

# Through A Critical Caring Lens: Social Support for CMC Family Caregivers

April 27, 2026

Heather Kennedy PhD, APRN, PCNS-BC



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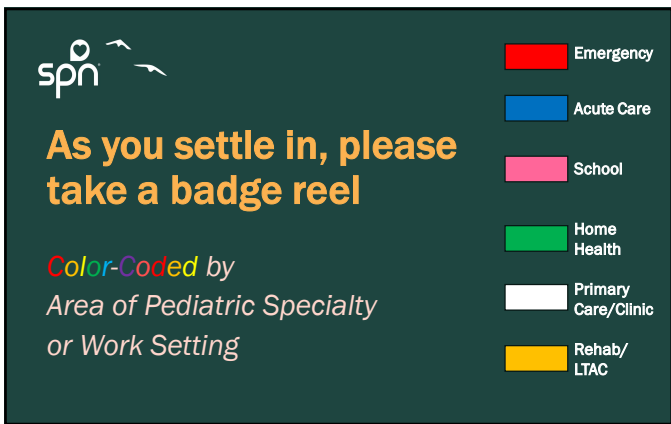
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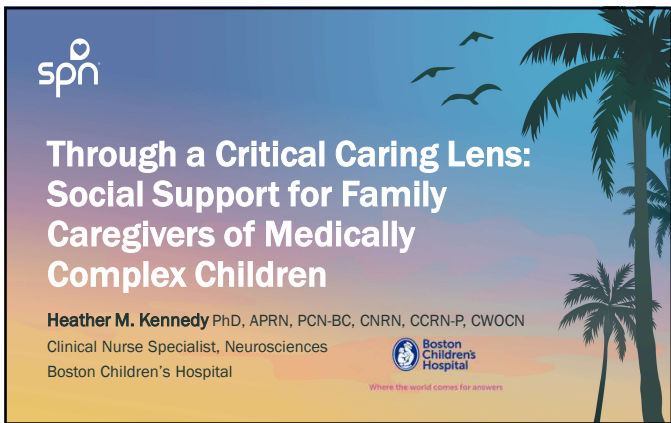
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**Disclosures** 

Current Secretary/Treasurer of the Agnes Marshall Walker Foundation (AMWF) for the American Association of Neuroscience Nurses.

- This board position in no way impacts the content presented today, the research study, analyses, or results.

No other disclosures.

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**Objectives** 

- 1) Explain current support needs family caregivers of children with medical complexity (CMC) have previously identified in the literature.
- 2) Describe the current evidence-based recommendation for a comprehensive system of care to promote optimal outcomes for CMC.
- 3) Identify 2 factors associated with CMC family caregiver perceived social support.
- 4) Discuss key components of Critical Caring Theory used to frame nursing research and interventions to explore caregiver support needs.
- 5) Apply an explanatory model of perceived social support to intervention planning for CMC and their family caregivers.

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**Background**

*Support Needs of Family Caregivers of Children with Medical Complexity*

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### Who are Children with Medical Complexity (CMC)?



CMC are a subset of the larger population of children & youth with special health care needs.

CMC are children who have:

- 1) > 1 complex chronic condition (CCC) that is expected to last > 1 year
- 2) Functional limitation(s) (i.e., dependency on a medical device)
- 3) High health care utilization (i.e., multiple specialty providers/services, ED visit use, hospitalizations)

**CMC = CCC + Functional Limitation → High Health Care Utilization**

(Cohen et al., 2018; Parente et al., 2021)

**Examples**

- Hypoxic ischemic encephalopathy with oropharyngeal dysphagia & G-tube dependence
- Spastic quadriplegic cerebral palsy with wheelchair dependence
- Chronic respiratory failure with tracheostomy & vent dependence

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### Health Equity Concerns for CMC



*Lack of trained/specialized community RNs*  
*Inadequate pay for the level of care provided in the home (Foster et al., 2020)*

- Limited access to accessible transportation (Batson et al., 2022)
- High out-of-pocket expenses impacts family finances
- Home care nursing services are hard to find
- Limited LTAC, rehab, or respite options (Foster et al., 2022)

