety from the patient.

Case Example 5: Allowing teens to be the expert

Patient was a seventeen-year old female with status post brain mass removal. The patient was in good spirits, but was concerned about missing school and social events. The author learned that she was interested in working with children with Autism Spectrum Disorders, so the author asked the patient to teach her what she had learned about the best ways to work with this population. The patient became very animated and spoke extensively about her knowledge base. A few days later, the patient gave the author a list of resources she thought might be helpful for working in the hospital with children with Autism Spectrum Disorders. Parents thanked the author for giving patient a sense of purpose, and getting her excited and happy during her hospital stay.
Class Three: Play

Learning Objectives

- What is play and why is it important?
- Medical play
- Being playful

Teaching Modalities

- Class discussion
- Presentation of “playscapes”
- Video
- Class play session
  - Medical play, play-doh, assorted toys

What is play and why is it important?

“Play allows children to approach threatening stimuli and assimilate information provided to them at their own pace” (Gaynard et al., 1998, p. 67). Play is a child’s way of communicating with others, and interpreting the world around them (Bolig, 2005). Play must be intrinsic, which means that the child must want to participate for it to be considered play (Bolig, 2005). Play is seen in children from all backgrounds and cultures, though the form of the play varies (Bolig, 2005).
“Childhood play is understood to be critical to children’s development for multiple reasons, including the opportunity to communicate feelings, misunderstandings and concerns in their own language” (Koller, 2008, p. 3). Children need play the same way they need safety and love (Jessee & Gaynard, 2009). Play is essential in cognitive, emotional, and psychosocial development, and therefore, should be promoted for hospitalized children (Gaynard, 1998). Play also normalizes the hospital experience. When everything else in a child’s life has changed because of a hospitalization, play gives them normalization, and allows them to forget their worries, or to work through their concerns in a way that feels normal and safe (Bolig, 2005).

Play also allows children to feel a sense of mastery and promotes a positive self-image (Bolig, 2005). By giving children play opportunities, we can boost their confidence and sense of control during a stressful and out-of-control situation (Bolig, 2005). Anxiety can also be reduced through play, and therapeutic benefits have been shown on heart rate and blood pressure when children are given opportunities to play in the hospital setting (Bolig, 2005).

Through play, children explore their world and are able to grow and develop. Play is how children learn and it enhances cognitive development (Jessee & Gaynard, 2009). Play can also consolidate and integrate learned information through the exploration of materials and the reorganizing of thoughts and ideas (Jessee & Gaynard, 2009). Play is an important aspect of developmental achievement and growth throughout childhood and adulthood (Jessee & Gaynard, 2009).
Play opportunities are extremely important in children’s lives, especially in a healthcare setting. Just because children are hospitalized, doesn’t mean they don’t need to play. Often, it is thought that children who are sick don’t need to play, or shouldn’t be able to play if they are “truly sick” (Gaynard et al, 1998). However, even children who are extremely medically fragile need and want play, even if they are in pain. Play can be as simple as reading a story, or painting a picture, or even having a parent or other adult paint a picture while the child directs the adult in what colors to use and what images to paint (Gaynard et al, 1998). By allowing for play in the hospital, physicians and other medical staff can ensure the optimal health of pediatric patients.

**Medical play**

Medical play involves the use of medical equipment during play sessions with patients (Gaynard et al, 1998). Medical play may involve the direct use of medical supplies, such as when a child uses a stethoscope to listen to a doll’s heartbeat. Medical play may also involve indirect work with medical supplies where a child might use IV tubing in a collage or carry their crayons in an emesis basin.

Medical play with direct use of medical equipment can be directed or non-directed. In non-directed medical play, the child is given a variety of medical supplies and is allowed to play freely, using the supplies in any way they choose (Gaynard et al, 1998). In directed medical play, there is a specific goal in mind, such as preparing a child for a procedure. In this type of medical play, specific supplies are used, and the child is facilitated by the medical professional to enact the specific
procedure on the doll or toy. This helps the professional to teach the child about the coming procedure as well as learn about any misconceptions the child might have (Gaynard et al, 1998).

Through medical play sessions, children gain a sense of comfort with medical supplies (Mahan, 2005). By being around these supplies in non-threatening ways, such as for use in art, the child becomes desensitized to the fearful connotations often associated with equipment such as syringes (Gaynard et al, 1998). Pediatric patients are also given the opportunity to work through feelings, fears, or experiences they have surrounding medical procedures in a safe way (Gaynard et al, 1998). Children also gain a sense of control when they become the doctor or nurse who gets to give someone else a shot, or who gets to perform surgery on a doll. Instead of having these things done to them, they are now the active participant (Gaynard et al, 1998; Mahan 2005).

Medical play can be used to quickly and efficiently explain medical procedures to pediatric patients, and to gage their understanding through their play (Gaynard et al, 1998). By using a doll and basic medical supplies during explanations, children are visually able to comprehend what they will be experiencing, and can then use this knowledge to prepare and better cope with the impending procedure (Mahan, 2005).

*Being playful*

Being able to be playful with pediatric patients is important in order to build rapport as well as make a child feel comfortable and at ease. Though physicians
need to be professional, it is also valuable for them to be playful with patients and families. Simple things such as wearing brightly colored stickers, or having a multi-colored stethoscope are seen as playful to children. However, the simplest way to be playful with children is to smile. A smile speaks to a child, and can make the child feel safer (Bolig, 2005). Being able to be playful in a professional role is a beneficial skill when working with pediatric patients and families.

In order to tap into the playful side of the students there will be toys, arts and crafts, and medical play equipment given out for the last twenty minutes of the class for the students to play and explore the materials. Before the end of class, the students will discuss how playing made them feel, and which materials they enjoyed playing with the most.
Class Four: Using clear, concise, and developmentally appropriate language

Learning Objectives

- Communication mistakes often seen in healthcare
- Developmentally appropriate language
- Clear and concise language

Teaching Modalities

- PowerPoint presentation
- Class discussion

Communication mistakes often seen in healthcare

One of the most frequently cited topics that came up on the child life survey given by the author was the need for developmentally appropriate, accurate language when working with children and families. Often, physicians are under a lot of time pressure to see many patients in a very short period of time. Because of this time crunch, many physicians quickly explain to patients and families about complex medical diagnoses or procedures. Often the families, and more often the patients themselves, understand very little about their own medical status and treatment. By teaching physicians how to quickly, efficiently, and appropriately explain medical concepts, we can help physicians communicate more effectively and efficiently. This in turn, helps patients and families understand their own medical histories.

There are many forms of communication. Body language, eye contact, and tone of voice are all significant ingredients of communication between physician
and patient (Klinzing & Klinzing, 2009). In the hospital, one of the central obstacles to effective communication is time. The doctors control the timetable; for example, they decide when to do rounds, and when to schedule procedures and tests. This control over time translates as control of the power in the relationship and can be understood by families as a lack of respect or understanding of the family’s time needs (Klinzing & Klinzing, 2009). The white lab coat that physicians wear also communicates power and authority to patients and families, and can signify impending pain to a pediatric patient (Klinzing & Klinzing, 2009). It is recommended that those physicians working with pediatric patients leave their lab coat outside, or choose not to wear one at all in order to avoid this fear response.

Another obstacle to effective communication in healthcare is jargon (Klinzing & Klinzing, 2009). Although most professions use jargon in one way or another, in medicine, the problem is how frequently it is used when speaking to patients and families. For example, a family might hear a physician say, “her CBC showed low WBCs, so we want to do an LP”. This way of speaking is like a foreign language to patients and families, and communicates nothing in terms of medical information (Klinzing & Klinzing, 2009). By using more precise, accurate language, physicians and other health professionals can ensure that children and families are not left confused about their own health status. An example of this approach would be to say, “we tested your blood and found that your white blood cells, which are the cells in your blood that help prevent infection, are really low. This is why you have been feeling sick lately. We want to figure out why this is happening, so we are going to do something called a lumbar puncture. This is where we take a very small needle
and get a small sample of fluid from your back so we can figure this all out”. Though this sentence is significantly longer than the first, it gets the point across the first time. This prevents medical staff from having to repeat themselves, which results in additional time spent explaining diagnoses and procedures to patients and families (Klinzing & Klinzing, 2009).

Using developmentally appropriate language is important in order to make sure pediatric patients are included in their own medical care. For younger children, using very precise, accurate language and avoiding euphemisms and jargon is extremely important. Because of the cognitive development of preschool and early school-aged children, euphemisms are often seen as reality, and can be misinterpreted (Gaynard et al, 1998).

*Developmentally appropriate language*

Understanding cognitive developmental theory should inform the way professionals speak to children at every stage. Infants are in Piaget's Sensorimotor stage (Pearson, 2005a). They learn through their senses. Touch is a huge part of this stage, so giving infants things to hold or put in their mouths is a learning opportunity. Speaking to infants in a higher-pitched, over-exaggerated voice (also known as baby talk) is actually beneficial for language and brain development (Turner, 2009).

Toddlers are in the Sensorimotor stage and move into the Preoperational stage throughout toddlerhood (Pearson, 2005a). These children are starting to be able to hold and recall ideas and images (Pearson, 2005a). Therefore, they will recall
past healthcare experiences, and this can have an effect on their feelings about the current medical experience. Children of this stage have a highly egocentric view of the world (Pearson, 2005a). Because of this, children of this age have a hard time understanding that not everyone sees or thinks about things the same way they do. In this way, we can find out a lot of information on how a child feels or thinks by asking about a doll or toy’s feelings or thoughts, which will often actually reflect the child’s thoughts and feelings (Pearson, 2005a). Children at this stage, though egocentric, may also feel more vulnerable speaking about their own thoughts and feelings, therefore, inquiring about a safer alternative (their doll) can help professionals gain insight into the child’s thoughts and feelings (Gaynard et al, 1998).

Preschool children continue to demonstrate Preoperational thought, although they begin to be able to think more logically (Pearson, 2005a). These children engage in magical thinking, which can lead to many misconceptions. Because children at this age are in transition, they may be able to think logically at some times and will think magically in others (Pearson, 2005a). It is for this reason that is especially important to repeat information in many ways, as well as continually check comprehension and misconceptions (Pearson, 2005a).

