EHSSENTIALS 2018

Environmental, Health & Safety Symposium for Healthcare

October 25, 2018
Stanford University Medical Center
Palo Alto, CA

PRESENTED BY

bsi.

KAISER PERMANENTE®

Stanford HEALTH CARE
STANFORD MEDICINE

Management of Challenging Parents and Patients: Extra Grace Required

Julie Collier, Ph.D. &
Elizabeth Hinchman, RN, MSN

EHSSENTIALS 2018
Environmental, Health & Safety Symposium for Healthcare

Objectives

- Overview of our approach to managing challenging patient and parent behavior in our organization
- Identification of management strategies

A Philosophical Question: Difficult or Challenging?

Definition of difficult

- 1: hard to do, make, or carry out: arduous a *difficult* climb
- 2a : hard to deal with, manage, or overcome a *difficult* child
  having a *difficult* time coping with her death
- b : hard to understand : puzzling difficult reading found calculus too difficult

Definition of challenging

- 1: arousing competitive interest, thought, or action a challenging course of study
  a *challenging* job
- 2: invitingly provocative : fascinating a challenging personality
  challenging questions

Extra Grace Required

- "Extra Grace" families
  - High information seeking
  - High anxiety (and/or mental illness)
  - High expectations
  - Low trust
- Provider experience of the "Extra Grace" family
  - Discussions with families can take hours
  - Demanding/difficult to please
  - Complaints made to Office of Patient Experience
  - High anxiety and lack of trust contributes to dysregulated behavior that can be experienced as hostile, aggressive, or "abusive"
- Provider reaction to the "Extra Grace" family
  - Anger
  - Avoidance
  - Blame
  - Compassion fatigue

Extra Grace Required

- So what does “extra grace” mean?
- Remembering that:
  - This family is going through something terrible and terrifying
  - Some families take longer to adapt, and they need our help to learn new coping skills
  - Disruptive behavior usually stems from fear and lack of trust
  - Trust takes time to build, and we need to assume responsibility for trust-building
  - It isn’t about you/it isn’t personal
  - Culture matters
  - Labels matter
  - No difficult families, just “difficult-for-me” families

Extra Grace Required

"Extra Grace" does not mean:

- That we have to put up with rude or disrespectful behavior
- That we can't set limits on the amount of time we spend meeting with parents
- That we can't say "no"
- That we can't have consequences for inappropriate behavior
- That we can't limit the time a parent spends at the bedside

*All of this is easy to say, and often very difficult to do. Busy and beleaguered providers often to not have the time or emotional bandwidth to develop a plan for containing disruptive parental behavior.

The Story of Lisa

- We learn from our most challenging families
  - 12 y.o., severe developmental delay and CP; underlying progressive neurologic disorder
  - Multiple hospitalizations; 100+ days in a year
  - Devoted parents, but high anxiety/low trust; behavior often experienced as hostile and aggressive
  - Brother with autism spectrum disorder and severe behavior = high stress in family
  - Hospitalizations often longer than necessary because parents refused discharge, saying she wasn't "ready" to go home; became clear that hospital used for respite
  - Multiple providers in tears; nurses felt "unsafe"
  - Engrained pattern of provider avoidance, which escalated parent behavior

Strengthening Alliances with Families Team (SAFTeam)

- Concept developed by Colorado Children's Hospital
- Adopted concept, but shaped by culture and resources of our organization

Strengthening Alliances with Families Team (SAFTeam)

- The purpose of this program is to provide non-emergent support for clinical staff working with patients or families who are exhibiting a pattern of disruptive behavior that is obstructive to clinical care, including profanity, verbal threats, physical threats, or other behavior that contributes to staff members feeling strained, unsafe, or threatened
- Not for imminent threat; Security called for immediate concerns
- Social Work consult needs to have been initiated first
- Range of possible responses to consult request:
  - Phone consultation; guidance provided
  - Meeting with care providers; guidance provided
  - Meeting with family to discuss behavioral concerns and expectations
  - Development of Collaborative Partnership Agreement
  - Ongoing support provided to bedside nurses

Strengthening Alliances with Families Team (SAFTeam)

- SAFTeam Key Tenets:
  - Parents are doing the best that they can
  - It is all about trust
  - It is not personal
  - Splitting is on us
  - Consistency is key
  - Proactive is better than reactive
  - Check your implicit bias

Compassionate Containment

Lisa's family:

- Process of gradually increasing boundaries
  - Communication of behavioral expectations
  - Clearly articulated consequences
  - Initial failure to improve behavior lead to increasing consequences, resulting in:
    - Written expectations for both parents and limited visiting hours for father
    - Delivery of limits was done by top Executives; highly emotional for parents

