Families as Partners in a Co-Designed Family Stress Screening/Response System

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Beth Silber, MPA, Family Consultant, Sala Institute for Child and Family Centered Care

March 21, 2017
Disclosures

• None of the speakers have anything to disclose.
Who We Are

- **Ron-Li Liaw, MD**, Director, Center for Child and Family Resilience, Sala Institute for Child and Family Centered Care & Child Psychiatry Consultation Liaison Service

- **Beth Silber, MPA**, Family Consultant, Sala Institute for Child and Family Centered Care & Co-Chair, Family Advisory Council
Learning Objectives

1) Develop strategies for integrating families as partners in designing, implementing, and evaluating quality improvement initiatives

2) Understand key elements and challenges in creating an interdisciplinary, effective, sustainable family stress screening/response system
Transforming Care at Hassenfeld Children’s Hospital
An Innovative Model to Advance Patient and Family Engagement in Care, Safety, Quality, Research and Education

- National Advisory Panel
- Sala Institute for Child and Family-Centered Care
- NYU Langone Children's Services Faculty and Staff
  - Center for Child and Family Resilience
  - Center for Child and Family Experience
  - Center for Patient Safety and Quality
  - Center for Education, Learning, and Innovation
How The Work Gets Done: The Magic Of The Connection

- Safety and Quality
- Learning and Innovation
- Resilience
- Experience
Center for Child and Family Resilience

Patients & Families

- Psychology & Psychiatry
- Social Work
- Family & Youth Advisors
- Nursing & Physician
- Spiritual Care
- Diversity
- Nutrition
- Integrative Health
- Pain & Palliative Care
- Child Life & Creative Arts
- Psychology & Psychiatry
- Psychology & Psychiatry
Center for Child and Family Resilience Strategic Goals

- Enhance and develop programs to provide **coping, comfort, and resilience support** for patients, families, and staff

- Develop and refine a comprehensive measurement strategy to assess the **effectiveness and impact** of resiliency programs
Can Hospitalization Precipitate Toxic Stress?

Anita N. Shah, DO,* Karen E. Jerardi, MD, MEd,* Katherine A. Auger, MD, MSc,* Andrew F. B
Published online April 1, 2016

During morning rounds, I introduced myself to the parent of a patient with bronchiolitis. As trainees, we are taught the medical management of bronchiolitis and how to set families' expectations for the course of illness. However, we are not taught how to help that trigger positive stress provide the opportunity “to observe, learn, and practice healthy, adaptive responses.” Alternatively, events that result in “extreme, frequent, or extended activation of the stress response,” without adequate buffering, are toxic.

http://developingchild.harvard.edu/science/key-concepts/toxic-stress/
AAP Policy Statement
Early Childhood Adversity & Toxic Stress

• Events that trigger POSITIVE and TOLERABLE stress may elevate the body’s physiologic response system,
  • SOCIAL SUPPORTS buffer and preventing harm
• Events that result in extreme, frequent, or extended activation of the stress response, without adequate buffering, are TOXIC

“Relationships lie at the roots of resilience.”
- Suniya Luthar, PhD

Shonkoff JP, Garner AS; Pediatrics. 2012;129(1)
Prevalence of significant traumatic stress:

- 20% of injured children
- 12% of ill children
- **21-32%** of children in the PICU
Using both an *improvement science* and *patient and family partnership* framework, our aim was to:

- Test, implement and sustain the use of
  - A co-designed *family stress screening tool*
  - An individualized yet standardized *response protocol*
Quality Improvement Team

**Team Leader:** Ron-Li Liaw  
**Nurse Managers:** Lea Devins & Tiffany Folks  
**Medical Director:** Yasir Al-Qaqaa  
**Resource Nurse:** Mary Rose  
**Nursing Champions:** Lauren Selikoff, Terri Yarri, Caitlin Coit, Lauren Arrigoni & Kelsey Hanrahan  
**Unit Clerk:** Guerline Dalrymple  
**Family Advisors:** Jennifer Daly & Erik Ward  
**Pediatric Social Work:** Lindsey Drewry, Dara Weiss, Debbie Dore & Erin Lauinger  
**Child Life:** Jami Barretta & Megan Walsh  
**Integrative Health:** Amy Eberhardt  
**Chaplaincy:** Matthew Dimick  
**Pediatrics Chief Resident:** Denis Chan  
**Child Psych:** Yamalis Diaz & Becky Lois  
**Nursing Education:** Kathy Linhart  
**Project Manager:** Jeanne Cho
Key Driver Diagram: Screening for Family Stress in the PICU

**SMART Aim**

*Increase the % of PICU families who are screened for stress during PICU stays from the current rate of 0% to 90% by June 30, 2016.***

