

Minimizing pediatric healthcare-induced anxiety and trauma

Julie L Lerwick

Julie L Lerwick, Northwest Psychological Center, Milwaukie, OR 97267, United States

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Correspondence to: Julie L Lerwick, PhD, LPC, NCC, RPT, Northwest Psychological Center, 6902 SE Lake Road, Suite 202, Milwaukie, OR 97267, United States. julielerwick@yahoo.com
Telephone: +1-503-6522810
Fax: +1-503-6528553

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Abstract

Frequently, episodes of care such as preventive clinic visits, acute care, medical procedures, and hospitalization can be emotionally threatening and psychologically traumatizing for pediatric patients. Children are often subject to psychological trauma, demonstrated by anxiety, aggression, anger, and similar expressions of emotion, because they lack control of

their environment. This sense of helplessness, coupled with fear and pain can cause children to feel powerless in healthcare settings. These emotional responses can delay important medical treatment, take more time to complete and can reduce patient satisfaction. Healthcare professionals are uniquely positioned to prevent healthcare-induced trauma and reduce healthcare-induced anxiety. This article introduces a new way to choice, agenda, resilience and emotion (CARE) for pediatric patients in the healthcare setting by implementing the four following treatment principles called the care process: (1) Choices: Offer power in a powerless environment; (2) Agenda: Let patients and families know what to expect and what is expected of them; (3) Resilience: Highlight strengths and reframe negatives; and (4) Emotional support: Recognize and normalize common fears and responses. Engaging the CARE principles helps patients and families feel empowered and mitigates, reduces, and may even ameliorate risk of anxiety and trauma responses.

Key words: Inpatient; Ambulatory; Pediatric patient compliance; Patient experience; Pediatrics; Anxiety; Healthcare-induced trauma

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Core tip: In an effort to reduce healthcare-induced distress leading to anxiety, trauma, and trauma responses in pediatric patients, this author has developed four principles in the choice, agenda, resilience and emotion (CARE) process to deliver emotionally-safe treatment to children: (1) Choices: Provide power in a powerless environment; (2) Agenda: Letting the patient and family know what to expect and what is expected of them; (3) Resilience: Start with strengths and reframe negatives; and (4) Emotions: Recognize and normalize common fears and responses. Through the process of implementing CARE, a child's healthcare-induced distress can be minimized.

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INTRODUCTION

Pediatric patients visit primary healthcare providers in ambulatory settings an average 31 times from birth to age 21 for general wellness visits^[1]. Additionally, in 2012 alone, 5.9 million United States children were hospitalized^[2], adding to the average number of medical interactions. Annually, millions of children further encounter ancillary medical caregivers, including medical assistants, nursing staff, laboratory and radiology technologists, occupational, speech, and physical and mental health therapists. These children can also be passive participants in sometimes-stressful conversations with administrative professionals regarding finances and insurance coverage. Most concerning, up to 20% of the population reports feeling "white coat syndrome" when coming into contact with medical doctors^[3].

Children commonly report feeling afraid or anxious as they anticipate and engage in healthcare settings with medical professionals^[4-6]. Due to their developmental level and limited cognitive development, children use behavior, instead of words, to communicate the emotions they feel. Common behavioral demonstrations of fear, anxiety, and helplessness include aggression, withdrawal, lack of cooperation, and regression^[7]. Of note, psychological and behavioral distress has been present regardless of the incidence of invasive or painful healthcare^[7]. This distress impedes provider execution of medical protocols, thus requiring more time in the treatment process.

Being that children are as emotive as they are cognitive, during episodes of care, interactions with medical providers can enhance anxiety or trauma, or at worst, cause trauma^[8-12]. It is important for medical providers to learn to mitigate psychological trauma in pediatric care. Left untreated, childhood trauma caused by healthcare-induced anxiety can cause significant mental health issues in a child's life^[4,5,13-15]. Trauma predisposes children to various forms of psychopathology including anxiety^[15], major depression^[13], and behavior problems^[14], which can increase cost of care in the future.

