- If you are viewing this course as a recorded course after the live webinar, you can use the scroll bar at the bottom of the player window to pause and navigate the course.
- This handout is for reference only. Non-essential images have been removed for your convenience. Any links included in the handout are current at the time of the live webinar, but are subject to change and may not be current at a later date.

Technical issues with the Recording?

- Clear browser cache using these instructions
- Switch to another browser
- Use a hardwired Internet connection
- Restart your computer/device

Still having issues?

- Call 866-782-9924 (M-F, 8 AM-8 PM ET)
- Email customerservice@OccupationalTherapy.com

Navigating Healthcare Journeys:
Therapeutic Strategies to Enhance Child and Family-Centered Communication and Discharge Planning

Presenters:
Christina Connors, Occupational Therapist
Jennifer Kelley, Certified Child Life Specialist

1

- **Presenter Disclosure:** Financial: The honorarium for this talk was paid to Get Well Map Foundation, 501c3, a nonprofit organization. Non-financial: Christina Connors is the founder of Get Well Map Foundation, 501c3.
- **Content Disclosure:** Get Well Maps will be demonstrated and utilized as an example of a child- and family-centered visual tool. Information will be provided in a scholarly manner, and only to illustrate therapeutic tools and methods. Full disclosure will be provided to all participants. No promotions or offers of any kind will be associated with our content created for continued.com.
- **Sponsor Disclosure:** This course is presented by OccupationalTherapy.com.

2

Learning Outcomes

After this course, participants will be able to:

- Define the key components of a child- and family-centered, interdisciplinary discharge planning framework.
- Describe the use of methods and strategies to partner with patients and families to facilitate therapeutic communication and navigation through various stages of medical care.
- Identify potential challenges, solutions, and opportunities to integrate child- and family-centered tools and methods into clinical workflows and medical education across diverse patient populations.

3

Family-Centered Perspective

Andrew's Story-https://www.getwellmaps.org/our-story/

4

The Trend Toward Increasingly Complex Discharges

- Discharging with High-Acuity Needs
- Learning and Processing Information is Challenging for the Child and Family
- Increasingly Complex Information & D/C Instructions
- Environmental Considerations
- Caregiver and Family Transitions

5

Research Review: Pediatric Discharge Data

- Each year **one in four children** will receive medical care for an injury, resulting in millions of emergency department visits & hospitalizations.
- Nearly **one of every six discharges** (5.9 million) from US hospitals in 2012 was for children aged 17 years or younger.
- On average, pediatric patients stayed in the hospital for 4 days (3.9 mean length of stay, days), with an average cost of over $6,000 per stay and accounting for 37 million in aggregate hospital costs (Witt, Weiss, Elixhauser, 2014).
- In recent years, there have been significant increases in the number of admissions for children w/ chronic conditions, a 6% increase 2010-2016 (Bucholz, Toomey, Schuster, 2019).

6

Research Review: Pediatric Discharge Data

- Substantial variability exists within settings of pediatric hospitalizations.
  - In the US in 2012, 2 million pediatric hospitalizations, more than 70%, occurred in a general hospital (Leyenaar et al. 2016).
  - 3,866 hospitals were general, 70 were free standing.
- While every child's discharge looks quite different, pediatric standards published in 2014 in the Journal of the American Medical Association indicate that high-quality, family-centered guidelines and processes can indeed be applied broadly, while still leaving room for individualized planning.

7

Trauma-Sensitive Considerations

- Currently, more than 46% (~34 million) U.S. children under age 18 have had at least 1 adverse childhood experience (ACE), and more than 20% have had at least 2 ACEs.
- Pediatric medical trauma as an ACE
- Risk Factors for persistent traumatic stress reactions include prior traumatic experiences or behavioral problems, more severe pain or exposure to frightening sights and sounds while in the hospital, subjective sense of life threat and injury / illness severity, and more severe early traumatic stress reactions.
- Parent presence and support, as well as a positive peer support system, appear to serve as Protective Factors.
  https://www.healthcaretoolbox.org/research-summaries.html

