Resilience in Children with Chronic Illnesses and Their Families

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This may be smaller than we thought

Resilience and positives may be larger than we thought
Background and Theory

• This presentation reviews information from three qualitative studies where interviews were used to assess child, sibling, and parent views of sources of resilience for the family and the child with a chronic illness (e.g., Woodson et al., 2015; Nabors & Liddle, 2017; Nabors et al., 2019).

• According to Walsh (2002), “...in family organization, resilience can be fostered through flexible structure, shared leadership, mutual support, and team work in facing challenges” (p. 132).
Participants and Methods

• **Participants** were parents and children with a variety of chronic illnesses who were either hospitalized or recovering from a medical procedure. Parents were residing at a *Ronald McDonald House (RMH)* while their child was undergoing a procedure or recovering from a procedure.
  • 42 parents, 25 children with chronic illnesses and 20 siblings participated

• **Qualitative Methods**
  • Parents and children completed semi-structured interviews assessing views of family coping, child coping, and stressors in three qualitative studies at a local RMH.
  • With children: Read all about it newspaper stories, build your own hospital
  • An open coding method was used to uncover themes in the data.
Findings

• **Mothers** mentioned that they relied on their faith and prayer to lift their spirits. Prayer also offered a way to find peace from worries over one’s child and his or her future.

• Additionally, hearing other families’ success stories could also boost mothers’ spirits.

• Other mothers depended on visits with counselors or therapists to discuss stress and cope.
Findings

• **Siblings** reported they were coping well and functioning positively. Parents typically described siblings as being well-adjusted in terms of home and school life.
• There were not descriptions of poor adjustment of siblings.
• Parents reported that siblings were protectors and helpers.
• They raised money to pay for bills; they made Facebook pages to help others stay connected to their siblings.
Findings

- **Children with illnesses** used a myriad of distraction strategies.
- Preschoolers typically engaged in fantasy play, whereas older children played videogames and listened to music.
- Contact with family members and friends via Skype or Face Time allowed strong “connections” for the child.
- A child’s personality (e.g., fighting spirit) could be a personal strength.
- Some children used a “can do” or “I can do it” mantra so that they were positive when facing painful procedures or were upset about being in the hospital.
- Working with physical or occupational therapists was helpful--through the relationship with the therapist and through being able to actively take steps to improve health.
- Cognitive-behavioral anxiety management strategies, including breathing, muscle relaxation, positive imagery and positive self-talk helped young children manage anxiety related to their illnesses.
Conclusions

• Children with chronic illnesses and their families may be marked by resilience and a search for meaning.

• Positive activities, such as positive self-talk and positive coping (e.g., through social support and having a fighting spirit), which are critical.

• Strategies central to positive psychology may promote resilience.
Conclusions

• Walsh (2003) discussed the importance of building family resilience by improving positive outlook and expressing emotions, which would, in turn decrease stress. Having a strong circle of support persons as a buffer in times of stress can be affirming and resilience-building for the child and his or her family members (Walsh, 2002, 2003).

• Study results are important, and they enhance our knowledge by showing that families are motivated to move in a strengths-based direction as they cope with their child’s illness (Mastin & Monn, 2015; Mullins et al., 2015).
Selected References


Keep Me Well

promoting lifelong wellbeing for children

Nancy Cunningham, PsyD
Medical Providers in a System of Care

- “A spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them to function better at home, in school, in the community, and throughout life (accountability through evidenced based care).”

- Opportunities for health care providers to up their game.

- Services for kids in foster care is one example: An effective health system of care is a coordinated health system where multidisciplinary partners — including child welfare, judicial, pediatric, mental and dental health professionals, and parents (foster and birth) and kin — work collaboratively to respond to, manage, and improve the health and well-being of children and teens (in foster care).
Fostering Connections at NCH

- Through The Center for Family Safety and Healing, a partnership organization focused on responding to family violence, a specialized care clinic offers comprehensive healthcare services to children and adolescents placed in foster or out-of-home care.

- Medical home for patients, providing initial assessments following placement, well-child or sick-child visits and care coordination. The initial medical evaluation includes a complete medical examination and a review of prior medical history. The patient will also undergo mental health and developmental screenings to identify additional treatment needs.

- The care coordination offered through the Fostering Connections Program is designed to help foster families and kinship caregivers in navigating the healthcare system for these various needs, while improving continuity of care among the other providers. The care coordinator assists with the collection of prior medical information, referrals and follow-up care.

- Opportunity for traditional primary care providers to recognize increased healthcare needs of foster care children in their practice.
Addressing the Whole Continuum of Care

- SOC emphasis has been primarily focused on multisystem youth.

- Need is to continuously link with mental health promotion, prevention, and early identification and intervention to improve long-term outcomes, including mechanisms to identify problems at an earlier stage and mental health promotion and prevention activities directed at all children and adolescents.

- Health care providers are in a unique position to track a child's changing needs over the developmental trajectory.
What does that mean for health care providers?

- Integrated primary care/behavioral health services
- Ongoing routine screening across developmental levels, with a strategy for care coordination (registry) for youth with ongoing concerns
- Resource links and supports for ACES (medical legal partnerships)
- Ongoing FV assessment (various forms of abuse and bullying predict future suicidal ideation and attempt)
- Suicide risk assessment and response (ASQ) and referral strategies for identified youth
- Engagement in ECHO projects for primary care providers
What does that mean for health care providers? (cont.)