Children who are school-aged are in the Concrete Operational stage of development (Turner, 2009). These patients are better able to think logically, and can understand a sequence and order of events (Pearson, 2005a). Because of this, children of this age benefit from procedural preparation that follows a sequence or list of events. When speaking to school-aged children, it can be tempting to speak to
them more like adults, as they are very curious and may ask a lot of questions using precocious language development. However, it is important to remember that children of this age are still not logical thinkers, though their thinking is becoming more and more logical (Pearson, 2005a).

Adolescents are in the Formal Operational stage of Piaget’s cognitive development (Turner, 2009). Adolescents can now imagine the future, use deductive reasoning, and think logically and abstractly (Pearson, 2005a). They can understand more complex ideas and sequences. It can also be tempting to speak to adolescents as if they were adults. Though it is important to have adult conversations with teens, it is also important to remember that cognitively and emotionally, they have feelings of invincibility, as well as the “personal fable” where they believe that they are the only person who has ever had these experiences and feelings (Pearson, 2005a). In this way, their worldview harkens back to the egocentric thinking of preschoolers, and therefore, care still needs to be taken when speaking to teens (Pearson, 2005a).

*Clear and concise language*

There are many pitfalls to avoid when communicating with children. For example, it is common to say, “we”, as in the phrase, “we need to change into a hospital gown,” when the speaker actually means “you” (Gaynard et al, 1998). In reality “we” aren’t doing anything, but it is the child, “you”, who actually needs to change into a gown. Another common mistake when speaking to children is asking questions and giving unavailable choices (Gaynard et al, 1998). An example would
be when a doctor asks a patient, “are you ready for the IV now?” This is not a realistic question unless the child actually has a choice over when the IV is inserted. A more appropriate choice needs to be given during this situation, such as “would you rather look at a book or watch TV during your IV?” (Gaynard et al, 1998). By giving viable choices, not only is the child given accurate information, but the child also gains a sense of control over their experience (Gaynard et al, 1998). One more issue that comes up when communicating with children is magical thinking. Children under and around the age of 5 tend to use magical thinking, which can lead to misconceptions (Gaynard et al, 1998). A child who hears that they need a CAT scan may believe there will be cats looking at them; a child needing an IV may start to cover their eyes to prevent the needle from going into them because they believe an IV goes in one’s eye; a child whose grandfather died in a hospital may think that hospitals are where people go to die. Because of these misconceptions, it is especially important to use clear, concise language with children, and to go into further detail about what each procedure means, as well as ask questions to find out what the child understands and believes (Gaynard et al, 1998).

In the following class session, procedural preparation will be discussed, which involves another set of language skills for explaining medical procedures and treatments to children and families.
Class Five: Procedural preparation

Learning Objectives

• Why preparation is important
• The language of preparation
• Basic preparation techniques

Teaching Modalities

• Class discussion
• Presentation of preparation materials
• Role-playing
• Website
• Video
  o DeVos Children’s (March 10, 2010). Pre-surgery preparation for kids-Helen DeVos Children’s Hospital. Retrieved April 30, 2013 from: http://www.youtube.com/watch?v=DsLdQe54qCk

Why preparation is important

Preparing children for painful medical procedures is a large part of what child life specialists do. However, child life is not a round-the-clock profession, which means that many times children experience procedures without child life preparation. Therefore, it is important for physicians to have a basic knowledge and skill set for preparation for these times. Also, it is the doctors that originally tell the
patient and family of an impending procedure or treatment, so having preparation skills will benefit these conversations as well.

Preparation can lead to children who are better able to endure procedures without being sedated, such as VCUGs, MRIs, or anesthesia induction (Sandy et al, 2011; Yun-ping, Zhen-hua, Finley & Yun-xia, 2012). In multiple studies, children prepared for outpatient procedures were better able to cope with the procedure without sedation than children who were not prepared (Yun-pin, Zhen-hua, Finley & Yun-xia, 2012). When children can tolerate basic procedures without sedation, or surgery without pre-sedation medication, fewer anesthesiologists are involved, fewer nurses are needed to continuously monitor the child’s vital signs, and less medication is used. This saves the hospital money and time. Additionally, parents have reported more comfort and satisfaction with the outcomes of procedures when children were prepared beforehand (Sandy et al, 2011).

Preparation can make patients feel more confident and ready to cope with procedures (Gaynard et al, 1998). If a child is prepared for an IV, they are likely to be less anxious during the IV insertion (Koller, 2007). If a child knows what is going to happen, they are less anxious because they are not using their imagination to try to guess what will happen during an IV or surgery (Koller, 2007). If a child is calm during a procedure, they are most likely going to successfully complete this procedure, and are less likely to be traumatized (Gaynard et al, 1998). Once they are able to successfully complete a procedure, a child may start to feel confident to cope with their overall hospitalization and illness experiences (Gaynard et al, 1998).
Preparing children for procedures can produce patients who are confident at their ability to cope, and able to cope better in future situations.

Language of preparation

When preparing children, we want to be as clear, concise, and accurate as possible. Though we want to make sure that children are given accurate information, the language must be non-threatening. For instance, instead of saying, “it might burn”, it is better to say, “it might feel a bit warm” (Gaynard et al, 1998). Another way to make language non-threatening is to use “softer language.” Using “soft language” was one of the most commented on lapses in knowledge from the child life survey. Most child life professionals surveyed felt that physicians used language that was too harsh or scary when explaining procedures, diagnoses or tests to pediatric patients. Therefore, by using softer language, such as “uncomfortable” instead of “hurt”, and “slide under your skin” instead of “stick into your skin”, we can ensure better outcomes as children cope with medical encounters (Mahan, 2005; Gaynard et al, 1998).

During a preparation, it is also important to use non-ambiguous language. Something as simple as, “I’m going to take your temperature” can actually seem ambiguous. A child may wonder, “where are you taking my temperature to?” A better phrase is, “I’m going to use this thermometer to see how warm your body is” (Mahan, 2005). Another ambiguous term is, “put you to sleep”. This is a problematic term for many reasons. First, many children associate being “put to sleep” with a pet
having been euthanized. Another issue is that if a child believes they are asleep during a surgery, that also means that they might wake up during the surgery. A better way to explain anesthesia is to say, “a medicine that puts you into a deep sleep. But this is a different sleep then when you’re at home in your bed. During this sleep, you won’t wake up until we stop giving you the medicine” (Mahan, 2005). You can even reiterate this point by pretending to give anesthesia to a doll, and having the child yell in the doll’s ear, saying, “nope! He still won’t wake up until we stop giving him the medicine.”

Lastly, when preparing children, it is important to use simple language. No matter the age of the child, during times of stress, it is harder for people to integrate information (Gaynard et al, 1998). Therefore, by using simple language, we can better ensure that our patients actually retain and understand the information we are giving them. Instead of saying that a tourniquet will be used, it is easier to show the tourniquet, and liken it to a big rubber band in order to make sure the child understands what a tourniquet actually does (Gaynard et al, 1998). The best and most important way to use simple language in preparing children is to be honest (Mahan, 2005). Honestly is what will resonate most with the child, and will best prepare them for whatever procedure or test they need to face.

Basic preparation techniques

As child life pioneer Gaynard writes, “when preparing children... it is only necessary to tell them about what they will actually see, hear, taste, smell, and consciously feel. If they express curiosity about the details of the surgical procedure
children are usually satisfied with a simple response that directly addresses their immediate question” (1998, p. 59). It is important to give accurate information while also making sure to not overwhelm children with more information than they need. By only giving them information on what they will actually see, hear, smell, taste, and feel the child isn’t given more anxiety provoking information about the actual procedure (Gaynard et al, 1998). During a surgery, the child will be anesthetized during the majority of the procedure, so preparing them for scalpels and other surgical tools is unnecessary, as these are not tools they will actually be experiencing. The five-senses approach is the best practice for preparing children. By focusing on what the child will hear, see, smell, taste, or feel, we can prepare them for a multitude of medical experiences.

When preparing a child, it is important to first assess what they already know about the procedure. By first asking the caregivers what they have told the child, we can better understand what information the child has already been given. Next, it is important to ask the child what they know about “what is happening today” to see if they are aware they are having a procedure. Once it is established that the child is aware they are having the procedure, it is beneficial to ask, “what happens when someone gets an IV?” (or surgery, LP, etc.) (Gaynard et al, 1998). By first discovering what the child already knows about the impending procedure, we can better prepare them by focusing on the unknown information or by correcting misconceptions. Once the child explains what they already know about the procedure, it may become important to correct a misconception. Instead of telling the child they are wrong, it is better to say, “I can see why you would think that, but
actually...” In this way, the child still feels like the expert on his or her own medical care, but is given correct information.

Another technique to use when preparing patients for procedures is to tie their experience to the experiences of other children. For instance, when preparing a child for IV anesthesia, one could say, “some kids have told me that it feels a bit warm, and others have said it has a funny taste.” By relating their experience to that of other children, we can make the information less threatening, as well as more comfortable for the child (Mahan, 2005). Another way to include other children is through debriefing after a procedure. “How was that for you? Is there anything I forgot to tell you about that you think would be helpful for other kids to know?” Again, we are making the child an expert, and building confidence (Mahan, 2005). Debriefing also helps the professional better prepare the next child, as well as make sure the child is aware that the professional tried to prepare them and didn’t “lie” by leaving out information (Mahan, 2005).

Yet another method that can be used while preparing children for medical experiences is medical play. A physician may not have time for a full medical play session, but we can use actual medical equipment in playful ways to show the child what they will experience (Mahan, 2005). For example, by using an anesthesia mask on a doll, the child will better understand what they will see and feel. By letting the child touch and feel the mask, we are helping to prepare with the five senses approach. Another quick way to use medical play with children is to show the child on a doll what will happen to them, and then give them the supplies and the doll so that they can do the procedure as well (Gaynard et al, 1998). By giving the child the
opportunity to not only feel and see the medical supplies, but to also use the medical supplies, we give the child a sense of control over the procedure, as they are now the actor, instead of a passive patient (Mahan, 2005).