8

Trauma-Sensitive Considerations

- Post Intensive Care Syndrome (PICS):
  - Advancements in critical care medicine and consequently, the improvement in survival after a critical illness have led clinicians to discover the **significant functional disabilities** that many surviving patients experience. This has led to further research which is focused on improving the long-term outcomes for critical illness survivors and their **functional recovery**.
  - PICS is defined as new or worsening impairment in physical, cognitive, or mental health status arising after critical illness and persisting beyond discharge from the acute care setting.
  - Psychological health of family members of the survivor may also be affected in an adverse manner, termed as PICS-Family (Rawal, Yadav 2017).
- Post Intensive Care Syndrome (PICS):
  - Of the more than 5.7 million individuals admitted to ICUs each year in the US, According to the Society of Critical Care Medicine, PICS affects:
    - 33% of all patients on ventilators
    - Up to 50% with an ICU length of stay for at least 1 week

9

Trauma-Sensitive Considerations

- Pediatric Medical Traumatic Stress (PMTS):
  - Defined as "a set of psychological & physiological responses of **child and their families** to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences" (National Child Traumatic Stress Network, 2003).
  - PMTS includes traumatic stress responses, such as arousal, re-experiencing, and avoidance, which can vary in intensity and disrupt functioning (Kazak et al., 2005).

10

Trauma-Sensitive Considerations

- The Integrative Model of PMTS (Kazak et al., 2005) emphasizes a **family-centered perspective**, and **need for assessment and intervention, for parents, as well as siblings.**
- Highlights the hallmarks typically present: life threat, and/or the likelihood of an event evoking fear, horror and helplessness (American Psychiatric Association, 1994).
- It notes, however, that the symptoms of PMTS are more **strongly correlated with subjective experiences** than objective characteristics of a particular illness or treatment course. (Kazak et al., 2005)

11

Trauma-Sensitive Considerations

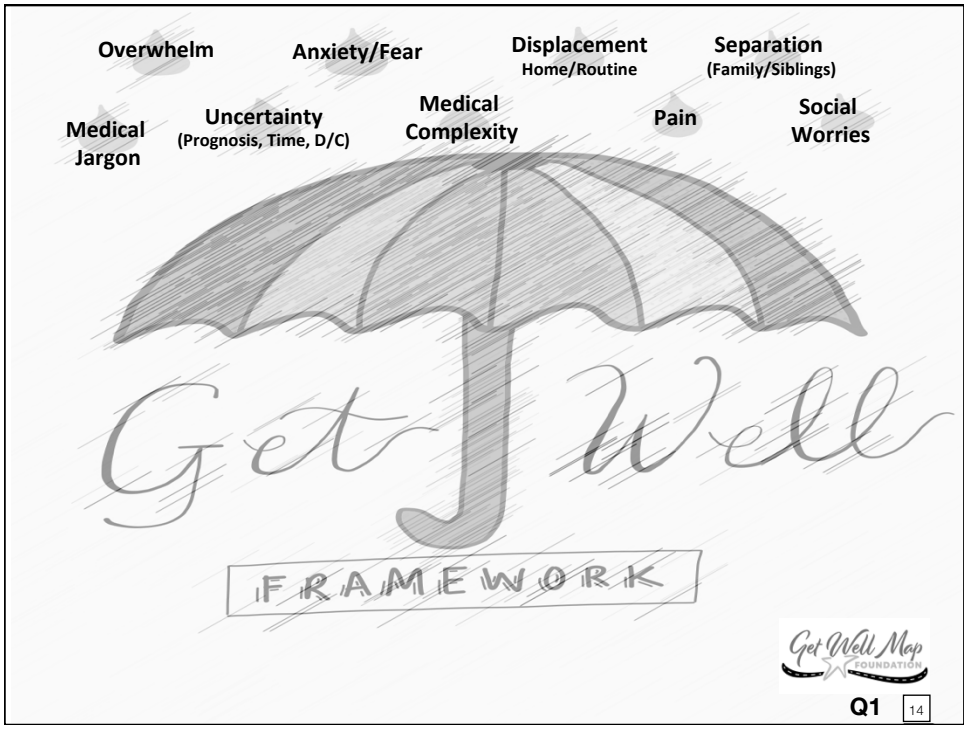
- This model advocates that PMTS be addressed:
  - In the delivery of acute medical treatment (by **changing the subjective experience** of Potentially Traumatic Events (PTE)
  - After the delivery of medical treatment (to **prevent the symptoms** of PMTS)
  - By primary care health providers and educators to identify ongoing concerns & link family with resources upon community & school re-entry (to **reduce the symptoms** of PMTS).
- As research continues to emerge, it is important to note that greater understanding, prevention, assessment and intervention has the potential to help children and families develop **adaptive long-term outcomes** after traumatic experiences.
- Post-Traumatic Growth (PTG)-Resiliency research is expanding.