Current strategies for reducing anxiety and stress in children include distraction^[16], creating an inviting physical environment^[17], child and parental preparation^[16,18] and positive staff interactions^[16]. Although these aspects of pediatric patient care are important, they are limited in scope to meet the emotional needs

of a stressed child. In an effort to reduce healthcare-induced distress leading to anxiety, trauma, and trauma responses in children, this author developed four principles in the choice, agenda, resilience and emotion (CARE) process: (1) Choices: Provide power in a powerless environment; (2) Agenda: Letting the patient and family know what to expect and what is expected of them; (3) Resilience: Start with strengths and reframe negatives; and (4) Emotions: Recognize and normalize common fears and responses. Through the process of implementing CARE, a child's healthcare-induced distress can be minimized. This article will introduce a new way to CARE for the psychosocial needs of pediatric patients across all healthcare settings.

ANXIETY AND TRAUMA IN THE HEALTHCARE SETTING

Throughout a child's life, approximately 15% to 20% will encounter some form of relatively severe trauma^[19,20]. Developmentally speaking, even common events, including medical care^[4,5], can lead to heightened anxiety, and trigger trauma responses in children^[20-24]. Because children are bewildered in an unknown medical environment, as caregivers are taking over control of their bodies, they feel a loss of autonomy and control. Further, unmet needs, sense of danger, and lack of competence amplify anxiety^[25]. Children fear mutilation, and suffer from guilt, pain, rage, and similar manifestations specific to their developmental level^[4,5,8-12]. Anxiety-provoking experiences such as hospitalizations and medical care can effect a child's physical growth, personality, or emotional development^[20-24]. In some cases anxiety-based trauma may prejudice the development of behavioral, emotional, or cognitive disorders^[26,27].

Findings from longitudinal studies have delineated three broad sets of factors that predict differential risk in developing psychopathologies^[24]. The factors noted include: (1) children who exhibit high degrees of psychopathology before traumatic exposure; (2) level of exposure and frequency of exposure to trauma^[28]; and (3) social factors emerge as the strongest predictors of risk among traumatized children^[15,22,23]. Many children who have been exposed to acute trauma have shown relatively strong outcomes with socially-supportive environments^[29]. Additional risk factors include children with limited intellectual ability, female, younger age, instability in family life, and intense exposure to frightening events; children with these risk factors may recover at a slower pace and may need professional intervention^[15]. Children, as well as their parents and guardians, are psychologically unprepared for anxiety and the resulting emotional strain from a medical crisis.

FACES OF HEALTHCARE-INDUCED TRAUMA

Most people can relate to an experience in their lives during which a healthcare visit or medical procedure was upsetting and anxiety-provoking. Some may even describe their experience as traumatizing. Distressing scenarios might include vaccinations as a child, a medical diagnosis with a poor prognosis, or perhaps a diagnosis requiring surgery. This author recalls an early childhood experience of undergoing anesthesia for a peritonsillar abscess. Her fear of and fight against needles prohibited a pre-op IV start and a mask was placed over her nose and mouth. She gasped for air, all the while pleading to the anesthesiologist she could not breathe. Her fear was dismissed and minimized when the anesthesiologist responded by telling her "she was fine". This author remembers feeling like she was in danger because she felt as if she could not breathe. She had no pre-surgical preparation for the sudden fear and panic. Had she been told in advance what it might feel like to have a mask placed over her face, or to know it is a common feeling to gasp for air as part of the anesthesia process, her fears and therefore healthcare-induced trauma, would have been prevented. Sadly, this is not an uncommon experience for children in healthcare settings.

Another example is Amelia, an 18-mo old, female recovering from acute stress disorder due to healthcare-induced trauma resulting from repeated episodes of care in the Emergency Department (ED) at a highly regarded Children's Hospital for flu-like symptoms causing severe dehydration leading to listlessness. Each time she was taken to the ED by her high-functioning parents, they were instructed to hold her down for catheterization in order to obtain a urine sample to rule out bacterial infection. Additionally, she was held down for intravenous (IV) fluids tube insertion, which was difficult to insert and took several attempts to place. This process of catheterization and IV attempts repeated itself several times as she was evaluated by the physician in the ED, released, evaluated again in the ED, admitted into the hospital, discharged, and then re-admitted. This little girl was scared, confused, and seemingly terrorized by strangers (medical providers) and those she trusted (parents). Each of these ED admissions took hours to complete as the child lay helpless in defense to the medical professionals that needed to triage and treat her illness. The parents looked on with bewilderment, doing their best to keep calm despite their daughter's condition.