Overall, the most important techniques when preparing children are to use a calm, confident tone of voice, keep sentences short and specific, and to be open to, and validating of, the child’s feelings. For instance, when a child says they are afraid of getting an IV because it will hurt, one could say, “sounds scary, let’s think of some ways we can make it a little easier.” By not trying to change the child’s feelings (“it won’t hurt! Don’t be scared!”) we validate how they feel, while then empowering them to discover their own ways of coping.
**Class Six: Procedural support**

**Learning Objectives**

- What is procedural support?
- Family presence
- Positions of Comfort

**Teaching Modalities**

- PowerPoint presentation
- Class discussion
- Videos

  - Seton Family (December 21, 2010). *Comfort Positioning for medical procedures*. Retrieved April 30, 2013 from: 
    
    [http://www.youtube.com/watch?v=VOqIVIFN5Bo&list=PL17C690E84E7F8ADD](http://www.youtube.com/watch?v=VOqIVIFN5Bo&list=PL17C690E84E7F8ADD)

  - Kickapoo785 (July 19, 2012). *All Children’s Hospital child life and iPads 2*. Retrieved April 30, 2013 from: 
    
    [http://www.youtube.com/watch?v=scZ7wD-mlfU](http://www.youtube.com/watch?v=scZ7wD-mlfU)

    
    [http://www.youtube.com/watch?v=NOx93bimNG8](http://www.youtube.com/watch?v=NOx93bimNG8)

*What is procedural support?*

Procedural support involves helping patients cope during a procedure or test. This can range from giving a child movie goggles during an MRI to holding and
soothing a patient during an IV start, to singing to a child during a lumbar puncture. Even after preparation, it is difficult for children to get through painful or time-consuming procedures. It may be necessary to remind the child of coping techniques they thought of and shared with a member of the care team during the preparation (Mahan, 2005). Consistently reminding the patient that, for example, they thought looking at a book would be helpful can make it easier for children to focus on their chosen coping technique (Mahan, 2005). Another way to support pediatric patients during procedures is to maintain a calm environment. By making sure there is only one person speaking at a time, and that those who are speaking are remaining calm and confident, we can help the patient feel calm and confident as well (Gaynard et al, 1998).

There are many ways to support patients through procedures, and through family presence and child life intervention, we can ensure that children have the most comfortable, safe environment during tests and procedures.

*Family presence*

During procedures, it is best, if possible, to include the family in order to minimize stress to the child (Gaynard et al, 1998). By including the family, the physician helps both family and pediatric patient to feel more secure and the patient is more likely to be calm and compliant with medical treatment (Gaynard et al, 1998; Goldberger, Mohl & Thompson, 2009).

There are many ways to include the family. First, is by allowing them in the room. There have been numerous studies on the benefits of parental presence
during anesthesia induction (Romino, Keatley, Secrest & Good, 2005). When parents are present until the child is completely sedated, there is less anxiety from both parent and child (Romino, Keatley, Secrest & Good, 2005). From what we know about development, younger children fear separation from caregivers; therefore, by allowing caregivers to be present during anesthesia induction, we can eliminate this anxiety point (Gaynard et al, 1998; Romino, Keatley, Secrest & Good, 2005).

Another way to include family is to give the caregiver a role during a procedure. When a child is in the hospital, a parent can feel extremely helpless and even feel that they are in the way (Rollins, 2005). Therefore, by giving the parent or caregiver a role to perform during the procedure, they can feel a sense of purpose, and manage feelings of helplessness by doing something to help during this helpless time (Gaynard et al, 1998). This role can be reading a book or singing to the child, holding the child, or helping keep the child calm and distracted in whatever ways they feel will be best. Giving the parents or caregivers a role in their child’s care can lead to happier, calmer family members.

Overall, involving the family as much as possible leads to better outcomes during procedures. Families are the experts on their children, and therefore, they are the most important resource we have when working with pediatric patients (Bell, Johnson, Desai & McLeod, 2009).

Positions of Comfort

Positions of Comfort (POC) are ways to safely and comfortably hold children during procedures. POC help the child to feel more secure and safe, instead of feeling
powerless while being restrained, while still making sure the child will not move during procedures such as IV placements. These positions give a role to caregivers as well as make the child feel secure. They also offer an alternative way to restrain pediatric patients without the use of a papoose or using medical staff to hold their bodies still.

There are three basic positions of comfort that are easy to do and help put the child in the correct position for a procedure. The first is back-to-chest. This position places the child sitting on the parents lap, facing outward, or sitting on the exam table while the parent holds onto them while standing behind (Children’s Hospital of the King’s Daughters, 2013). This position can be used for IVs, injections, or general physical exams (Children’s Hospital of the King’s Daughters, 2013). The next is chest-to-chest. This is where the child sits on the parent’s lap facing the parent, either on the exam table, or in a chair next to the exam table (Children’s Hospital of the King’s Daughters, 2013). This can also be used for IVs or blood draws where the child’s arm is on the exam table, or can be used for injections, or even lumbar punctures (Children’s Hospital of the King’s Daughters, 2013). The last position is the froggy. In this position, the parent usually sits at the head of the exam table, while the child lays their head on the parent’s lap, and the parent can help hold the child’s knees in the froggy position (Children’s Hospital of the King’s Daughters, 2013). This can be useful for catheterizations, VCUGs, or pelvic examinations in which the child’s legs need to be bent upward (Children’s Hospital of the King’s Daughters, 2013).
All of these positions lead to a child who can be more easily restrained without feeling the discomfort of being pinned down or held down on an exam table (Mahan, 2005). This also helps children feel more secure and safe, leading to more seamless procedures (Gaynard et al, 1998).
**Class Seven: Patient and family-centered care**

**Learning Objectives**
- What is patient and family-centered care?
- How to implement PFCC into practice
- Including siblings

**Teaching Modalities**
- PowerPoint presentation
- Class discussion

**What is patient and family-centered care?**

Dealing with illness and hospitalization is difficult for every child and family. Having to watch their child in pain and distress can be very traumatic for families. However, when these families also feel completely powerless in their child’s care, not only does the family experience emotional crisis, but the child’s health can also suffer. Patient and family-Centered Care (PFCC) has been implemented in many hospitals to ensure that children and their families receive the best possible care by being involved in decisions, and being the experts on their children. Through patient and family-centered care, children’s hospitals are not only a place for physical healing, but for emotional healing as well.

“Family-centered care is based on the recognition that the family is the constant in an individual’s life, and that is has significant influence over and individual’s health and well being” (Bell, Johnson, Desai, & McLeod, 2009, pp. 96).

The ideas of family-centered care started in the 1940s when the children being
treated in hospitals were seen to become detached, and lose developmental gains (Wojtasik & White, 2009). By the 1950s and 1960s, new research showed that separation from parents resulted in negative psychosocial outcomes for hospitalized children. However, parents and family members were still considered “visitors” and could only spend time with their ill children during certain time periods (Bell et al., 2009). It wasn’t until the 1980’s and 90’s that parents were finally seen as an integral part of the child’s healthcare needs, and were allowed to be in the room at all hours, as well as sleep over in the hospital room (Bell et al, 2009).

How to implement PFCC into practice

The tenets of patient and family-centered care cover a wide range of ideals and actions that see the family as the most important part of the patient’s life. The first and arguably most important idea of family-centered care is respect for the family (Bell et al., 2009; Gaynard et al., 1998; Julian & Julian, 2005). Respect involves not just being respectful and professional, but seeing the child and family not just as a job, but as human beings who deserve to be treated with the utmost care and compassion. This respect leads to the majority of the ideas behind family-centered care, which include involving patients and families in medical decisions, policy-making, and relying on the parents as the experts on their children (Bell et al., 2009).

One important aspect of patient and family-centered care is two-way communication. This means listening to the families, being open to their collaboration with the healthcare team, giving them education on diagnoses, and
discussing difficult issues surrounding care (Hollon & Palm, 2007). By being open to listening as well as talking to children and families, we can give families the highest degree of involvement in quality care for their child.

Another ideal of patient and family-centered care is that of empowering patients and families. By giving pediatric patients the tools to speak up for their own healthcare, such as allowing them to ask questions and responding to those questions appropriately, we empower pediatric patients to be invested in their own health. This approach teaches children to be the executers of their own healthcare, which is important training as they become adults (Coyne & Gallagher, 2011). In a family-centered care approach, caregivers should feel that they have a right to speak up and question the medical team’s thought process and decisions regarding their child’s healthcare. Another way to empower children and families is by giving them opportunities to discuss their healthcare with doctors and nurses. By teaching them tricks, such as writing down questions to remember to ask later, or speaking up during rounds, we can help these children and families become key players in their own healthcare experiences.

One of the easiest things medical practitioners can do to enact PFCC is to include the patient and family. For example, a doctor can ask them questions about, give them a role in, and make them feel they are part of, their own medical care. Other ways include inviting a parent to hold their child during a procedure, asking a patient about what he knows about his illness, or involving parents and patients in planning a treatment regime that will fit their lifestyle. All of these things will lead to patient and family-centered care in everyday practice.
By respecting each individual child and family, hospitals can implement the ideals of family-centered care. Listening and talking openly with families, involving them in their own healthcare, and empowering them to make decisions, cope and educate themselves are all ways in which family-centered care is realized.

Including siblings

A patient and family-centered care approach also includes siblings in the care of each patient. “Healthy siblings operate as active members of a family. They endeavor to participate to support family cohesion in the midst of strain” (Cindy Dell Clark, 2009, p. 32). Siblings are a large part of a patient’s life, and they deserve, therefore, to be a large part of the patient’s medical experience as well. Including siblings is as simple as making sure they are given explanations of the patients medical status (with parental permission), and giving siblings a role when they are present (Bell, Johnson, Desai & McLeod, 2009).

When working with a family who has other children at home, it can be beneficial to suggest bringing in siblings to visit, or having siblings draw pictures or write letters to the patient in order to help them feel they are still a part of the patient’s life (Julian & Julian, 2005). Siblings should also be prepared to see an ill sibling, which is another reason to contact child life, in order to make sure siblings understand what they will see when they enter the sibling’s hospital room (Julian & Julian, 2005).