How do we help inspire & promote this trajectory among families?

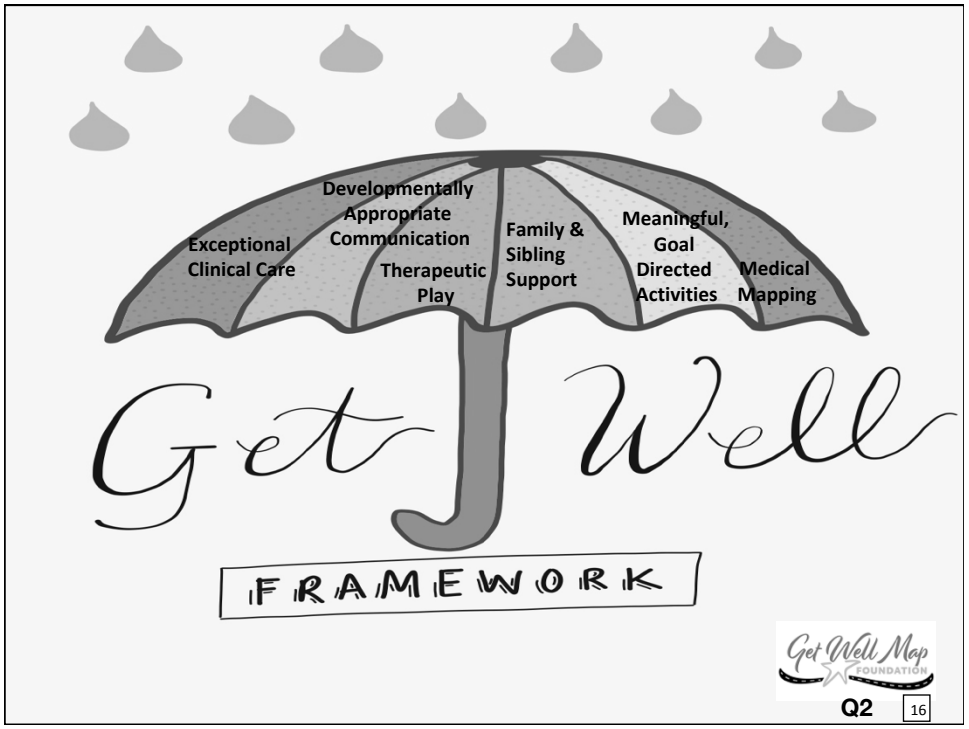
12

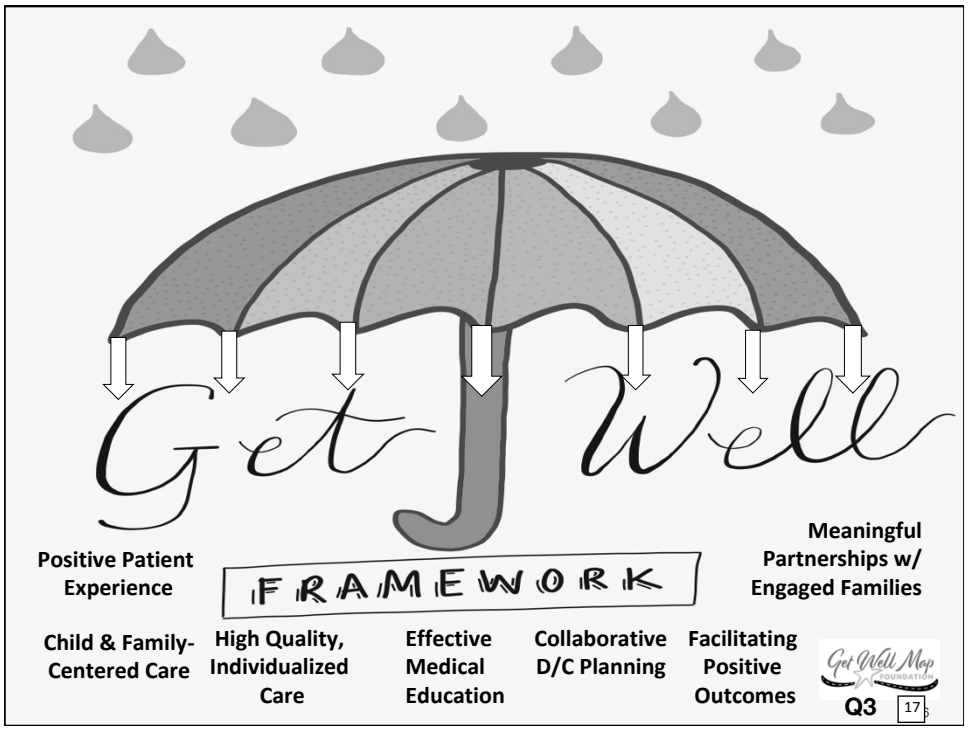
Developed as Therapeutic Framework that was the result of Occupational Therapy and Child Life Collaboration

13



Q1 14

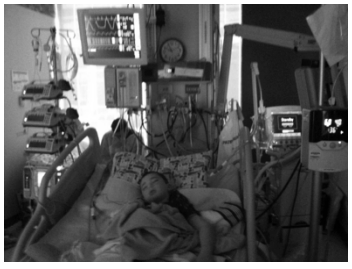

Exceptional Clinical Care
Developmentally Appropriate Communication
Therapeutic Play
Family & Sibling Support
Meaningful, Goal Directed Activities
Medical Mapping
Get Well
FRAMEWORK
Get Well Map FOUNDATION
Q2
16


Get Well
Positive Patient Experience
FRAMEWORK
Meaningful Partnerships w/ Engaged Families
Child & Family-Centered Care
High Quality, Individualized Care
Effective Medical Education
Collaborative D/C Planning
Facilitating Positive Outcomes
Get Well Map FOUNDATION
Q3
17

CONTINUED

Therapeutic Intervention: Exceptional Clinical Care

- Evidence-Based Diagnostic Methods
- Evidence-Based Treatment Protocols
- Clinical Judgement & Decision-Making
- Staff Consistency
- Individualized Care



18

Therapeutic Intervention: Communication

- Need for multi-sensory learning strategies and medical education in healthcare settings:
  - Child- and Family-Centered
  - Developmentally-Appropriate
- Rising numbers of children with Autism Spectrum Disorder, ADHD, auditory processing disorder, sensory processing disorder
- Language barriers