Upon hearing the parent's distress over the psychological state of their child throughout the course of hospitalization and discharge, a Child Life Specialist provided the patient's mother with this author's name and recommended that she follow-up for her daughter's post-hospitalization mental health care.

At first they saw no reason to call, then after a few weeks, the author saw the child at an office visit and evaluated her. Behavioral issues, intense separation anxiety, refusal to allow diaper changes without being held down, and severe sleeping issues were noted on the intake form as new or regressive behaviors. The author went to work immediately with bi-weekly play therapy appointments, giving the toddler control and power in the playroom by inviting her to direct her own play (non-directive play therapy^[30]). The goal was to invite some semblance of power in her life after the medical care experience ripped away what she knew of safety and security. After 16-sessions over 8-wk, the child's symptom's completely resolved and she was back to her usual self. To be clear, it took one month before mental health intervention for the trauma to get worse, and 2 mo of psychological treatment to resolve.

Medical providers must be aware of the impact of these potential scenarios and act quickly and proficiently to ease the fear, anxiety and trauma for pediatric patients in their care. The impact of fear and anxiety relating to medical care can persist long after the encounter and will influence coping in the moment and management of future painful or anxiety provoking medical experiences^[31].

COPING AND THE PEDIATRIC PATIENT

Research indicates there is a clear correlation between healthcare, hospitalization and coping with anxiety for children^[4,5,32-38]. Children's cognitive development prohibits their capacity to define the parameters of an event, specific to the duration or intensity^[25,39]. They are often inaccurate in their assessment of when an event actually occurred^[39]. Because of this, children can be triggered into a trauma response by feeling that they are experiencing more frequent or severe medical care than actually occurred.

Trauma causes increased levels of catecholamines (epinephrine and norepinephrine), which results in increased sympathetic nervous system activity^[40]. It also decreases corticosteroids, and serotonin, which results in the inability to moderate the catecholamine-triggered fight or flight responses^[40]. In children, these physiological responses commonly result in dissociative patterns such as a freeze or surrender response. Children may surrender in helplessness, hide from the frightening experience, cling to an attachment figure or object, be unable to communicate their needs clearly, or be overcome with disabling emotion^[40].

Coping in children and adults universally includes three facets, none of which are one-dimensional: (1) active vs avoidant; (2) internal vs external; and (3) emotionally-focused vs problem-focused^[36]. Researchers^[41] found that avoidant coping is used more during the acute phase of healthcare or hospitalization and active coping was used more often in the recovery phase. By focusing children's attention

on a specific aspect of medical care, they feel better equipped to recover faster than children who are avoidant in their experience. This focus introduces internal locus of control.

An internal locus of control refers to the belief that events or outcomes come as a result of one's own choices and actions; an external locus of control is described as less influenced by one's own choices and actions and more predisposed by outside influences^[42]. Choosing an internal locus of control correlates positively with active coping approaches, such as seeking information about the illness or procedure and alertness to stressful stimuli^[43,44]. In young children aged 0-2, the internal locus of control is associated with attachment of the primary caregiver and the child will rely upon them for age-appropriate information and for physical safety. An external locus of control has been shown to be interrelated with avoidant coping strategies, such as avoiding information about the event, denying worries, and distancing one's self from stressful stimuli^[43-45]. This response is commonly displayed in children with a disruptive or avoidant attachment pattern with their primary caregiver.

As coping behaviors differ from child to child, the role of a safe and empowering medical professional is all the more important. If a child does not possess a strong attachment to their primary caregiver, such as a parent, medical personnel may need to step in and offer the child additional assistance in identifying their internal locus of control. Choices foster personal power to children and can encourage a strong internal locus of control. Those that deliver healthcare should have awareness and training in how to treat children appropriately based on style of coping in hopes of decreasing levels of perceived trauma and healthcare-induced anxiety.

A NEW WAY TO CARE

When asked, most patients and their family members communicate the desire for respect, communication, appreciation, and confidence in the skill of the caregiver. In an effort to meet patient needs and increase patient satisfaction with hospital staff interaction, Quint Studer of Studer Group^[46] developed 5 fundamentals of service to increase patient satisfaction: (1) Acknowledge: Acknowledge the patient by name. Make eye contact. Ask: "Is there anything I can do for you?"; (2) Introduce: Introduce yourself, your skill set, your professional certification, and experience; (3) Duration: Give an accurate time expectation for tests, physician arrival, and tray delivery; (4) Explanation: Explain step by step what will happen, answer questions, and leave a phone number where you can be reached; and (5) Thank: Thank the patient for choosing your hospital, and for their communication and cooperation. Thank the family for assistance and being there to support the

patient.