Patient and family-centered care is an integral part of complete medical care. Medical care isn’t just about physical health, but about the full health of each patient.
Since family is a large part of a person’s life, family members should play just as important a role in a person’s healthcare. Working with families deepens our respect and understanding of how they are affected by the adverse health of one of their members. Through PFCC we can lessen this stress.
Class Eight: Culture

Learning Objectives

• What is culture?
• Weaving cultural considerations into practice
• Finding out about different cultures and using a translator

Teaching Modalities

• Discussion of cultural themes from The Spirit Catches You and You Fall Down
• Small group discussions of culture
• PowerPoint presentation

What is culture?

Culture is a set of ideas, beliefs, traditions, and practices specific to a group of people (Johnson, 2005). Culture can include clothing, language, food, race, ethnicity, religion, or gender (Johnson, 2005). Even within each culture, every family has a culture of their own. During a hospital experience, a family is expected to understand yet one more culture: the culture of the hospital system. Hospital culture also includes a different language, way of dressing, food, schedule, and environment (Johnson, 2005). Integrating all of these cultures can be overwhelming for a family, and many experience a type of culture shock as part of the hospitalization experience (Johnson, 2005). Because of this, it is important for healthcare workers to try and understand each family’s culture, in order to make each family member feel more of a sense of comfort within a new situation.
Culture can also have a large impact on how a family views the hospital system, and therefore how they respond to medical treatment (Johnson, 2005). By learning about different cultures, physicians can better address the needs of their patients through meeting them at their level and incorporating cultural beliefs into appropriate medical care (Johnson, 2005).

*Weaving cultural considerations into practice*

Part of working with children and families is being sensitive not only to their specific needs as patients, but of their specific cultural needs by having basic cultural competence and being able to ask each family what their cultural values are (Baggerly, 2009). By meeting the family on their grounds, health care specialists can better discuss patient care and meet the needs of each individual family.

Knowledge of cultural norms and traditions can help healthcare specialists adapt practices and improve communication. If a family is patriarchal, it is important to direct all information to the father, even if in one’s own culture this seems uncomfortable or even unacceptable (Johnson, 2005). Each person carries cultural bias. It is important to be self-aware of these feelings, and to address them so that these biases do not affect our interactions with patients and families (Johnson, 2005).

Different cultures also have different beliefs about illness and healthcare. Therefore, it is essential to speak to each family about their beliefs on the particular illness they are dealing with. In *The Spirit Catches You and You Fall Down*, the doctors learned the hard way that the Lee family had very different opinions about
what was causing Lia’s epilepsy than Western Medicine’s belief system (Fadiman, 1997). By speaking to a family about their perceptions of illness and of medical care, we can better implement treatment plans that are culturally relevant to the family (Johnson, 2005).

Many families have spiritual or religious needs that are important to them (Clutter, 2005). Referring to Chaplain services is a helpful way to provide religious support, as and a healing presence for the patient and family (Clutter, 2005). Other healthcare team members can also supply this presence, but it is something that Chaplains are known for. When working with families with strong religious beliefs, it is important to be self-aware of one’s own comfort level. Would you feel comfortable praying with a family? Do you feel comfortable being a part of other religious rituals? There is no black and white answer to these questions, but it is important that the practitioner feels comfortable. It is ok to say no thank you to a family in these situations, as long as you show a respect of their beliefs and need to perform these rituals (Clutter, 2005). Supporting a child’s spiritual needs during the healing process has been shown to have physical benefits such as faster healing, less depression, and stronger coping (Clutter, 2005).

All in all, the best way to have culturally competent interactions with families is to be genuinely interested in learning about other cultures, showing respect to individuals’ beliefs, being flexible, and being transparent about any lack of knowledge about a culture (Johnson, 2005). Simply attempting cultural competence is the sign of a well-rounded, compassionate, and sensitive practitioner.
Finding out about different cultures and using a translator

If a medical staff member needs to interact with a patient of family from a cultural group they are unfamiliar with, there are many ways to still give culturally competent care. The first step is to do your research. What do you already know about this culture, what can you find out? Is there a member of your staff that identifies with this culture that you could speak to? Once these outside sources are utilized, the medical professional can feel a sense of confidence when going in to address a family. Another way to ensure you are providing competent care is to ask the family themselves. Even within a culture, each family and individual practices differently or has altered beliefs (Bell, Johnson, Desai, & McLeod, 2009). Therefore, by asking the family what they believe, how they would like to be addressed, their thoughts on illness, and so on will give the practitioner the most accurate, culturally competent information. By using the information gained from the family, not only can physicians ensure they are treating the family the way the family wants to be treated, but they also show respect for the family by taking the time to ask questions and to listen to the responses.

Most importantly, use a translator. Even if another staff member is fluent in the unknown language, or another family member speaks English and can therefore translate, it is absolutely necessary to use a licensed medical translator. Though a staff member may speak the language, understanding and translating medical terminology is not something they may be able to do. Using a family member is unadvisable, because the family member may not be translating accurate information, and this may put unnecessary pressure on this family member,
especially if the family member is a child (Fadiman, 1997). For these reasons, it is essential to use a translator. Using a translator doesn’t have to take a lot of extra time. Most hospitals have access to a translator phone, wherein the user picks up the phone and asks for the specific language needed. In this way, culturally competent care can occur for patients and families who are English language learners.
Class Nine: Children on the Autism Spectrum

Learning Objectives

• What is Autism?
• Best practice for working with children with Autism in healthcare

Teaching Modalities

• PowerPoint presentation
• Class discussion
• Videos

What is Autism?

Autism Spectrum Disorder (ASD) is a range of neurobehavioral impairments with unknown cause (American Psychiatric Association, 1994). Though there is a range in terms of severity of symptoms, there are three general behavioral patterns: impairments in social interaction, which includes difficulty understanding social cues, tone of voice or facial expression; impairments in communication, which
includes limited or absent speech, repetitive speech, or problems with word meaning; and restrictive or repetitive play and routines, which includes narrow and intense interests, repetitive or harmful behaviors, rigid adherence to routines, and sensory issues (Autism Speaks, 2012).

There are many medical conditions that are co-morbid with ASD such as Muscular Dystrophy, Epilepsy, Hypothyroidism, Gastrointestinal issues, and many others (Lord & Risi, 2000; Scarpinato, Bradley, Kurbjun, Bateman, Holtzer & Ely, 2010). Therefore, it is very likely that all physicians will come into contact with adult and pediatric patients with ASD. Because of this, it is important for all physicians to become familiar with the best ways to work with patients on the Autism Spectrum.

Best practice for working with children with Autism in healthcare

ASD is a spectrum disorder, which means that children with ASD cover a wide range of symptoms and have a range of levels of functioning (American Psychiatric Association, 1994). Therefore, there is no distinct profile for the child with Autism. This can make working with patients with ASD overwhelming for medical professionals, as each patient may have a unique set of strengths and challenges. However, there are many things medical professionals can do to make their practice conducive to patients with ASD, as well as ways to work with each patient specifically.

Patients with ASD tend to keep a rigid schedule, and have a difficult time dealing with changes or delays in that schedule (Autism Speaks, 2012). Therefore, it
can be beneficial to schedule these patients for the first or last appointment of the day to ensure there are little to no delays when they visit the office (Autism Speaks, 2012). Another way to minimize wait time is to prepare all supplies before going into the room (Autism Speaks, 2012). For instance, in the hospital, preparing IV materials outside the room, as well as asking the parent to prepare the child for the IV can help the placement go as quickly and smoothly as possible. Being prepared is one of the best ways to make sure that children with ASD are less removed from their routines, leading to calmer patients (Autism Speaks, 2012).

Another tenet of best practice with children with ASD is to work closely with the family. For all patients, we see the family as the expert on their child (Julian & Julian, 2005). However, this is especially true for children on the Spectrum because of the wide range of symptoms and needs (Autism Speaks, 2012). Therefore, medical professionals need to work very closely with these families to determine the best practice for working with each specific child. Asking the family questions regarding developmental level, coping techniques, sensory issues, behavioral plans, and communication techniques can lead to more effective treatment in the medical setting (Scarpinato et al, 2010). First, figuring out the developmental level of a child across multiple domains of development can help better inform practice as well as help medical practitioners better assess the child’s coping (Scarpinato et al, 2010). Coping techniques are important, as the child may have been hospitalized many times and caregivers have worked out the best coping strategies for their child. This may include a parent needing to hold the child, or using a vibrating toy, or even making sure a certain show is played on a TV or iPad (Scarpinato et al, 2010).
Sensory issues can play a large role in how children on the Spectrum cope with medical care. There are many types of sensory inputs that may be craved by the child or be upsetting to the child. The sensory inputs are visual, tactile, auditory, proprioceptive, and vestibular (Woodward, 2011). Proprioceptive stimulation is the feeling of one's own body movement or body position in the environment (Woodward, 2011). These children may stimulate by rocking, climbing, using physical strength to push or pull, or may enjoy being tightly squeezed (Woodward, 2011). Vestibular stimulation refers to the feelings of body position in the inner ear. These children may enjoy spinning, or want to be pushed or pulled in a wagon, or may enjoy balancing activities such as standing on one leg (Woodward, 2011). For children with auditory stimulation issues, it is best to keep noise to a minimum, turning off loud machines when necessary and keeping only one person speaking quietly at a time (Scarpinato et al, 2010). If a child benefits from auditory stimulation, playing music, singing, or having a television on can be beneficial (Woodward, 2011). For visual stimulation issues, keeping the room darkened, as well as keeping away toys or items with bright lights or colors (Scarpinato et al, 2010). For those who thrive with visual stimulation, bringing in light-up toys or brightly colored items, as well as keeping the light or television on can be beneficial (Scarpinato et al, 2010). Lastly, for tactile stimulation issues, it is best to keep the child in whatever clothing, or lack of clothing is most comfortable. In addition, the care team should remove blankets or other textures that may be upsetting, and refrain from touching the child more than necessary (Woodward, 2011). For those
children who need tactile stimulation, papoosing or tight holds can be beneficial, as well as heavy or light touch depending on the child (Woodward, 2011).