- Medical jargon
- Multiple Team Members with Various Communication Styles

Q4 19

Promoting Developmentally-Appropriate Communication

- Translating medical jargon
- Helping children identify tangible, child-centered goals
- Helping children and families understand interdisciplinary goals/medical education
- Medical Rounding: support before/during/after
- What to do when a "setback" occurs

20

Therapeutic Intervention: Therapeutic Play

- Types of Therapeutic Play include:
  - Emotional Expression
  - Instructional Play
  - Medical Play
- Therapeutic Play allows children to:
  - Express feelings or concerns
  - Become familiar with medical equipment
  - Increase understanding
  - Learn and practice coping techniques
  - Re-enact healthcare experiences
  - Develop feelings of mastery
  - Communicate fears
  - Ease and clarify misconceptions

Q5 21

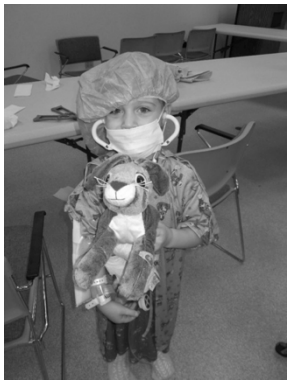
Therapeutic Intervention: Therapeutic Play

- Research provides evidence for the effectiveness of therapeutic play in reducing psychological and physiological stress for children facing medical challenges.
- Therapeutic play offers long-term benefits by fostering more positive behavioral responses to future medical experiences.
- Since childhood play transcends cultural barriers, play opportunities should be provided for children of all ages and backgrounds.