Compassionate Containment

Lisa's family: Pain leading to gain…

- Anger at the hospital led to a significant decrease in admissions
- Because they were invested in avoiding the hospital, they became more open to exploring appropriate respite care alternatives, and learned they could trust those resources; number/length of admissions decreased
- Subsequent admissions went more smoothly because father decided to not be present at all, and remain home with autism spectrum son
- Parents would tend to escalate each other when both present; mother generally calmer, and more open to support from team when on her own; developed more trust

SAFTeam Evolution: The Story of Joey

- 12-year-old boy, admitted for treatment of possible PANS (pediatric acquired neuropsychiatric syndrome)
- Autism spectrum disorder at baseline, with onset of increasingly maladaptive and aggressive behavior (e.g., refused to wear clothes or toilet appropriately)
- High conflict between parents and medical team and disagreement about discharge plan
- Hospitalized for 8 months
- Multiple staff injuries

SAFTeam Expansion of Scope

- Not just for parent behavior
  - Driven by unique skill set of SAFTeam psych nurse and the need to respond to staff distress and injuries secondary to patient aggression
  - Successful reduction of injuries caring for Joey lead to recognition that we could improve how we care for patients who have potential for aggressive behavior

Management of Patient Aggressive Behavior

SAFTeam Key Tenets:

- Behavior is rarely random
- Anticipate and prevent
- We need to accommodate our behavior (not the other way around)

Post-Anesthesia Procedure Care Unit Aggressive Behavior Prevention Program

- Several staff injuries led to development of a screening protocol for patients who will undergo surgical procedures
- Developed by Anesthesiologist, SAFTeam, Child Life
- The busy, time-driven environment of the PACU can be overwhelming for patients with developmental disabilities or autism spectrum disorder
- Questions added to pre-procedure phone screening already in place
- ”Flagged” patients receive more in-depth assessment by SAFTeam psych nurse or Child Life Specialist
- Written plan is developed that includes details such as:
  - Triggers
  - Comfort items
  - Security involvement
  - Environmental considerations and adjustments

SAFTeam: Best Practices

EHSSENTIALS 2018
Environmental, Health & Safety Symposium for Healthcare

Tools of the Trade

- Presence and Reassurance
- Collaborative Partnership Agreements
- Visitation Management Plans
- Behavior Plans
- SAFTy Cards

SAFTeam – Jose's Family

8-year-old boy with developmental delay and heart failure; on a ventricular assist device and awaiting cardiac transplant

- Primary cardiac team requested SAFTeam support due to break down in communication with family
- Parents intermittently refused care, e.g., **PT/OT, diaper changes**
- Parents identified as difficult and disruptive to care, leading to concerns about whether Jose should remain listed for transplant
- Parents' primary language was Spanish; very limited English

SAFTeam – Jose's Family

Assessment:

- Meet with team and parents; together and separately
  - Problem behaviors identified from team's perspective
  - Problem behaviors identified from parents' perspective (several valid care concerns identified)
- Parents' behavior driven by lack of trust and confidence, and exacerbated by language barrier
  - Open to SAFTeam support

SAFTeam – Jose's Family

Interventions:

- Collaborative Partnership Agreement to set expectations and eliminate miscommunication
- Increased use of interpreters and interpretation apps, even for minor issues
- Worked with nursing management to increase consistency of staffing, particularly with nursing assistants/sitters
- SAFTy Card developed to facilitate consistent nursing approach
- Encouraged parents to contact SAFTeam if they felt they needed help with communicating their concerns effectively
- Real-time feedback to parents when starting to deviate from expectations allowed prompt course correction

SAFTy Card

A multidisciplinary treatment team meeting involving the SAFTeam was held on 04/24/18 to address communication concerns and approaches to care by both family and staff. Please see highlighted points below.

If communication concerns arise

1. Monday – Friday 8-3pm please contact E. Hinchman (VOALTE) SAfteam
2. Interpreting services for real time translation or use of IPAD for tele-translation

PCU 200 CARE CONSIDERATIONS (Management and Medical team approved 05/04/18)

1. **Daily rounds:** Interpreter present when possible as well as at 130pm check in time
2. **Patient remains on 1:1 sitter**
3. **Care considerations:** Due to language barrier family will greatly benefit from use of real time interpreter or use of IPAD for Spanish interpreter. Family appreciates

****IF THERE ARE ANY POINTS OF CONFUSION TO CARE PLEASE DISCUSS OUTSIDE OF ROOM AND NOT WITH FAMILY.**
Due to language barrier these staff to staff discussions have been mis-interpreted as something has been done "wrong". Please be sure to clarify whenever possible that may be more than one way to do intervention and that doesn't mean alternative way is "wrong" or "better".