When working with children with Autism Spectrum Disorder, it is important to find out what behavioral and communication techniques the parents are using (Autism Speaks, 2012). There are many behavioral modification techniques used with children with Autism, which may be undermined by hospitalization, so therefore, it is best to speak to the caregivers about what rewards or limits need to be used with their child (Autism Speaks, 2012). Communication can also be different for each child with ASD, such as communication boards or sign language (Autism Speaks, 2012). By figuring out what techniques are best for each child, medical professionals can better work with these patients and families.
Class Ten: Death, dying and bereavement

Learning Objectives

- Children’s understanding of death by developmental stage
- The American discomfort with death
- Self-care

Teaching Modalities

- PowerPoint presentation
- Class discussion
- Video

Children’s understanding of death by developmental stage

Though children grieve in similar ways to adults, their grief process, as well as their understanding of death differ at each developmental stage (Walsh, 2012). These principles of children’s understanding of death and grief reactions can be applied to both children who are dying as well as the children of dying patients.

In infancy, there is no understanding of death. However, infants are extremely affected by the emotions of those around them (Walsh, 2012). They may also notice the absence of a caregiver, and may become harder to soothe or exhibit feeding or sleeping issues (Walsh, 2012). Infants may become inconsolable, or withdrawn if their caregiver dies, or if their caregiver is grieving (Walsh, 2012). If a
caregiver is grieving, the infant may not be receiving appropriate stimulation or care, therefore, it may be beneficial for a family member or friend to watch the infant while the parent grieves (Walsh, 2012). For infants, it is best to try to be consistent with caregivers, as well as providing extra comfort and physical contact (Walsh, 2012).

Toddlers also have no concept of what death really means and cannot understand the difference between someone being gone for a short time and for forever (Walsh, 2012). Therefore, children may respond to the loss of a caregiver by becoming extremely upset when a family member leaves, and may become clingy or show attachment issues (Walsh, 2012). Similar to infants, toddlers may also become withdrawn or show sleep and feeding disturbances (Walsh, 2012). Toddlers may also show regressive behaviors, such as potty training regression, or asking for help doing tasks they were formally able to do on their own, such as eating or getting dressed (Walsh, 2012). In order to help toddlers cope with grief, it is important to maintain routines and keep consistent caregivers as well as allow for some regressive behaviors without shaming the child (Walsh, 2012). It is also important to allow the child to move in and out of grief reactions, as they may be upset one moment and then want to play the next (Walsh, 2012). Lastly, it can be helpful to name feelings for toddlers. For instance, one could explain, “Dad is sad, that is why he is crying” (Walsh, 2012). By labeling feelings, we help toddlers to better label their own feelings, which will help with stresses throughout their development.

Preschool-aged children understand death in a concrete, magical, and egocentric ways. They may confuse death with sleep, and they do not understand
the permanence (Walsh, 2012). For instance, a child may ask if their mom is cold in her casket, or if she’ll have enough to eat when she is buried. They may also focus on how the death will affect them (Walsh, 2012). They may wonder who will read them a bedtime story, or who will make their sandwiches with the crusts cut off. These are perfectly normal and developmentally appropriate concerns, and should be addressed through validation of feelings and concrete, simple explanations (Walsh, 2012). Children at this age may also show regressive behaviors, which should be tolerated, but they should also be given structure and extra compassion in order to get through the stressful period (Walsh, 2012). Children in preschool may also see death as a punishment for something they did or said, so it is important to reassure them that they are not at fault (Walsh, 2012). Some ways to help children of this age cope are to keep routines, as well as assure children that they will still be taken care of (Walsh, 2012). Lastly, giving concrete, honest answers while assessing the child’s understanding is beneficial for children of this age.

Children of school age can be split into two distinct age groups: six to nine and nine to twelve years old. Those in the younger group are starting to have a more complete understanding of death, though they still use some magical thinking in their understanding (Walsh, 2012). For instance, they may understand that their grandmother died, but they may still wonder if she can hear what we are saying. Children of this age are extremely curious and may ask questions that adults may see as inappropriate (Walsh, 2012). However, their questions should be answered honestly and with compassion. These children may become withdrawn or depressed, and may feel abandoned (Walsh, 2012). For this age, it is important to
give honest feedback, as well as extra comfort and attention (Walsh, 2012). For children any age, but especially this age, it is vital to use the real words such as “died” when discussing death in order to avoid confusion (Walsh, 2012). It is also beneficial to allow children to speak about the deceased or about their feelings about death (Walsh, 2012). It is also important to allow children of this age to go in and out of overt grief reactions, and allow play and other diversionary activities (Walsh, 2012).

For those aged nine to twelve, the understanding of death is fully formed (Walsh, 2012). These children are more involved in the beliefs of their family, and their reaction may reflect the reactions of those around them, as well as their family's religious beliefs (Walsh, 2012). Spiritual beliefs, which carry feelings of family support and tradition, may emerge as a coping strategy for this age group (Walsh, 2012). Preteens tend to look to those around them to learn how they should be reacting as well as how they should be coping with these situations, so being open and honest about one's own feelings, as well as discussing possible coping techniques are beneficial for this age (Walsh, 2012).

Adolescents completely understand death and it's permanence, although they may still act in ways that contradict this fact through their dangerous behaviors (Walsh, 2012). Adolescents are able to converse at length, and show mature reflections on their own feelings about death (Walsh, 2012). Teens may also withdraw or act out in the wake of a death or in learning about their own mortality (Walsh, 2012). It is beneficial to have open, honest, thoughtful conversations with teens, in order to better help them discover coping strategies and to find outlets for
their feelings such as art or physical activity (Walsh, 2012). Lastly, for all ages, but especially adolescents, it can be helpful to make memory items, such as photo albums or scrapbooks (Walsh, 2012). Allowing teens time to connect with peers going through the same issues can also help these children cope with the loss of a loved one, or with their own death (Walsh, 2012).

*The American discomfort with death*

Americans tend to avoid the topic of death. We use euphemisms for death for fear of upsetting others with the words “dead”, “died”, or “dying”. However, in many other cultures, death is seen as a natural part of life, and even celebrated (Johnson, 2005). Because of our discomfort with death, it is much harder for children in this country to cope with and to understand death (Walsh, 2012). Using euphemisms such as “put to sleep” can cause fear and anxiety in children around bedtime, so these phrases are not recommended or beneficial for children (Gaynard et al, 1998). Other euphemisms, such as “with God” or “passed on” can be confusing and ambiguous to children, therefore making their understanding of death even more unclear (Pearson, 2005b).

The video shown in this session is one that is generally seen as sweet or hopeful. A child leaves her parents notes that they continue to find long after she has died. However, towards the end of the video we learn that the child was not told that she was dying. Students will discuss whether or not this was beneficial to the child, how the child may have come to know she was dying, and how not being able to discuss her feelings about death with her family affected her coping.
In medicine, it is important that we use the correct, accurate terminology, though it can be uncomfortable within our culture. There may also be resistance from parents to use these words with their children, but it is our job as medical professionals to explain why using the correct terms are beneficial, as well as advocating for total honesty with children and pediatric patients. However, it is still important to work with family members to make sure that they are aware of, and give them consent for, these types of conversations. It may become important to advocate to a family why one feels being honest is important with the child.

**Self-care**

When working with patients who are ill and dying, it can be difficult to cope as a professional. Because of this, self-care is extremely important for the mental health of professionals working with these populations (Walsh, 2012). It can be difficult to find the time to take care of oneself when working with difficult populations, however, without self-care, there is a very high risk of burnout. Burnout is the state when a helping professional becomes unable to care for patients emotionally: they may avoid difficult patients, dread going to work, or become irritable and angry when working with patients and coworkers (Walsh, 2012). This state is also known as compassion fatigue, and can lead to a professional no longer being able to successfully complete their daily job tasks (Walsh, 2012). Through self-care, professionals can minimize the risk of compassion fatigue, and can lead longer, more fulfilling careers.
There are many ways to practice self-care, and certain techniques work better for some than others. Among the many options are (Walsh, 2012):

- Reading a book
- Taking a bath
- Exercising
- Spending time with friends and family
- Listening to music
- Seeing a movie
- Going on vacation
- Dancing
- Getting a treat
- Getting a massage
- Making art
- Going for a drive
- Going for a walk
- Spending time with pets
- Laughing
- Meditating
- Practicing religious beliefs/praying

(Walsh, 2012).

By taking time for self-care, helping professionals can make sure that they are at their best, so they can be the best for their patients.
Class Eleven: Pain

Learning Objectives

- Assessing pain in children
- Pain management techniques

Teaching Modalities

- PowerPoint presentation
- Website
- Videos
Assessing pain in children

It used to be common practice to perform smaller surgeries and procedures on children and infants without the use of analgesics (Turner, 2009). However, it is now understood that children experience as much, if not more, pain than adults (Turner, 2009). It is important to be able to assess pain in children in order to prevent medical traumatic stress reactions, wherein children become traumatized by their medical experiences because of intense or constant pain (C. Baish Cameron, personal communication, February 25, 2013). Studies today still show a lack of adequate pediatric pain management in the hospital (Tsze, Melland & Gilbert, 2013). Therefore, it is important for medical professionals to be educated on assessing and treating pain in children effectively.

There are many ways to detect pain in children. First, is to continuously ask older children about their pain levels, and treat accordingly (Baulch, 2010). However, there are cultural components to pain assessment. Many times, children of color, or those from low socioeconomic backgrounds are seen as “faking it” or “drug seeking” (Chen, 2009). Adolescents, especially those with painful diseases such as Sickle Cell, also experience medical practitioners not believing their reports of pain (Chen, 2009). By using this knowledge, medical professionals can make sure to be self-aware of their own bias and hopefully become more open to all reports of pain.

For children who cannot express their pain through words (either because of language development or because of other medical reasons such as being intubated or having their jaw wired shut) it becomes essential to be able to read the physical and physiological signs of pain. Specifically, crying, grimacing, body contortion, or
irritability (Baulch, 2010). Children between the ages of three and seven can generally respond to the question, “where does it hurt”, but may not be able to describe or rate the pain numerically (Baulch, 2010). It is not until around age ten or eleven that children can start to numerically rate pain on a scale of 1 to 10 (Baulch, 2010). For children younger than ten, using a pain scale, such as the faces scale, can be used to assess pain (Tomlinson, von Baeyer, Stinson & Sung, 2010). For infants, body language and facial expressions are used to determine pain, such as crying, altered facial movements, vigorous movements, and noticeable stress (Baulch, 2010).