22

Promoting Therapeutic Play

- Medical Preparedness and Education
- Partnering with caregivers & siblings
- Assessing Readiness & Communicating with the Team
- Guiding, Modeling & Facilitating Therapeutic Play with Families & Staff during hospitalization & after discharge
- Red Flags to look for beyond D/C



23

Therapeutic Intervention: Family & Sibling Support

- Caregivers know their child best, although stress and demands of hospitalization can compromise their confidence in their caregiver roles
- Challenges of having a hospitalized sibling/child
  - Disruption of family unit and daily routines
  - Emotional hardships
  - Adjustment problems
  - Shift in family boundaries
- Important to incorporate the entire family in the hospitalization, including the discharge planning process.
- Roles often shift due to hospitalization and again upon discharge.

24

Promoting Family & Sibling Support

- **Education and Family Engagement**
  - Teach back method
  - Amount of information
  - Active listening
  - Goal Setting
  - Previous transitions within the family
- **Siblings**
  - Current understanding/current needs
  - Inclusion in teaching and offering support
  - Assessment for additional needs-Recognizing needs beyond your scope of practice
- **Resources**
  - Short-term (during hospitalization and medical care)
  - Long-term (beyond discharge)

Q6

25

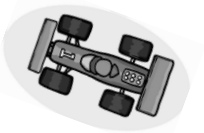
Therapeutic Intervention: Meaningful, Goal-Directed Activities

- **Incorporating Therapeutic Play into Meaningful, Goal Directed Activities**
  Functional Activities
  Activities of Daily Living
  Functional Mobility
  Play/Leisure

- **Establishing Goals**
  Measurable STG & LTG
  Meaningful Child and Family-Centered Goals
  (Stoffel et al., 2017)

26

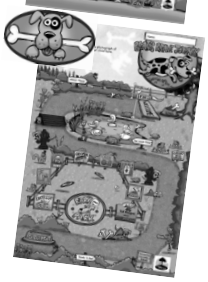
Promoting Meaningful, Goal-Directed Activities



- Provide opportunities for choice and control in unfamiliar environment & situations
- Promote enhanced independence in preparation for discharge and/or transitions
- Encourage & motivate children & families to work towards skill development from a “modified normal”.
- Teach skills needed for successful re-integration to home/school/community environments

27

Therapeutic Intervention: Medical Mapping



- Families often have difficulty navigating evaluation and treatment courses and require facilitation from healthcare professionals for guidance & empowerment
- Use of child-friendly themes tailored to the child’s interest to increase engagement & normalization of healthcare experience.
- Use of photographs or illustrations to enhance personalized goal setting & individualized care that is visible to the child and family
- Use of a “Neutral Zone” to encourage consistent, developmentally-appropriate communication during medical setbacks or delays in progress
- Milestone markers to highlight individualized aspects of medical experience & incorporate interdisciplinary goals

Q7 28

Therapeutic Intervention: Medical Mapping

Our Visual Get Well Maps are created on firm 12"x18" easy-to-maintain boards that can be easily incorporated into admission & discharge planning processes

Q7 29

Promoting Strategies Medical Mapping

Utilizing Get Well Maps and Milestone Markers as a Patient and Family Medical Education Tool:

- A member of the child's medical team should apply 1 sticker (or 2-3 maximum at a time) to the child's Get Well Map to provide families with a visual tool that prepares them for the next upcoming milestone that needs to be addressed in the discharge planning process/ pathway
- Stickers should be applied in the sequence that best aligns with the team's Interdisciplinary Plan of Care
- Don't forget that a milestone can be depicted in the neutral zone, as it might be the milestone that must be achieved to end a set-back or pause in medical progress
- Adjustable & removable as the child may request that these milestones are removed after achievement.
- Members of the child's medical team can autograph the back of the child's Get Well Map upon discharge.
- The Get Well Map becomes an individualized keepsake that depicts a child and family's bravery and perseverance!