*Out of pocket exceeds > \$1000/yr for > 50% of CMC (Allshouse et al., 2018)*

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### Health Equity Concerns for CMC



- Hospital related concerns for CMC
  - As high as 37.9% of pediatric 30-day hospital readmissions are children with medical complexity (Kennedy et al., 2023)
  - Prolonged hospital LOS
  - Increased need for ICU level care
  - Higher risk of mortality during hospitalization than other children (Cohen et al., 2018)
- CMC account for 1/3 of health care costs for children in the US
  - Coverage for services varies by insurer, State policies/programs
  - Health care system is increasingly more complex to navigate d/t need for home health, specialty providers, durable medical equipment, changing health care policy (Cohen et al., 2018)

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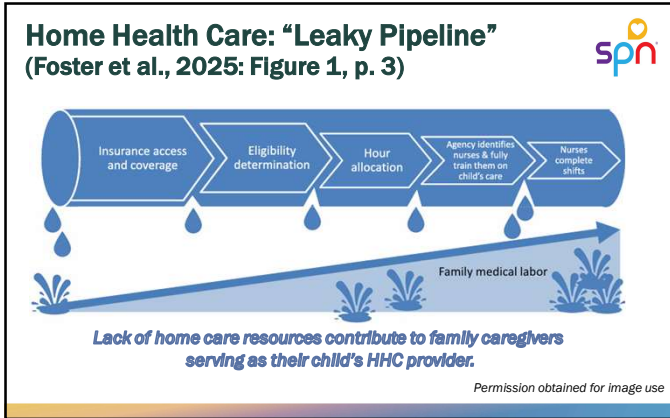
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**CMC Caregivers Need Support**

- To meet their child's needs
- To be able to meet their own needs (i.e., physical & mental health)
- To ensure they can meet the needs of their entire family

Image from <https://courageousparentsnetwork.org>

The slide features the SPN logo in the top right and a photograph of a caregiver sitting with a child in a hospital bed.

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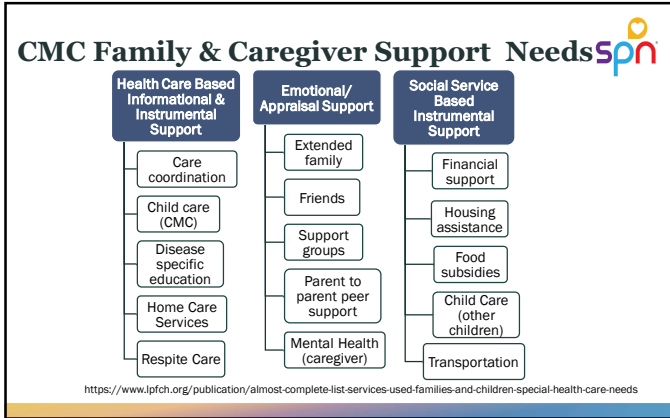
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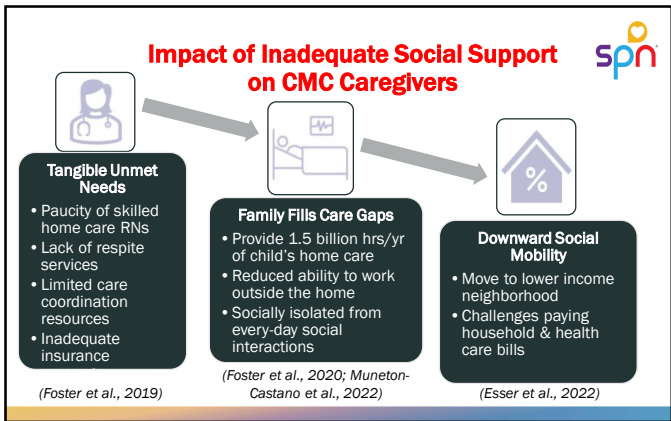
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**Family Caregiver-Identified Support Needs** 

**MENTAL HEALTH MATTERS**

- Home Care Nursing Hours
  - With adequate training
  - Off-shift hours so they can sleep
- Respite care for their child
- Mental Health services for themselves
- Child Care for other children
- Financial support

References:  
(Edelstein et al., 2017; Foster et al., 2022; Geyer et al., 2025; Muneton-Castano et al., 2022; Yu et al., 2021)

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**Comprehensive System of Care for CMC**

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**What does a well-functioning system of care for CMC look like?** 

- (1) Family feels like a partner in their child's care,
- (2) Child receives care within a medical home,
- (3) In the past year, the child has had both a preventive medical and dental visit.
- (4) Insurance coverage is adequate,
- (5) Child has no unmet needs or barriers to services.