Overall, assessing pain is the first step in working with pediatric patients in pain. Asking family members how they feel their child’s pain is controlled is another great tool in assessing and managing pain in children (Baulch, 2010). The family is more likely to notice a change in their child’s behavior indicative of being in pain, and the family is also with the patient more often, and therefore sees the child’s pain reactions most. By using the family reports as well as other pain assessment methods, we can more accurately assess, and therefore treat, the pain experienced in pediatric patients.

**Pain management techniques**

Pain, especially for children, is not always based on physical pain. Anxiety can also manifest as pain. However, this does not make a child's complaints of pain any less real (M. Brauntauch, Lecture, March 29, 2012). It is said that pain is whatever the person experiencing the pain says it is. Because of this, it is hard to standardize, but this does not make it unnecessary to treat (Baulch, 2010). This
does, however, make it more difficult to effectively treat pain. There are many pain management techniques, both pharmacological and otherwise that can be used to treat and minimize pain for pediatric patients.

There are the pharmacological ways of treating pain, such as topical anesthetics, intranasal analgesics, or IV pain medications (Baulch, 2010). However, the fact that these medications exist does not guarantee that they are used, or that they are used properly. There are many time parameters for the topical anesthetics, and many must remain on for a certain period of time before they become effective (Baulch, 2010). Intranasal analgesics are beneficial because they have a similar effectiveness to IV medications without the use of needles (Tsze, Melland & Gilbert, 2013). Intravenous medications, such as morphine, can be controlled by the patient, leading the patient to feel less anxiety about their possible pain, as well as better assuring that the patient's pain is managed (Baulch, 2010).

One non-pharmacological way to lower the pain of simple procedures, such as immunizations, is to inject more than one immunization at a time (Schechter, Bernstein, Zempsy, Bright, & Willard, 2010). It has been shown that having two immunizations at once tricks the brain, and pain is only felt for one immunization site (Schechter et al, 2010). By doubling up immunizations or other injections, we are minimizing pain for patients. However, it is important to explain the pain management technique to patients and families to lessen their fears of receiving multiple injections at once.

There are also many non-medical ways to address pain, such as through the arts. The arts are known to distract from pain and reduce pain by calming anxiety
Through art activities, we can help lower chronic or post-operative pain that is longer lasting. This would be less effective for procedural pain, as it is difficult to enact art during a procedure. However, singing and music can be used during procedures to help manage pain (Rollins, 2005).

Another way to manage pain is through meditation and guided imagery (Tsze, Melland & Gilbert, 2013). Meditation can consist of specific thought paths, or solely of relaxation and restorative breathing techniques (Dobson, Bray, Kehle, Theodore & Peck, 2005). This type of breathing technique can lower blood pressure and heart rate, as well as aid in pain management (Kuttner, 2008). These breathing techniques are also used in guided imagery, which uses deep breathing in conjunction with mental images to help transport the patient away from their pain, help them control their own pain experience, or help them relax their muscles to aid in pain relief (Klein, 2001). Guided Imagery techniques can be performed by child life specialists, nurses, physicians, or can be taught to caregivers to use with their children (Klein, 2001). Guided Imagery can be used before, during, or after painful procedures, and can even be used to treat chronic pain (Kuttner, 2008).

Topics discussed earlier in the course such as positions of comfort and family presence can also act as pain management strategies (Tsze, Melland & Gilbert, 2013). Music, play, and other distraction techniques can also be beneficial pain management options that are easily done during and post-procedure (Baulch, 2010). For infants, oral sucrose, nursing, and being held by a caregiver are a few pain management techniques that have been proven beneficial (Baulch, 2010). There are multiple pain relief options, so working closely with the family to discuss
which techniques they prefer or believe would work best for their specific child can lead to minimizing pain for all pediatric patients.
Class Twelve: Trauma and the emergency department

Learning Objectives

• Trauma reactions in children

• The importance of child life intervention in the ED

• Spending time to save time (case examples)

Teaching Modalities

• PowerPoint presentation

• Class discussion

• Case examples

Trauma reactions in children

It was long thought that children were extremely resilient, and that therefore, they would not experience long-lasting trauma from events during childhood (Dyregrov & Yule, 2006). However, research has shown that children are greatly affected by traumatic events, even though they show resilience for many stressors (Dyregrov & Yule, 2006). Although children do not always present to the emergency department because of medical trauma, nevertheless, emergency hospitalization can be traumatic for children and families (Mahan, 2005).

Children react differently to trauma depending on age and development (Mahan, 2005). For children younger than six or seven, trauma reactions are more overt and aggressive (Dyregrov & Yule, 2006). They may repeatedly draw or act out the traumatic event, or they may become irritable and easily frustrated (Dyregrov & Yule, 2006). After September 11, 2001, many children built and destroyed block
towers over and over as a way of working through the trauma they had experienced (Klein, Devoe, Miranda-Julian, & Linas, 2009). Children dealing with medical trauma may focus on one aspect of their care, for instance, they may give injection after injection to a doll, or hit a doll over and over in the same place they experienced a trauma (Gaynard et al, 1998; Bolig, 2005).

Older school-aged children and adolescents tend to react more similarly to adults, and are better able to discuss and reflect on the trauma (Dyregrov & Yule, 2006). These children may withdraw or have nightmares about the event (Dyregrov & Yule, 2006). Trauma in this age group can also be worked through via the arts. Arts activities can help traumatized children to better understand the experience, as well as help them cope with their feelings and fears (Rollins, 2005).

All children who have been through a trauma should have the opportunity to discuss their thoughts and feelings openly, as well as given opportunities to work through these feelings, such as play, the arts, or writing (Rollins, 2005). However, most physicians do not have the time or availability to do this type of work, which is where child life services can be beneficial.

The importance of child life intervention in the ED

One of the most frequent answers on the survey given to child life specialists for the question, “in what areas have you seen need for more training in working with hospitalized children and families from medical staff?” was the Emergency Department. This was a common answer because most child life specialists felt that in the fast-paced unit, physicians would quickly perform procedures, even in non-
emergent cases, without consulting child life or preparing children and families themselves. By involving child life in interactions with patients in the Emergency Department we can minimize trauma reactions, create calm patients and families, and promote prepared patients who are more quickly able to get through procedures (Rollins, 2005).

Through the child life interventions seen throughout this course, child life specialists can work with patients and families in the ED to minimize trauma reactions (Gaynard et al, 1998; Rollins, 2005). By quickly preparing patients for impending procedures, we minimize trauma; by supporting children through emergency procedures and tests, we minimize trauma; and by working with patients after procedures and tests to work through issues, misconceptions and fears, we minimize trauma reactions in these children (Rollins, 2005; Squires & Eury Allen, 2009).

Through preparations and family support provided by child life specialists, patients and families become calmer during an ED admission (Goldberger, Mohl & Thompson, 2009). The Emergency Department can be chaotic and loud, but with child life working to lower stress, the ED can become a calmer, quieter environment more conducive to healing (Squires & Eury Allen, 2009). Having a calm environment leads to better communication with patients and families, more restorative healing, and less stress on both patients and practitioners (McCuskey Shepley, 2005). By employing child life services to help calm patients and families through support and preparation, an ED can lower the risks of communication errors as well as anger or other outbursts from patients and families (Squires & Eury Allen, 2009).
Lastly, by utilizing child life services, physicians can actually save time and shorten the time they need to do procedures on each patient. Through preparation, patients are better able to sit through procedures (Gaynard et al, 1998). When a child sits still during a procedure, it is easier for the medical team to more quickly perform the procedure. A calm, still child is easier to suture than a screaming, kicking child. By working with a child life specialist, physicians can actually reduce the amount of time they need to spend working with each patient, leading to their ability to work with more patients in the same time frame.

*Spending time to save time (case examples)*

In the emergency department, time is limited. There is a large patient turnover, and there are constantly patients being admitted, discharged, tested, and treated. Because of this, it can be difficult for physicians to take the time to work closely with patients and families in the emergency department. However, many simple techniques, which may take a few moments more at first, may actually save time in the long run.

Case Example 1: Preparing for IV start

An eighteen-month-old male patient came to the Emergency Department because of possible dehydration after suffering from a stomach flu. The patient required an IV start, and the medical staff was anxious to begin as soon as possible. The author asked for a few minutes to prepare the patient and mother for the procedure. Using positions of comfort, the author seated the patient between his mother’s legs on the hospital bed, and quickly prepared the mother for what would
be happening. During the procedure, the author worked with the mom to distract the patient, who was able to stay still and happy during the IV start, and the team was able to get the IV started on the first attempt.

Case Example 2: Appendix removal

A thirteen-year-old female patient was brought into the ED by her mother, complaining of abdominal pain. Medical staff chose to perform an ultrasound, and the author was able to prepare the patient for the procedure. The patient seemed anxious after the ultrasound, and was quickly told that she was suffering from appendicitis. The patient became overtly emotional and stated that she didn’t want surgery. Medical staff tried to quickly move her to the surgical unit, but the author and her supervisor quickly advocated for a few minutes to calm and prepare the patient. The author then prepared the patient, and helped plan coping techniques while advocating for parental presence at anesthesia induction. Once the patient understood that her mother would be present while she received anesthesia, her anxiety started to wane, and she noted that she was now ready to go to the OR.

Case Example 3: Sutures

A nine-year-old female was brought into the ED from school after getting her finger slammed in a door. The front of her finger was almost completely removed. The patient was calm and focused on the preparation by the author. However, as the medical team started to set-up for the sutures, the author noticed that the patient’s mother seemed very anxious. The author suggested that the team wait a few moments to start the procedure, so that the mother’s concerns could be addressed. It was quickly learned that the mother was afraid to watch the procedure, so the
author suggested that the father stay with the patient while the mother was moved into the hallway. Once the mother was taken to another room, the sutures were able to begin. During the procedure, the father noted that his wife would probably have fainted had she stayed during the procedure.