30

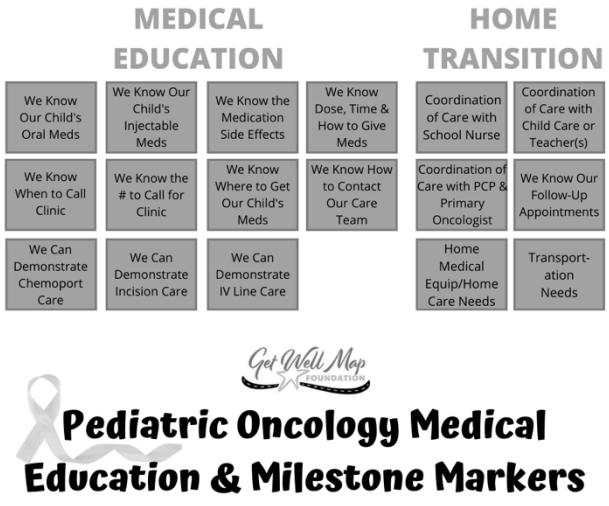
CONTINUED

Example of Milestone Markers-Oncology

31

CONTINUED

Example of Milestone Markers-Oncology



32

Clinician-Centered Perspective

- **Pediatric Oncology Case Study**

Emily

- 11 year old female, mild CP
- Bone Marrow Transplant recipient
- 2 hours from home
- Cultural Considerations
- Hospitalization lasting approximately 2 months
- Discharge planning process initiated ~2 weeks prior
- Discharge delayed by fevers-Clinical vs. Non-Clinical Goals

33

Outcomes

- Creating a Process for Promoting High Quality Individualized Care in a Family-Centered Healthcare Environment
  - Admission → Discharge
- Improved Consistency of Developmentally-Appropriate Medical Communication & Medical Education among the Interdisciplinary Team
- Preparing Families for Transitions
  - To different units within the hospital, Ronald McDonald House, and Home
- Empowering Families throughout the Discharge Planning Process
  - Use of visual supports, small chunks of medical education for children & families to process, and multi-sensory learning strategies

Q8 34

Child- and Family-Centered Care = Improved Satisfaction & Outcomes

- Positive Patient Experience
- Child & Family-Centered Care
- High Quality, Individualized Care
- Effective Medical Education
- Collaborative Discharge Planning
- Meaningful Partnerships with Engaged Families
- Facilitating Positive Outcomes

35

Potential Barriers

- Disengaged Child &/or Family
- Working in Clinical Silos
- Inconsistent Staffing
- Organization Demands &/or Insurance Pressure
- Lack of Experience with Medically Complex Patients & Families
- Unestablished or Unrealistic Expectations
- Lack of Resources-Financial, Time, Support
- Difficulty Sustaining a Child- & Family-Centered Focus
- Language Barriers

Q9 36

Potential Solutions & Opportunities

- Advocacy
- Embrace & Encourage New Ideas
- Teamwork
- Consistent Approach
- Sharing and Promoting Evidence-Based Practice among Colleagues
- Being a Champion for Child- and Family-Centered Care Initiatives

Q10

37

Questions and Feedback

- Christina.Connors@getwellmaps.org
- Jennifer.Kelley@Nemours.org

38

References

- Anderson, M., Grinder, S. (2017). Occupational therapy's role in social-emotional development throughout childhood. *American Occupational Therapy Association OT Practice* 22(7), CE1-CE8.
- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy,* 68, S1-S48. Retrieved from http://dx.doi.org/10.5014/ajot.2014682006
- Arbesman, M., Bazyk, S., & Nochajski, S.M. (2013). Systematic review of occupational therapy and mental health promotion, prevention, and intervention for children and youth. *American Journal of Occupational Therapy*, 67, e120-e130. Retrieved from http://dx.doi.org/10.5014/ajot.2013.008359
- Bonner, M. J., Hardy, K. K., Guill, A. B., McLaughlin, C., Schweitzer, H., & Carter, K. (2006). Development and validation of the parent experience of child illness. *Pediatric Psychology, 31*(3), 310-321.
- Bucholz, E. M., Toomey, S. L., & Schuster, M. A. (2019). Trends in pediatric hospitalizations and readmissions: 2010-2016. *Pediatrics*, *143*(2), e20181958. Retrieved from https://doi.org/10.1542/peds.2018-1958
- Case-Smith, J. (2013). Systematic review of interventions to promote social-emotional development in young children with or at risk for disability. *American Journal of Occupational Therapy*, 67, 395-404. Retrieved from http://dx.doi.org/10.5014/ajot.2013.004713
- Child Life Council. (2002). *Official documents of the Child Life Council.* Rockville, MD: Author.
- Coss, D. (2019). Occupational therapy interventions in cancer care. *American Occupational Therapy Association OT Practice, 24(7), 10-14.*
- Gill, K. M. (1993). Health professionals' attitudes toward parent participation in hospitalized children's care. *Children's Health Care, 22*(4), 257-271.