Population: Families with PICU stays ≥ 24 hours

**Global Aim**

*To enhance emotional support for families and prevent crisis*

**Key Drivers**

- PICU staff well-trained & comfortable in using the ST & response protocol
- Staff (PICU & support services) engagement & buy-in
- Reliable process for administering ST
- Adequate staffing to administer the ST
- Open, bidirectional communication with diverse families
- Generalizable response protocol
  - Time-efficient, value added
  - Ability to tailor for family’s unique needs & situation
- Stress management & resiliency support for PICU staff

**Interventions**

- Design & implement ST tool for assessing family stress (1)
  - Train staff to use the ST tool – just in time & simulation
  - Create scripting & orientation materials
  - Embed ST screening in PICU work flows (2)
- Design & implement staff engagement campaign (1)
  - Orientation & unit awareness of impact of stress
  - Monthly stress reduction hours/events & incentives
  - Resiliency / wellness support programs
- Design & test family stress response protocol (1)
  - Train staff on response protocol & roles
  - Embed response protocol in PICU work flows (2)
  - EPIC smart phrase & #PICUCares email (2)
- Integrate ST tools within EPIC (2)
  - Design ST mHealth app, flowsheet & communication systems
- ST staffing back-up
  - Unit clerk ST completion log & audits (2)
  - Task assistance offered by charge nurse & other disciplines trained to complete ST w/ families (1)
- Engage FAC, senior family advisors, and family communication experts to create optimal approach for diverse families (2)
- Create mirrored family-facing materials (1)
  - Bedside ST & resource list (welcome book)
  - Family-facing response protocol & stress management resources

**Key**

- Gray shaded box = completed intervention
- Purple shaded box = what we’re working on right now
Co-Designed Family Stress Thermometer

How are you doing? (Caregivers)

When your child is in the hospital, it is natural for parents to feel stressed. If you are stressed, we want to support you.

On the thermometer below, please circle the number from 0 to 10 that best matches your stress level over the past 24 hours.

High Stress

Medium Stress

A Little Bit of Stress

No Stress

Caregiver #1: ___

Caregiver #2: ___

What Would Be the Most Helpful To You Right Now?

Caregivers	--	Date:														Time:															Rvd:	

¿Cómo se siente? ( cuidadores)

¿Cómo se sienten? ( cuidadores)

¿Cómo se sienten? ( cuidadores)

¿Cómo se sienten? ( cuidadores)

¿Cómo se sienten? ( cuidadores)

¿Cómo se sienten? ( cuidadores)

¿Cómo se sienten? ( cuidadores)

¿Cómo se sienten? ( cuidadores)

¿Cómo se sienten? ( cuidadores)
FOR STAFF (Last updated April 19, 2016)

Instructions: After completing the Stress Thermometer with the patient’s parent/caregiver, mark the responses you completed in the check boxes below. Please see the back of this sheet for the Response Log. If you have any questions about the response protocol, please reach out to Lea, Caitlin, or Kelsey.

If you are concerned about a safety issue, **CUS** with the PICU Nurse Leader and Attending

I am **CONCERNED**!

I am **UNCOMFORTABLE**!

This is a **SAFETY ISSUE**! “Stop the Line”

**Stress Thermometer: Response Protocol**

**Stress Thermometer Score**

5 or higher

or

Staff Perceived Family Stress

**HUDGLE**

Nursing Leader & Attending

Huddles are ad hoc sessions to review and modify the established plans to ensure all team members are on the same page and adjustments are made as needed. Keep them brief!

Did you address concerns about:

- Medical condition
- Care plan
- Communication
- Coordination
- Comfort

Did you schedule a family meeting?

**ADD SUPPORT**

Hospital + Community

Referrals: Mon-Fri, 9am-5pm

- Social Work: (212) 263-5018
- Child Life: (212) 263-5585
- Chaplaincy: (212) 263-5903
- Intg Health: (917) 240-7243
- EPIC IP consult: (212) 263-5767

Nights & weekends, call page operator at 212-263-7300

**PERSONALIZE CARE**

What would be most helpful right now?

- Any other interventions used?

See the Response/Re-assessment Log on the Back of this Sheet

**Place Patient Label Here**

Date & Time: ____________

Staff Name: ______________

Time to complete (min): ___

Caregiver #1 Stress Score: ___

Caregiver #2 Stress Score: ___

**Did you send a #PICUCares email update?**
#PICUCares (email alias)

- PICU Nursing & Physician Leadership
- Nursing Champions
- Social Work
- Child Life & Creative Arts
- Integrative Health
- Chaplaincy
- Child Psych
- Pediatric Chief Resident
- QI Project Manager

..PICUCares (EPIC SmartPhrase)