(Yu et al., 2021)

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**Family-Centered Medical Home** 

- Views the child in the context of the family & community
- Family-centered, community-based care that is:
  - Accessible
    - Have a usual source of sick care and have a PCP
  - Continuous & comprehensive
    - Receives needed referrals
  - Coordinated among services (care coordination)
  - Culturally effective

(Flasch, 2024)

**Gold Standard for CMC**

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**Update: Comprehensive Care Coordination** 

**2022-2023 National Survey for Children's Health Results related to CMC living in the United States**

- 51.2% reported gaps in care coordination
- 88.3% reported unmet health care needs
- 2 in 3 CMC caregivers reported spending time each week to coordinate their child's care

(Kennedy et al., 2026)

(Minnaert et al., 2025)

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**What if the system is not comprehensive or well-functioning?** 

- The family caregiver fills gaps in the system to meet their child's needs (often at the expense of their own health)  
OR
- The child's needs are unmet and they experience frequent hospitalizations  
OR
- The family makes the difficult decision to place their child in a care facility (if one is available)

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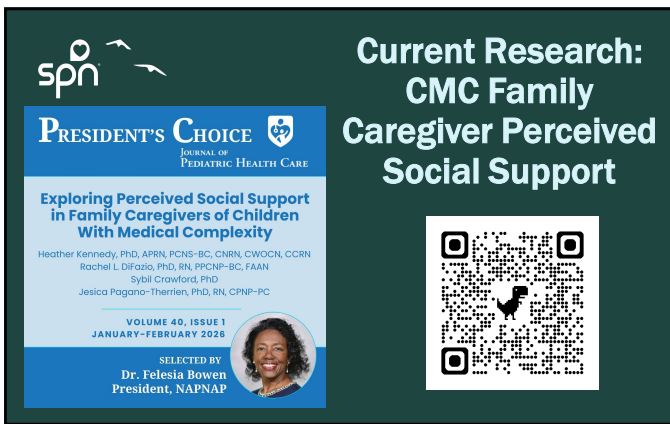
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**Current Research: CMC Family Caregiver Perceived Social Support**

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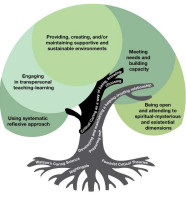
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**Study Overview** 

**Purpose**

To describe the relationship between perceived social support (PSS) for family caregivers of CMC and potential predictors, primarily social determinants of health (SDoH) and the child's degree of medical complexity.



*Critical Caring Theory* was the theoretical framework for the study.  
(Falk-Rafaël, 2005)

**Aims**

- 1) To describe the association between PSS and SDoH risk for CMC family caregivers.
- 2) To evaluate an explanatory model for PSS for CMC family caregivers using SDoH risk and factors associated with the child's degree of medical complexity.

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## Methods



- Design** Descriptive, correlational, explanatory
- Setting & Sample** Pediatric Specialty Academic Medical Center (single center); patient-caregiver dyads from 15 states
- Data Collection** Online survey (REDCap); Aug 2024 - Feb 2025  
*REDCap reference: (Harris et al., 2019)*
- Recruitment** Email, In-person (Neuro/Epilepsy, Cerebral Palsy, Complex Care Clinics); Electronic consent (IRB)
- Analysis** Descriptive statistics (sample description); Pearson & Spearman rho correlation (Aim 1); Linear regression (Aim 2)