In all of these cases, by spending a little more time before a procedure or test to prepare patients and families, or to help distract and calm patients, the medical staff was able to quickly get through their procedures. Patients who may have become distressed and prevented a quick and successful procedure were able to sit through the procedures (sometimes even happily!). By spending a few more minutes in the Emergency Department, medical staff can actually save time in the long run that may have been spent in a struggle with a fearful patient or family.
Class Thirteen: Role-playing and assessment of class comprehension

Learning Objectives

• Role-playing of scenarios covering themes from the semester
• Peer and self-evaluation
• Course Evaluation

Teaching Modalities

• Role-playing of scenarios
• Class discussion

Role-playing of scenarios covering themes from the semester

For this class session, the students will be broken up into groups of four or five and approximately five scenarios or cases. For each scenario or case, one student will act as the doctor, while the others will act as the other members of the scene, or observe the role-playing. Scenes will cover topics ranging from cultural competence to procedural preparation, to bereavement. Each student will have the opportunity to act as the physician, and after each scenario, the students will discuss what the strengths and areas for growth were in the physician's actions and decisions.

By giving these students scenarios, not only are we helping them to put theory into practice, but we are also making them the experts on child life theory within their professional lives. They become critics on what the best practice would be for these situations, and this type of learning further solidifies their knowledge (Kumagi, 2012).
In the last few minutes of class, everyone will come back together to discuss themes or issues they observed during role-playing. Discussion of how they will utilize what they have learned in their everyday practice as physicians will also be a large part of this penultimate session.

Peer and self-evaluation

At the end of class, students will be given evaluations to fill out before the last class session. The evaluation will cover what the students thought they learned from the course, and how much they think they will use in the future. The last evaluations will be of the other three to four members of their role-playing group. It will be one survey about how they thought their peers did as a whole, as opposed to individual evaluations for each student. In this way, the professors can gain insight into how each student felt his or her peers had integrated the material learned into their practice. Hopefully, through these surveys, the class can continue to grow and change to better optimize class content, as well as optimize the amount of material learned and integrated into practice.

Course evaluation

The students will also be given an evaluation of the course itself; what they felt were the best, most useful parts of the course, and which they felt were less so. This evaluation will help the educators to better edit the class and help it to grow and evolve each year. By evaluating course content, teaching methods, and
assignments, the students can have more control over how the class will be run in the years to come.
Class Fourteen: Presentation of final projects

Learning Objectives

• Course wrap-up: Understanding what it’s like for children and families with chronic illness

Teaching Modalities

• Class presentations

Course wrap-up: Understanding what it's like for children and families with chronic illness

By interviewing families dealing with chronic illness, the students can start to understand what it is like for a child or family who lives with illness everyday. It can be easy to forget when we see patients in the office or the hospital that they have lives outside of their illness (as it’s possible that patients forget that doctors have lives outside of their jobs). By seeing these families outside of a medical setting, the students can start to see these people as humans first and patients second.

For this assignment, the students will be encouraged to create anything that shows what they learned from interviewing these families: a presentation, a poem, a piece of artwork, or whatever else they can imagine. This not only gives students a chance to be creative, but it also helps further solidify this important experience into their lives. By creating something meaningful, this assignment becomes a more than just an assignment. Making meaning leads to lifetime learning, and will hopefully better etch these ideas of optimal patient care into the minds of these future
physicians. Also, by tapping into their own creativity, the students will hopefully gain greater self-awareness of their own processes, as well as better insight into the coping of pediatric patients through play.

By showing these presentations to their peers, every student will benefit not only from interviewing a family, but also from the experiences related by the other student interviewers. This should be a very powerful class session for these students, filled with creativity, joy, and a better understanding of how to become better, more compassionate, medical practitioners for all children and families.
Measuring Success

Measuring the successful outcomes from this course proves a complicated endeavor. How does one measure how compassionate a physician is and how well he or she communicates with patients and families? During this course, it is possible to assess how much information the students are retaining, as well as what they feel they are getting out of the course.

During the second-to-last class of this course, the students will be evaluated on their role-playing through different situations and scenarios reflecting the techniques learned in class. They will also be given evaluations to fill out before the final class on how they felt the class was run, what they would change, what they feel they learned, and what parts they enjoyed the most. In this way, the child life specialist and physician can constantly edit and update the class to meet the needs of the students, as well as evaluate what the students are actually learning and planning to implement in their future work with children and families.

It could also be possible to have the physicians who supervise these students in the hospital assess how they feel the student has grown throughout the course, and what they feel they have learned. By using professionals in the field who see these students working with patients and families, we can better assess not only self-assessed learning, but also more applied learning outcomes.

I think it will also be important to have peer evaluations. During the scenario and role-playing groups, each group member will fill out an evaluation for the other members of their group. Because peer support is a large part of how these students learn and will function as professionals, it will be important to gain insight from
these perspectives. Also, by giving each student the power to evaluate, it solidifies the knowledge they themselves have acquired from the course by making them look critically at how their peers are using that same knowledge.

For the future of this course, it would be important to implement a long-term study showing the efficacy and importance of child life training for physicians. This study could consist of following these students for the first five years of their professional lives after graduating medical school and comparing their patient satisfaction scores with those physicians in the same year of work without this course. In this way, it could be shown that patient satisfaction scores go up when physicians are trained in child life. With the changing face of healthcare, patient satisfaction scores are becoming more and more important for reimbursement, therefore, it would be beneficial for hospitals to hire physicians who will have higher patient satisfaction scores, therefore making more money for the hospital (Caramenico, 2011). Because of this, courses such as the course outlined here may become more and more important in the changing healthcare environment.
Conclusion

The hope of this work is that in the future, every physician will be required to take a course similar to this one so that all patients and families will be given the opportunity to work with highly qualified, well-rounded physicians with a knowledge and respect of child development, appropriate language, preparation and play, and patient and family-centered care. By covering a variety of topics, as well as consistently evaluating the effectiveness of the course, the author hopes that this course can continue to grow and change to meet the changing needs of physicians and the healthcare environment.
References


Appendix I

* Required

Your Name *

What hospital do you work for?

In which area of the hospital do you work?
(for example: PICU, Outpatient Surgery, Emergency, General Inpatient, etc.)

How large is your child life department?

What type of hospital setting?
(for example: Community, Private, Free-Standing Children’s, Children’s hospital within adult hospital, etc.)

Are you a teaching hospital?
☐ Yes
☐ No

Does your hospital provide any training for medical staff?
☐ Yes
☐ No

If your hospital DOES provide training, to whom is training provided?
(check all that apply)
☐ Medical Residents
☐ Fellows/Attendings
☐ Nursing Staff
☐ Physical/Occupational/Speech/Other Therapists
☐ Mental Health Staff
☐ Other:

If your hospital DOES provide training, how is the training provided?
(check all that apply)
☐ Inservice Presentations
☐ Shadowing of Child Life Staff
☐ Co-Treating
☐ Other:

If you could make sure that every pediatrics resident that came to your hospital knew 3 things about psychosocial care, what would they be and why?

In what areas have you seen need for more training in working with hospitalized children and families from medical staff?

Do you know of any medical schools that are already training their students in child life theory or other ways of working with children and families in the hospital?
Selected answers to: “If you could make sure that every pediatrics resident that came to your hospital knew 3 things about psychosocial care, what would they be and why?”

• “1. Validating a child’s emotions helps kids to feel heard and decreases anxiety. Any emotion is okay, it's behaviors that may need adjusting.

2. Play is how children learn. Play normalizes the hospital environment and helps children cope more effectively. This is important for residents to know because they often think that the job we do is like babysitting. It's not.

3. Psychological preparation is imperative. Children who know what to expect cope better during and after a procedure. Preparation also maintains trust, which helps kids feel confident in their providers and in turn be more cooperative. Preparation needs to be taught at the child's developmental level.”

• “1. Try and provide as much choice/control for the child as possible because they often have very little choice/control over much of the hospital experience

2. Remember that the parents/caregivers are the expert regarding their child so utilize them as a resource.

3. You are not alone in providing psychosocial care to the patient and families. Use the hospital resources (social work, child life, pastoral care, school services, translation services, music therapy, arts in medicine, psychology). Each service as something unique to help support the family during their hospital encounter.”

• “1. Use small, "real people" words. It’s good for the kids, but it’s also good for the parents.

2. Don’t lie to kids or keep things from them because you’re scared it will make them upset. They will be more upset that you weren’t honest with them. Kids can handle more than you think.

3. Smile! Be Playful! Wear a toy somewhere on your person. You are a person in a serious profession, but you can be a playful person in a serious profession.”

• “1. The importance of preparation and procedural support - children and
Appendix I Continued

families who are prepared and have knowledge about something that could be stressful helps them to better cope. As well preparation and procedural support also reduces the frequency of using sedation during paediatric procedures (which increases safety and saves money and reduces recovery time), increases patient and family satisfaction.

2. Opportunity for play while a child is in the hospital – to help provide normalization and familiarity and also helps health care professionals (including doctors) build rapport with children and gain their trust

3. What Child Life is and what services and help they can provide to doctors and nurses to make their job easier – you want to emphasize the importance and benefit of what Child Life does in helping to make their job easier.”

• “1. The parent (or primary caregiver) knows the child best and is their best advocate. It is always valuable to seek their input and really listen to what they have to say.

2. The child’s family and culture are integral parts of who they are. Trying to isolate the child from these contexts makes treating them harder, not easier.

3. Psychosocial care at its best is not an entity unto itself. It can and should be incorporated into every encounter that medical professionals (doctors, nurses, child life specialists, etc.) have with patients and families. Doing this is easier than many medical students and residents may think.”

• “1. Positions of Comfort – proven to be so important and education may dispel the myth that children need to “lay down” for procedures

2. Developmentally appropriate language – evident by the number of times children misunderstand things and the lack of awareness staff have around language

3. Patient/Family Centered Care – I think continued awareness on the importance and ways to include family.”
Appendix I Continued

Selected Responses to “In what areas have you seen need for more training in working with hospitalized children and families from medical staff?”

• “Situations where time is limited, such as the emergency department and IV placements. Many providers just want to get the procedure done (not because of medical necessity but because they want to move on), and the child’s psychological well-being is not considered. Also, many providers still believe the myths that young children don’t feel pain or won’t remember pain/trauma and that kids need to "tough it out” because it builds character. These are detrimental to the child and need education to be combated.”