Although these 5 steps may offer respect, communication, appreciation and confidence in the skill of the caregiver, it fails to address a very important need in patients - emotional containment and support. Current research and literature is limited regarding ways to reduce healthcare-induced distress. Recognizing the unique emotional and relational needs of pediatric patients, this author developed a new way for medical providers to CARE while interacting with pediatric patients: Choices, agenda, resilience and emotional support.

CARE: CHOICES

When children are brought into healthcare settings, they often feel scared, are often in pain, and are expected to adjust to new settings and submit to the bewildering array of questions, exams, tests, and treatments with little to no preparation. Their largest fear is of the unknown^[47,48]. Therefore, it is crucial medical professionals take time to explain to the child the reason for the treatment in a developmentally-appropriate manner. Children need as much control and choice as possible^[49,50]. If this informative step is not accomplished, anxiety increases. When anxiety increases, feelings of helplessness result. Helplessness results in lack of cooperation^[48]. Furthermore, trust is broken once the child feels anxiety-stricken. Patients and their family members are empowered by choice.

The power-differential is clear and felt between patient and provider. By simply providing developmentally-appropriate choices, anxiety can be reduced and emotional containment can be provided to a patient. Power through choice-giving in a medical setting can seem laborious to medical providers at first, but rather simple to implement once there is a common understanding of the goal. The goal is to empower patients and their families in an effort to provide psychological-control of the environment. Surely there are circumstances requiring urgent or emergent care, but overall, a few extra seconds of choice-giving in the moment can go far to reduce perceived or actual psychological trauma immediately and in the long-term and improve patient cooperation^[4]. Further, it sets up expectations for future episodes of care.

Examples of medical professionals taking power from patients include: Requiring the patient take off their clothes and get up on the exam table; speaking to the parent only, about the child, during the visit; choosing the pace and flow of the exam; holding children down for injections, venipuncture, intravenous fluids starts, or examination; and, prohibiting the patient to explore the room, instruments being used, or to ask questions. Patients without power are immediately vulnerable to increased anxiety and can even be triggered into a trauma response. Healthcare providers must be cognizant of their power to

potentially cause the medical care process to become a traumatic event for patients, regardless of their age or developmental stage.

The goal of healthcare providers should be to empower patients in their medical care experiences. Providing an empowering environment significantly decreases a patient's risk for healthcare-induced trauma and other undesirable psychological effects of treatment. Examples of medical professionals offering power to a pediatric patient are as follows: Asking the patient where they would like the medical provider to start the exam (e.g., "Would you like me to listen to your heart first or look in your ears first?"); Asking the patient which ear they would like to be examined first (e.g., "Would you like me to look into your left ear or right ear first?"); Letting the patient decide which arm is used to measure blood pressure (e.g., "You get to decide. Should I squeeze your left arm or your right arm to measure how fast your blood is pumping through your body?"); Providing small choices about seemingly insignificant matters, such as having socks on or off (e.g., "You can leave your socks on or off for today's exam. Which do you choose?"); and finally, instilling power by normalizing that a patient may have questions they wish to be answered (e.g., "What questions do you have today?") Each of these word-choice examples provides context of how a small shift in language can foster empowerment to a patient in a medical provider's care.

Genital exams can be a potentially trauma-provoking experience for a child -especially in children with a prior sexual trauma. One in five girls and one in twenty boys is a victim of child sexual abuse^[51]. Communicating openly and offering choices to the patient will go far to create an environment of safety and empowerment. Speaking directly to the patient, providing the reason for the genital exam, what is being assessed, and how it may help will let the patient know exactly what to expect. If there are several family members present, ask patients whom they would like in the room. Wait for permission to begin the examination. If necessary, ask for permission to touch the child's genitals, explaining that it's safe because a parent is present. For example during a well-child exam say, "Today I need to check your private area to make sure it is growing the way it should. I will just take a quick look and I might need to feel different places on it to make sure everything is okay. Who would you like to be in the room during the exam? It's okay to ask your brother or dad to leave. You get to decide... With your mom right here, can I begin?"