Type: Progress Notes  Service: Pediatrics, Psych  Date of Service: 5/10/2016

- Cosign Required

**Family Stress Screening & Response**

- **Patient Name:**
- **Room:**
- **MRN:**
- **Family/Caregiver Relation:**
- **Stress Thermometer Score:**
- **Main stressors for family:**
- **Stress response protocol followed as marked below:**
  - [ ] Huddle with ______________ (Charge RN or RN Leadership) and
  - [ ] Physician ______________
  - [ ] Safety concerns identified and discussed (if applicable):
  - [ ] Family meeting recommended
  - [ ] Support service referrals requested include:
    - [ ] Social Work
    - [ ] Child Life/Creative Arts Therapy
    - [ ] Chaplaincy
    - [ ] Integrative Health; IP consult placed in EPIC
  - [ ] Other: ______________
Stress Thermometer: Our Family Partners
Family Stress Thermometer - Heat Map

n = 415 family responses

<table>
<thead>
<tr>
<th>Stress Level</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Stress (8-10)</td>
<td>124</td>
<td>29.9%</td>
</tr>
<tr>
<td>Medium Stress (5-7)</td>
<td>111</td>
<td>26.8%</td>
</tr>
<tr>
<td>A Little Bit of Stress (2-4)</td>
<td>95</td>
<td>22.9%</td>
</tr>
<tr>
<td>No Stress (0-1)</td>
<td>85</td>
<td>20.5%</td>
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</table>
## Common Stressors: Child’s Hospital Stay

<table>
<thead>
<tr>
<th>Stressors Related to Your Child’s Hospital Stay</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your Child’s Comfort/ Well-Being</td>
<td>54.58%</td>
</tr>
<tr>
<td>Your Child’s Medical Condition</td>
<td>69.58%</td>
</tr>
<tr>
<td>Your Child’s Medical Care</td>
<td>19.58%</td>
</tr>
<tr>
<td>Communication and Coordination</td>
<td>9.58%</td>
</tr>
<tr>
<td>Health Care Team</td>
<td>2.50%</td>
</tr>
<tr>
<td>Shared Room/Privacy</td>
<td>17.50%</td>
</tr>
<tr>
<td>Language/Cultural Issues</td>
<td>3.75%</td>
</tr>
<tr>
<td>Other</td>
<td>5.00%</td>
</tr>
</tbody>
</table>
Common Stressors: Day to Day Living

Stressors Related to Day to Day Living

- Insurance/Finances: 27%
- Work/School: 38%
- Child Care: 36%
- Transportation: 28%
- Housing: 15%
- Other: 14%
Common Stressors: Caregiver Health

Stressors Related to Caregiver’s Health

- 35% Pain/ Discomfort
- 19% Nausea/ Loss of Appetite
- 11% Headaches
- 20% Sleep problems
- 8% Fatigue
- 7% Fatigue
- Other

- 11% Other
- 8% Other
- 7% Other
- 35% Other
- 19% Other
- 20% Other
- 8% Other
- 7% Other
- 11% Other
- 20% Other
- 19% Other
- 35% Other
- 11% Other
Common Stressors: Family, Relationships & Feelings

Family and Relationships

• Partner/Spouse
• Children/Siblings

“Good Catches”

• Postpartum depression / trauma
• Suicidal ideation
• Safety in the home

Your Feelings

- Worry and Anxiety: 53%
- Sadness and Depression: 17%
- Loneliness: 2%
- Anger and Irritability: 9%
- Confusion and Uncertainty: 2%
- Spiritual Questions/Concerns: 2%
- Others: 2%
Day 1
Parents assessed for stress:
  Mom: 10+
  Dad: 10
#PICUCares alert
Huddle & Interdisciplinary Team Response

Day 2
Parents re-assessed for stress:
  Mom: 5
  Dad: 3
#PICUCares alert
Huddle & Interdisciplinary Team Follow-Up

Day 3
Senior Family Advisor Check-In
Interdisciplinary Team Support

“Helping families manage stress or even noting their stress factors along with amazing care has made a positive impact on many families.”

- Senior Family Advisor
Pre- and Post-Intervention Scores

- There is evidence to suggest that families scoring 5 or higher (mean= 7.63, SD=1.92) experienced statistically significant decreases in stress scores (p<0.0001) after receiving support service interventions (mean= 4.30, SD= 2.19). The 95% confidence interval for the difference is 2.70, 3.95).