• “The Emergency Department”

• “Pediatric ER”

• “In facilities where it is a children’s hospital within an adult facility, there is always a need for more education in the adult areas where pediatric patients are treated along with adults. For example, at our facility the majority of procedures are done in adult areas (MRI, CT, Surgery, Infusion Therapy) and often they have medical staff/nurses that are not necessarily pediatric nurses or have very little experience working with pediatric patients. Often, the role of the CCLS in these areas is educating staff regarding how to interact with the pediatric patients and families.”

• “Pain free pediatrics. I think some medical staff have a ‘suck it up’ attitude. If you have the ability to make even 1 shot less traumatic or painful then you should.”

• “Pain management Child development Play Communication - child friendly language, listening skills, delivering bad news, problem solving, avoiding / explaining medical jargon. Family Centered Care Stress and Coping Special needs - Autism, Psych issues, Trauma, Sensory Integration etc Trauma Informed Care.”

• “Better understanding children’s cognitive and emotional development. Use of "soft" language. Importance of parental presence and involvement.”
Appendix II

Special thanks to Deb Vilas from Bank Street College of Education for inspiring many of these assignments

Assignment 1: Playscape

For children, play is essential. Play is how children learn and grow, and many of our childhood memories are around where, how, and who we played with.

For this assignment you will go on a nostalgic journey about your own play history, remembering who you played with, where you played, and what you played with as a child (or at any age). Using drawings, computer animations, or other art modalities, make a playscape of your childhood play memories. This assignment should be fun, and should help you remember how play shaped your childhood.

This assignment will be due during Session Three: Play. There is an option to present your playscape during class, but a presentation is not required.
Appendix II Continued

Assignment 2: Loose Parts Preparation Tools

Children going through procedures may feel anxious. Preparing these children for what they will see, hear, feel, smell, or taste is extremely helpful in lowering anxiety and leading to confident patients who are better able to complete a procedure.

For this assignment, you will create a preparation tool for a specific procedure. However, for this tool, you are not allowed to use medical supplies (or to use them in the way they are supposed to be used). For instance, a tourniquet could be used as a blood pressure cuff instead of as a tourniquet. You should also use other non-medical items such as toys, art materials, or whatever else you can find -- also known as “loose parts”-- that you might find in a hospital or playroom. This is a place to use your creativity to implement more interesting preparation materials that can not only be used to prepare patients for procedures, but can also be made WITH patients in order to help teach and prepare patients.

Here is a list of options for procedures/teaching materials. There will only be one student per procedure, so sign-up is first come first serve. You may also pick a procedure not on this list as long as it is cleared by the professors. You may also make other teaching materials concerning diagnoses or treatments.

- IV
- MRI
- CAT Scan
- Nebulizer Treatment
- Lumbar Puncture
- Port or Broviac Access
Appendix II Continued

• Blood Draw
• EEG
• Sutures
• Cast Removal
• NG Tube Placement

• Dialysis
• Anesthesia

Induction/Surgery

• PICC Line Placement

This project is due during Session Five: Preparation. Each student will present his/her project to the class, and is required to make a hand-out for each student about the items used for the preparation material, as well as how the material was assembled. Please include photographs when possible. Presentations should be no longer than five minutes.
Assignment 3: Debriefing Paper

When working in healthcare, we often deal with death and loss. Though it is our job to help these patients and families through difficult times, it is also important that we as professionals take care of ourselves. Self-care is extremely important when working with these difficult issues, as is being able to debrief with the entire medical team. Debriefing can involve specific activities designed for coping, or even just time laid aside for staff members to talk about their memories of a patient.

For this assignment, you will write a paper detailing a debriefing protocol for a hypothetical hospital. This is your chance to research the types of debriefing already out there in different hospitals, as well as to research best practice for debriefing and self-care.

In this hypothetical hospital money is no option, so design what you believe is the best program for debriefing.

This paper should include:

- Definitions of debriefing, self-care, secondary trauma, disenfranchised grief, and burnout.
- Protocol for a debriefing protocol among medical staff including:
  - When the protocol will be used (for instance, only after a death, after all difficult cases, etc.)
  - Who is in charge of the protocol?
Appendix II Continued

- What activities/seminars/workshops will be a part of the debriefing process

Appendix II

- Who will be involved in the debriefing activities

  • Why debriefing is important, and any programs you have found that led to your own protocol.

This paper will be due during Session Ten: Death, Dying, and Bereavement
Appendix II Continued

Final Presentations

This semester, you will be assigned to a family with a child dealing with chronic illness. You and your group will be required to meet with this family twice to discuss what it is like for the child and for the family dealing with chronic illness as well as the medical system.

At the end of the semester, you will create a project showing what you learned from this child and family: what it is like to be in the hospital, what it is like dealing with medical staff, and how chronic illness affects a child and family.

This project requires creativity. It can be a poem, music video, sculpture, collage, or whatever else you feel portrays the feelings and experiences these children and families had. Each group will create one project, and will present it to the rest of the class during our final class session.

Although it is best to let the families steer the conversation, here are some interview questions to get the conversation started.

For caregivers:

- “What has been the hardest part about having a child with a chronic illness?”
- “How does your family balance time with your children in the hospital and outside the hospital?”
- “What do you wish your child's doctors did better?”
Appendix II Continued

- “What do you remember about the day you found out your child had XYZ illness?”
- “What is the worst part about being in the hospital?”

For children:

- “What is the hardest part about having XYZ illness?”
- “How do you talk to your friends about your illness?”
- “What is the worst part about being in the hospital?”
- “If you were a doctor, what would you do that your doctors don’t do?”
- “What is your favorite thing to do when you’re in the hospital? When you’re not in the hospital?”
Appendix III

Role-Playing Scenarios

(Number of scenarios used will change based on number of students and are provided based on experiences and the imagination of the instructors)

Scenario:
A five-year-old male patient has come into the emergency room after hitting his head on the coffee table, and now needs sutures on his forehead. His mom, dad, and nine-year-old sister are in the room. The patient is anxious, and is tightly squeezing an Elmo doll.

Scenario:
A fifteen-year-old female is in the hospital for abdominal pain, and you have just received test results that show that she is six-weeks pregnant. Her father and boyfriend are in the room. They are watching television.

Scenario:
A nine-year-old female patient has been receiving chemo for AML for the past two years, and scan results have shown that the cancer has spread to her bones and her brain. There is nothing more the medical team can do except keep her comfortable. She is coming in for a visit with her mom, dad, and grandmother this afternoon.

Scenario:
A seven-year-old male patient with ASD comes into the emergency room for an infection on his hand stemming from biting behaviors. The patient is non-verbal and is very agitated. His mother and nineteen-year-old brother are with him.
Appendix III Continued

Scenario:

A sixteen-year-old male patient has come in to the outpatient surgical unit for a hernia repair. The patient tells you that his preferred language is Spanish, but he explains that he understands English. He is with his Aunt, who has limited English proficiency, and is his legal guardian.

Scenario:

A ten-year-old female was brought into the emergency department for abdominal pain, and the medical team has discovered that she has appendicitis and needs surgery. The patient’s mother and father are with her and are extremely anxious. The mom is crying and the dad is trying to calm her down. The family still hasn’t been told that the patient needs surgery.

Scenario:

A nineteen-year-old male patient is in the dialysis unit after acute onset kidney failure. He has become withdrawn and irritable. The patient’s mother is worried about him, and is concerned that he isn’t taking his medications.

Scenario:

A four-year-old female patient was brought into the emergency department for dehydration. The team has decided that she needs IV fluids. The patient is anxious about IV placement, and has never had an IV before. The mother seems calm, and wants to know what she can do to help.

Scenario:

A thirteen-year-old male patient is inpatient after being newly diagnosed with ALL. The patient’s ten-year-old sister is anxious and doesn’t understand why her brother is in the hospital.
Appendix III Continued

Scenario:

A family from Honduras comes into the emergency room after their nine-year-old daughter had a seizure. They are on vacation to this city, and do not speak English, or understand what is happening to their daughter.

Scenario:

A six-year-old female patient is dying in the Intensive Care Unit after a battle with Lymphoma. Her family is of Chinese descent and is requesting to do a special service in the patient’s room. They have also requested that they are given space for their extended family that will be visiting for the rituals.

Scenario:

A two-month-old female patient was brought in for constipation. According to her parents, the patient has been crying more than usual, and has been grimacing and been agitated in her body movements.

Scenario:

An eleven-year-old female patient was brought in for severe headaches. She needs an MRI, but has never had one before. The patient is extremely anxious and is asking every staff member about how much the MRI will hurt.

Scenario:

A twelve-year-old male patient with ASD is admitted to the inpatient unit after an appendectomy. The patient’s father is present, and is concerned that nursing wants to restrain his son during an IV placement. The father wants to use preparation for the IV instead of restraints.
Appendix III Continued

Scenario:

A seven-year-old male patient was brought in after passing out at school. It is determined that he has Type-I Diabetes. His mother has just arrived and is asking what is going on. The patient and mother need to be told about his diagnosis.

Scenario:

A three-year-old female patient was brought in for a VCUG. Her mother is with her and states that she and the patient are very anxious. The mother also wants to know if she can stay in the room during the procedure.

Scenario:

A seventeen-year-old female patient is brought in by ambulance after being in a car accident. She is trauma level II and is conscious but extremely anxious. Neither parent is present, but you are told that the father is on his way. The patient was brought in with a friend, who is in critical condition. The patient is asking about the status of her friend and is complaining of pain “everywhere”.

Scenario:

A sixteen-year-old patient with Sickle-Cell Disease is in the outpatient unit complaining of abdominal pain at a scale of 7 out of 10. The nursing staff isn’t sure if the patient is really in pain or drug seeking. The patient has been very quiet, withdrawn, and anxious during this visit.

Scenario:

An eight-year-old male patient has been on the inpatient unit for two weeks status-post open-heart surgery. The parents are complaining that patient is bored and restless, and wonder what the patient is allowed to do. The family is on a unit without a playroom or child life specialist.