The result is empowerment and emotional safety for a child, in a potentially traumatizing situation. The physician can set up an environment of trust and safety that will serve as a foundation to medical care for the rest of the patient's life. If a physician is forceful, uses parents to hold a child down, dismisses

the child's fear or fight response-verbally or physically-without validating the emotions, assumes permission to examine the patient's genitals, or fails to give the child power of who was present in the room for the examination, there may be a different outcome. Choices communicate power and care.

CARE: AGENDA

Fear and anxiety can increase when patients are unsure or unprepared for what is going to happen in an episode of care. Trauma is a normal response to fear, especially in pediatric patients. In an effort to mitigate trauma responses, providers can provide their agenda to patients and their families. The agenda includes what to expect during the healthcare visit and what is expected of them. Introducing detail makes the unpredictable, predictable - and fear dissipates. The benefits are clear. When patients know what to expect and what is expected of them, they feel more in control of the situation and are therefore less fearful, anxious, and less likely to have trauma responses.

In outpatient settings, a physician may choose to set the agenda in the following manner for a well-child exam: "In our time together today we have 20 min...; I'm going to talk to you (child) and then talk to your dad...; Then I'm going to listen to your heart, and take a look inside your ears, nose and mouth...; After I take a look at everything, we will discuss other choices that need to be made today, such as vaccines...; And then, you will get to choose a sticker on the way out!"

Hospital providers have additional stressors, such as urgent and emergent medical conditions to treat and manage. With these considerations in mind, the following recommendations should help communication with children and their families in inpatient settings: "I'm going to track how you are breathing and how fast your blood is pumping through your body-the process is called getting vital signs"; "Then I'm going to ask you and your mom a lot of questions to get to know you"; "Things move quickly around here. Then suddenly they stop. It could feel frustrating to wait"; "You may have to wait a while for the doctor to come in"; "I will ask you to change your clothes"; "I will hook you up to a machine that tracks your breathing-it makes beeping sounds, that's normal"; "If the doctor wants to see what's going on inside of your body, I might take a sample of your blood and it pinches a bit". "We might go to a special room that doesn't have many lights and take pictures of your body. It's called an X-ray and it's important to stay really still for the pictures".

Setting the agenda and making expectations clear to the patient and their families is a vital part of preventing healthcare-induced anxiety and trauma responses. Each of the above statements of explanation and expectation can act as a preventive measure to create emotional and psychological safety for pediatric patients and their families. By adding a

few moments of explanation, healthcare providers can aid in establishing rapport and trust that will last throughout a child's lifetime of engaging with medical professionals. Further, a few moments of explanation on the front end will save time in the long run.

CARE: RESILIENCE

Identifying a patient's resilience, or strengths, is a powerful marker of establishing a trust-filled relationship. Beginning a healthcare visit with a patient's strengths and identifying how a patient and their family have managed other struggles in their life immediately fosters rapport and trust. For example: "What was helpful when you sought out help for this previously?" or "What else should I know about you in order to best understand your situation and help you today?" "That seems really important to you - tell me more about it".

During an evaluation process, by starting with a patient's strengths, a medical professional also communicates to the patient that even if there are concerns, the provider wants to hear about what is good. This may be the only time in the day a child hears about their positive qualities. Further, by asking a parent to identify their child's strengths with the child present, it aids to strengthen the parent-child relationship. A note of caution, if a child is present in an office visit, which they almost always are, providers should limit negative talk about the child. For example, night enuresis is a shame-filled topic for many school-aged children and can be exacerbated by critical evaluation with a medical provider. Further, behavioral issues, including attention deficit hyperactivity disorder symptoms, can equally be shame-inducing topics for children.

A practical way of addressing the issue of concerns and problems is instead of asking, "What are your concerns and what problems do you have?" ask, "What would you like to be different?" There is a therapeutic and psychological difference in the way this question sounds to and is internalized by a child. Examples to empower patients by identifying strengths are as follows: "'Tell me what's going really well in your life right now...!' 'What are you the most proud of in your child?' 'What is the best thing in your life?' 'What are you really, really good at?' 'What is the best thing about being (child's) parent?'"