- Promoting and linking services including home visiting, ECMH prevention and treatment services; child advocacy and family violence services

- Community advocacy and voice regarding mental health access, anticipatory guidance about health hazards of firearms, knowledge and support for local systems of care and reducing reliance on inpatient or out of home care for youth with complex needs
Children are Special Activities to Raise Hopes, Promote Fun, and Encourage Positive Thinking!

Activities for preschool and early elementary school-age children

We hope these ideas may help you in engaging in fun activities to build support, hope, fun, and positives for your child.

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Activity 1: Happy List

Instructions:

Help your child discuss what makes him or her happy, then make a picture and list the items and draw a picture beside each one so that your child can recognize the items on the list. Try to mention or do one thing on the list every day for a week!

Materials Needed:

- Construction paper
- Crayons
- (Optional) Stickers
Activity 2: Wishing Well

Instructions:

Have your child share his or her wishes for a wishing well. Draw a wishing well and have your child make a wish and color a special spot on the wishing well. Talk to your child about his or her wish and if possible try to help make the wish come true for your child.

Materials Needed:

- Construction paper
- Crayons or paint
Activity 3: I am special weekly calendar

Instructions:

Write one special thing a day about your child on a calendar or post it on a mirror in his or her room. Or, have your child draw a picture with your help of one special thing each day for a week. Talk about what makes your child special and wonderful with him or her. In our weekly calendar a child said he or she had a special day when watching a movie, going to the zoo, or getting a hug from his or her parent! Once a parent knows of these things, it is a great list to have to cheer your child and raise his or her spirits.

Materials Needed:

- Calendar or construction paper
- Crayons

Monday
- Cat in the hat
- Reading a Book

Tuesday
- Basketball
- Playing basketball

Wednesday
- Watching a Movie

Thursday
- Playing with my dog

Friday
- Going to the Zoo
- Going to the Zoo

Saturday
- Singing songs

Sunday
- Hug from mom
- Hug from dad
Activity 4: Safe and Happy Heart

Materials Needed:

- Construction paper
- Crayons

Instructions:

Draw a large heart on a piece of paper. Help your child make a list of all the things that make his or her heart feel happy and safe. Put the list next to the heart and help your child illustrate the picture. Then, when your child needs a pick-me-up get the picture and go through the list and recapture or re-enact the things that lift his or her spirits. For example, one little girl had us write next to her heart that going to the lake for a visit with her family was fun as was spending time with her dog. We helped her imagine these things and "make a picture of the good times in her mind" and this helped her to reduce feelings of "missing home." Another little girl reported that she liked chocolate, a blankie and the Woah Woah song from Bruce Springstein -- and her parent helped her write this next to her heart. She and her parent promised to sing the song she liked every day and her parent went out and bought the girl a blankie and she felt more at home! Thus, this small art activity gave the parent an idea of how to cheer a little one!
Activity 5: Dynamite Dinosaur

Instructions:

Draw a dinosaur with three squares or circles on its shell or back. Let the child know that this is a Dynamite Dinosaur where the child can list 3 good things about him or herself. Have the child list the 3 good things. Then, let the child decorate the picture!

Materials Needed:

- Construction paper
- Crayons
Activity 6: Warm and Fuzzy Poster

Instructions:

Have the child create a list of things that make him or her feel good—warm and positive. Then for each idea, glue a cotton ball on a piece of cardboard or a piece of construction paper. Keep the list of warm fuzzies to recall and review when a pick-me-up is needed. And, of course, decorate the paper!!!

Materials Needed:

- Construction paper or cardboard
- Crayons
- Cotton Balls
- Glue
Activity 7: I am a “Superstar” Poster

Materials Needed:
- Construction paper
- Crayons
- Glue
- Felt
- Stickers

Instructions:

Draw a star on a piece of construction paper or purchase some felt and cut out a star and glue it on a piece of construction paper. Have the child decorate the star with stickers or color it. Then, make a list of all the ways in which your child is a superstar! It may be because he or she is good at jump rope, likes to play and dance, or is a good friend. Draw pictures next to each thing and keep the superstar poster and hang it in a special place so that your child can go over things that are special about him or her when needed!
Activity 8: Helping Hands Butterfly

Instructions:

Have your child hold his or her hands together -- with thumbs next to each other on a piece of paper. If your child can’t hold his or her hands together don’t worry about it. Trace your child’s hands and it will make a butterfly shape. Color in the butterfly and put a sky around it. Let you child know it is a helping hands butterfly and ask him or her what helps with coping and have a list of ideas for helping your child cope handy-- along with some cool art!

Materials Needed:
- Construction paper
- Crayons
**Activity 9: Tree of Support**

**Instructions:**

On a piece of paper draw the trunk and branches of a tree. Then, you and your child can add some leaves. On each leaf write down someone that is a support to your child. Have your child picture that person or make a plan to call them. As you do this exercise you have a chance to process how loved and special your child is.

**Materials Needed:**

- Construction paper
- Crayons
- Tape (optional)