Daily care considerations

Transparency: Family benefits greatly from full transparency in regards to care

Please have interpreter present when at all possible in communicating care concerns

TLC – **Family responds to warm and friendly bedside manner**. Due to previous care experiences in which the patient did receive the wrong care, family does have heightened anxiety and concerns. Please remain mindful of this when family is asking questions or when they are leaving the room for a break as these are high times of anxiety for them.

Collaborative Partnership agreement (please see RSN binder) also on back of this sheet for review

SAFTeam – Jose's Family

Outcome:

- Parents developed greater trust with team
- Behaviors that disrupted care decreased
- Team perception of family shifted – from recalcitrant to workable (reputation rehabilitation)

SAFTeam – Aunt Sally

21-year-old male with cerebral palsy, significant developmental delay, admitted with severe pressure ulcer; primary guardian was maternal aunt

- Aunt's behavior disruptive to care
- Yelled at staff
- Placed hands on staff in an attempt to guide care
- Weapon in possession by Aunt

SAFTeam – Aunt Sally

Assessment:

- Met with team
- Met with Aunt
- Concerns for underlying cognitive and mental health issues that limited her ability to partner with staff and modify her behavior

SAFTeam – Aunt Sally

Interventions:

- SAFTy Card
- Ultimate restriction to hospital

Management of Challenging Parents and Patients

- We have standard patient-care protocols and policies that are designed to ensure that we provide the safest and highest quality care. It is sometimes the case that our policies dictate that care be provided in a manner that is different from what parents do at home. We will work with you to identify areas where modification of our usual practice is acceptable.

- Allow routine care or procedures, such as physical exams, nursing assessments, radiologic procedures (x-rays, CTs, etc.), medication administration, blood transfusions, and implementation of hydration orders, to proceed promptly when initiated by the care team. This includes routine daily assessments by nursing and care team which are deemed clinically necessary. Protracted discussions or negotiations can lead to delays that can undermine the safety of the care provided.

- Understand that there will be times when we must change the treatment plan based on new test results or an unexpected change in your child's condition.

- We understand some care will differ from what has happened at home. If staff are unable to provide care we will first do our best to ensure understanding or your concern, although we may have to ask you to step out of the room in order to complete the task.
    - Please contact SAFTeam (business hours) or ANS (after hours) prn.

Task	Time	If NOT Completed why?
Q2h Repositioning	Every 2 hours	
Suctioning	As needed	
Respiratory treatments	Vest, 3 times daily 8am, 2pm, 8pm	
Wound Care	Daily. Please see sheet created by NP in room.	

SAFTeam – Aunt Sally

Outcome:

- Ultimately Aunt was removed as guardian of patient and restricted from hospital

SAFTeam – Simon's Family

18-month-old boy with acute lymphoblastic leukemia, undergoing stem cell transplant

- Only child of young parents, limited financial resources, poor social support
- Father with concerning behavior
- Parents frequently argued – verbal and physical

SAFTeam – Simon's Family

Assessment:

- Met with team
- Met with parents

SAFTeam – Simon's Family

Intervention:

- Collaborative Partnership Agreement
- Visitation Plan eventually

SAFTeam – Simon's Family

Outcome:

- Father's disruptive behavior diminished
- Parents remained frustrated with visitation restriction, but complied; no further altercations
- Overall, relationship between parents and team improved

SAFTeam-PACU: Timothy

17-year-old male w/autism spectrum disorder, seizures, history of self-injurious behavior, complex bilateral retinal detachment, s/p multiple past ophthalmologic procedures, ongoing eye pain

SAFTeam-PACU: Timothy

Assessment:

- Pre-Assessment SAFTeam work up
- Concerns identified:
  - Nonverbal
  - Wears protective gear to protect self from his self-injurious behaviors
  - Triggers
  - Past experience in PACU including ER PRN medications and restraints

SAFTeam-PACU: Timothy

Interventions:

- SAFTy Card
- SAFTeam psych nurse present in PACU on day of procedure, and followed patient after admission

SAFTeam-PACU: Timothy

Interventions:

- PRN pre-medication upon arrival
- Transitions were minimized
- Environmental changes
- Unexpected 24h PICU stay

SAFTeam-PACU: Timothy

Outcome:

- Patient tolerated the hospital experience without escalation of aggression
- No staff injuries

Questions?

EHSSENTIALS 2018
Environmental, Health & Safety Symposium for Healthcare