Each of these examples are a quick re-frame of common and necessary questions around problems and concerns that healthcare providers ask children and their caregivers. By starting with strengths and re-framing negative talk around the child a healthcare provider continues to make actionable principles to decrease anxiety and trauma responses in the healthcare setting, regardless of what brings the child in for medical treatment. Focusing on resilience and strengths communicates great respect to a patient and family members.

CARE: EMOTIONS

It is common and expected for pediatric patients and their families to experience myriad emotions with each healthcare encounter. Medical professionals serve their pediatric patients well by making a concerted effort to normalize common emotions, including fears. By creating freedom for patients to experience and convey emotions, the healthcare provider communicates the patient's emotions are valuable, worth listening to, and creates opportunity for deeper connection in the patient-provider relationship. When patients feel understood and validated, they feel safe - mental health professionals call this relational process attunement. Patients want to know everyone feels afraid sometimes. Reflect emotions when they are observed clearly. Express wonder about emotions that are unclear.

Practically speaking, the following, said in a soft and comforting tone of voice, depicts reflecting and normalizing emotions in the healthcare setting: "'Sometimes I feel nervous when I meet new people too'; 'It's okay to feel scared or nervous'; 'It looks like you feel worried'; 'I wonder if you are feeling afraid or unsure'; 'There's a lot of sounds here - that can feel overwhelming'; 'You look suspicious - it's okay to ask me any questions you may have'"

The effort to emotionally attune with patients bolsters their trust in their medical provider, creates safety in the unknown environment, and decreases acute anxiety and healthcare-induced trauma. This is not always a natural skill and it takes practice to reflect emotion accurately and curiously; however, the benefits are well worth the effort as it aids in the patient-provider relationship for the long-term, including increase in patient-experience, which is important to all medical providers and health systems.

CULTURAL CONSIDERATIONS OF CARE

As medical providers serve a variety of people from numerous cultures and ethnicities, it is important to address clinical considerations impacting the CARE protocol as it pertains to diversity awareness. Begin by identifying the cultural background of the patient. From there, what is known about the culture, ethnicity, and preferences of the patient? With all multicultural issues, medical providers must begin medical relationships with a respectful curiosity and an intentional invitation to understand differences and similarities. Of note, some cultures desire a lot of interaction with their providers, others do not. Among other things, some patients with differing race or cultural experiences from the provider may prefer that the provider assume a power position in regard to decision-making and avoid collaboration about process and course of treatment. Ask patients what needs to be known about their values surrounding healthcare.

Healthcare-induced anxiety and trauma can present differently in varying cultures. Some cultures celebrate emotional awareness and attunement; and equally, some cultures shun emotional awareness and attunement. It is important to recognize these values in one's patient population and to be cautious in implementing protocols and interventions that could cause more emotional distress to a patient. When in doubt, ask the patient. Patients and their family members are often more than happy to provide context and information surrounding their values and definition of excellent medical care.

CONCLUSION

Pediatric patients require an extra level of care in their healthcare process. They require added patience, flexibility, and containment for their ever-changing emotions. Their primary need is to know they are safe and to be given age-appropriate and developmentally-appropriate information in order to combat heightened anxiety levels and trauma responses, which can hinder the delivery of quality healthcare and create harmful long-term psychological effects. Healthcare providers have a valuable opportunity to control the negative outcome of pediatric stress in the medical setting, no matter their function in a child's episode of care. By utilizing the four principles in the CARE protocol: (1) Choices: Provide power in a powerless environment; (2) Agenda: Letting the patient and family know what to expect and what is expected of them; (3) Resilience: Start with strengths and reframe negatives; and (4) Emotions: Recognize and normalize common fears and responses providing emotional support, children will feel emotionally safe and protected in their medical treatment.

Understanding the risk of anxiety and trauma in pediatric patients with regard to receiving medical care is imperative to effective outcomes. Although universal application can be made to patients throughout the lifespan, the mission of CARE is to provide a voice to the world's most vulnerable, powerless, and disregarded population in medical care-children. The CARE protocol was developed to foster trust in medical care providers and to mitigate the risk of anxiety and trauma in pediatric patients while receiving necessary and pertinent medical care. Most patients remember how they feel about an episode of care, not what was said or done. CARE enough to allow pediatric patients to feel empowered and safe in their healthcare experience.

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