39

References

- Kaddoura, M., Cormier, K., & Leduc, J. (2013). Resource collaboration: The benefits of utilizing child life specialists when dealing with pediatric stress. *Educational Research Quarterly, 37*(2), 3-21.
- Kazak, A. E., Kassam-Adams, N., Schneider, S., Zelikovsky, N., Alderfer, M. A., & Rourke, M. (2005). An integrative model of pediatric medical traumatic stress. *Journal of Pediatric Psychology, 31*(4), 343-355.
- Kornburger, C., Gibson, C., Sadowski, S., Maletta, K., & Klingbeil, C. (2013). Using "teach-back" to promote a safe transition from hospital to home: An evidence-based approach to improving the discharge process. *Journal of Pediatric Nursing, 28*, 282-291.
- LeBlanc, C. K., Naugler, K., Parker, J. A., & Chambers, C. T. (2014). Parent perceptions and satisfaction with inpatient child life specialist interventions and the role of child temperament. *Children's Health Care, 43*(3).
- Leyenaar, J. K., Bergert, L., Mallory, L. A., Engel, R., Rassbach, C., Shen, M., Woehrlen, T., Cooperberg, D., & Coghlin, D. (2015). Pediatric primary care providers' perspectives regarding hospital discharge communication: A mixed methods analysis. *Academic Pediatrics*, *15*(1), 61–68. Retrieved from https://doi.org/10.1016/j.acap.2014.07.004
- Little, L. M., Walisch, A., & Irvin, D. (2016, August). Interdisciplinary assessment of social-emotional development for young children with developmental disabilities. *SIS Quarterly Practice Connections, 1* (3), 2-4. Retrieved from http://www.aota.org/Publications-News/SISQuarterly/Developmental-Disabilities/8-16-measure-asess.aspx
- Rawal, G., Yadav, S., & Kumar, R. (2017). Post-intensive care syndrome: An overview. *Journal of Translational Internal Medicine*, *5*(2), 90–92. Retrieved from https://doi.org/10.1515/jtim-2016-0016
- Saleeba, A. (2008). The importance of family-centered care in pediatric nursing. *School of Nursing Scholarly Works, 48*.

40

CONTINUED

References

- Statile, A. M., Schondelmeyer, A. C., Thomson, J. E., Brower, L. H., Davis, B., Redel, J., White, C. M. (2016). Improving discharge efficiency in medically complex pediatric patients. *Pediatrics, 138*.
- Stevenson, P., Costello, P. (2020). Playing well together: Interprofessional practice in pediatrics. *American Occupational Therapy Association: SIS Quarterly Practice Connections, Volume* 5(1), 5-7.
- Stoffel, A., Rhein, J., Khetani, M., Pizur-Barnekow, K., James, L., Schefkind, S. (2017). Family centered: Occupational therapy's role in promoting meaningful family engagement in early intervention. *American Occupational Therapy Association OT Practice* 22(18), 8-13.
- Streissand, R., Braniecki, S., Tercyak, K. P., & Kazak, A. E. (2001). Childhood illness-related parenting stress: The pediatric inventory for parents. *Pediatric Psychology, 26*(3), 155-162.
- Witt, W. P., Weiss, A. J., & Elixhauser, A. (2006). Overview of hospital stays for children in the United States, 2012: Statistical brief #187. In *Healthcare Cost and Utilization Project (HCUP) Statistical Briefs*. Agency for Healthcare Research and Quality (US).
- Quick Links: Tools and Resources. (2016, August 30). Retrieved May 29, 2020, from https://www.healthcaretoolbox.org/tools-and resources.html

41