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>N</th>
<th>SD</th>
<th>SEM</th>
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<tbody>
<tr>
<td>Pre</td>
<td>7.63</td>
<td>43</td>
<td>1.92</td>
<td>0.29</td>
</tr>
<tr>
<td>Post</td>
<td>4.30</td>
<td>43</td>
<td>2.19</td>
<td>0.33</td>
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</table>
PICU Average Length of Stay (ALOS)

PICU ALOS (Quarterly)

<table>
<thead>
<tr>
<th>Quarter</th>
<th>ALOS</th>
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<tbody>
<tr>
<td>Q1 2016</td>
<td>10.6</td>
</tr>
<tr>
<td>Q2 2016</td>
<td>8.7</td>
</tr>
<tr>
<td>Q3 2016</td>
<td>5.5</td>
</tr>
<tr>
<td>Q4 2016</td>
<td>4.3</td>
</tr>
</tbody>
</table>

59.7% decrease from Q1 to Q4
Balancing Measure: PICU ADC & Occupancy

PICU ADC and Occupancy by Month
August 2015 - January 2017

PICU ADC
PICU Occupancy

ADC
0 2 4 6 8 10 12

Occupancy Rate
0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Balancing Measure: PICU CMI
Security Calls to Pediatrics

Security Calls for Distressed Patients, Families or Visitors

64% decrease from baseline

No. of Security Calls

Year

Frequency (#)

2013 2014 2015 2016
“Relationships lie at the roots of resilience.”

Suniya Luthar, PhD
Patient & Family Engagement in Quality Improvement

Co-Design → Test → Implement → Sustain → Spread

Patient and Family Engagement
Patient & Family Engagement in Quality Improvement

- Family Consultant
  - Family Education
- Family Advisory Council (FAC)
  - Youth Advisory Council (YAC)
- Senior Family Advisors
- Cultural Diversity Advisors
Family Advisory Council (FAC)

Youth Advisory Council (YAC)
Senior Family Advisors & Family Faculty
Great Interest – from Family Advisors

- Engaged and trained
- Using what they know
- Increasing impact
- A few more hours
Senior Family Advisor Program

- Paid employees with valuable expertise
- 10 Advisors from the Family Advisory Council
- Diversity of Background
- Diversity of Experience
Stress Thermometer: Being Human
Engaging Families by Families

- You know your child best.
- We deeply respect your knowledge.
- We welcome you in all discussions about your child.
- We are here to listen and respond to your questions and concerns.
- We are ready to partner with you in your child’s care, including safe care.
Anticipatory Guidance in working with Senior Family Advisors

For Clinical Teams
• The value of family perspectives
• How to engage families
• How families might be helpful

For Families
• How to “jump in”
• Providing context
• Hearing about things going wrong
Patient & Family Engagement in Quality Improvement

- Family & Youth Advisory Councils
- Family Education & Diversity Advisors
- Senior Family Advisors
Co-Designed Family Stress Thermometer

Checking in with families early on about how they are doing shows that we care and opens the door for dialogue and support.

- Senior Family Advisor
Patient & Family Engagement in Quality Improvement

Co-Design

TEST

Implement

Sustain

Spread

- Family & Youth Advisory Councils
- Senior Family Advisors
- Diversity Advisors

Patient and Family Engagement
Patient & Family Engagement in Quality Improvement

- Senior Family Advisors
  - AM Huddles
  - Staff Education
  - Family-to-Family Audits
  - Closed Loop Communication w/ Team
What Would Help to Decrease Your Stress?

“Learning about how to care for my child and being able to look for signs following discharge”

“To know my child will be as back to normal as possible”

“Not having to miss work next week”

“The more information I have to understand, the less stress I feel”

“Feeling less helpless about my child’s pain”

“Understanding my own coping style”

“Helping my wife (baby's mother) will help me”

“Talk with a strong and warm person from community”

“Getting help for my child's mental health care”
Patient & Family Engagement in Quality Improvement

- Co-Design
- Test
- Implement
- SUSTAIN
- Spread

- Senior Family Advisors
- Family & Staff Education
- Family-to-Family Hour

Patient and Family Engagement
Patient & Family Engagement in Quality Improvement

- Develop
- Test
- Implement
- Sustain
- SPREAD

- Senior Family Advisors
- Family and Youth Advisory Councils
- Diversity Advisors
Stress Thermometer: The Family Partner Role
Lessons Learned

• Family advisors and nursing champions played crucial and complementary roles in the success of this improvement initiative.

• Interdisciplinary team collaboration led to reliable and sustainable improvement even in the context of increasing acuity, complexity and staffing changes seen in the PICU.
Challenges & Opportunities

Ongoing challenges and opportunities include:
1) Integration of new processes and tools into the electronic health record and systems-level workflows
2) Interactive, interdisciplinary models of providing staff education
3) Streamlined data collection of process and outcome metrics
Next Steps

- Current adaptation and spread to the congenital cardiac ICU and system-wide by year end
- Development of a Stress Thermometer mHealth app with EPIC integration
- Evaluate program impact and outcomes measurement
QUESTIONS & DISCUSSION
Thank you!

- Presentations: www.childrenshospitals.org

- Presenter contact information:
  - Ron-Li.Liaw@nyumc.org
  - Beth.Silber@nyumc.org