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## Conceptual & Operational Definition of Perceived Social Support (PSS)



| Social Support Attributes    | Conceptual Definitions<br><small>(Hutchison, 1999; Langford et al., 1997)</small>   | Associated Social Provisions* |
|------------------------------|---|-------------------------------|
| <b>Emotional Support</b>     | Providing caring, empathy, love, and trust to help one navigate their emotions  | Nurturance<br>Attachment      |
| <b>Informational Support</b> | Providing information to promote problem solving and reduce associated stress.  | Guidance                      |
| <b>Instrumental Support</b>  | Providing material goods and resources when there is an immediate need.   | Reliable Alliance             |
| <b>Appraisal Support</b>     | Providing information that allows a person to evaluate and affirm their actions.  | Reassurance of Worth          |
| <b>Social Integration</b>    | The presence of both a support network and a connection to people in that network so that one is embedded within their support network. | Social integration            |




Photo from <https://familyvoices.org>

**\* Social Provisions Scale to measure PSS**

**Perceived Social support =  $\frac{\text{Social Support Attributes}}{\text{Acknowledgement by the Individual}}$**

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## Sample Inclusion Criteria



|                  | Inclusion Criteria   |
|------------------|--|
| <b>Child</b>     | <ul style="list-style-type: none"> <li>Receives specialty health care at the study site</li> <li>Age ≥ 6 months to &lt; 18 years old</li> <li>At least 1 confirmed complex chronic condition</li> <li>Dependent upon at least 1 medical device</li> <li>Followed by &gt; 1 specialty provider or has evidence of high health care utilization in the past 12 months</li> <li>Resides at a U.S. address</li> <li>Resides with their legal guardian and not at a long-term care</li> </ul> |
| <b>Caregiver</b> | <ul style="list-style-type: none"> <li>Child's legal guardian</li> <li>Resides with and provides care regularly to the child</li> <li>&gt; 18 years old</li> <li>Able to read English or Spanish</li> <li>Consents to participation</li> </ul>   |

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**Data Collection Tools**  
English & Spanish translations 

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| <p><b>Perceived Social Support</b></p> <p><u>Social Provisions Scale (SPS)</u></p> <ul style="list-style-type: none"> <li>• 24-item, Likert scale</li> <li>• Measures 6 Social Provisions (categories of social support)</li> <li>• Score Range 24-96</li> <li>• Cronbach's alpha             <ul style="list-style-type: none"> <li>• English = .915</li> <li>• Spanish = .85</li> </ul> </li> </ul> <p>(Cutrona &amp; Russell, 1987)</p> | <p><b>Social Determinants of Health Risk</b></p> <p><u>PRAPARE Tool</u></p> <ul style="list-style-type: none"> <li>• 17 required (scored) items</li> <li>• Each item represents a SDOH risk:</li> <li>• Total Risks= 0-22</li> <li>• Cronbach's alpha = .86</li> <li>• Validity = .935 (Greatest Lower Bound)</li> </ul> <p>(<a href="https://prapare.org/the-prapare-screening-tool/">https://prapare.org/the-prapare-screening-tool/</a> )</p> |
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**SDoH Risks Measured by PRAPARE** 

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| <ul style="list-style-type: none"> <li>• <b>Personal Characteristics</b> <ul style="list-style-type: none"> <li>• Race/Ethnicity</li> <li>• Language (if not English)</li> </ul> </li> <li>• <b>Family &amp; Home</b> <ul style="list-style-type: none"> <li>• Household size</li> <li>• Housing status &amp; stability</li> <li>• Zip code/neighborhood</li> </ul> </li> <li>• <b>Social &amp; Emotional Health</b> <ul style="list-style-type: none"> <li>• Stress</li> <li>• Isolation vs Social Integration</li> </ul> </li> </ul> <p>(Weir et al, 2020)</p> | <ul style="list-style-type: none"> <li>• <b>Money &amp; Resources</b> <ul style="list-style-type: none"> <li>• Education</li> <li>• Employment Status</li> <li>• Insurance Status</li> <li>• Income</li> <li>• Insecurities (food, utilities, childcare, phone, medicine and health care)</li> <li>• Material security needs</li> <li>• Transportation needs/barriers</li> </ul> </li> </ul> |
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**Data Collection of Caregiver & Child Demographics** 

- Caregiver Age (years) & Gender
- Approved Home Care Nursing Hours/week
- Home Care Nursing Hours received in the past week
- Medical devices the child uses at home ("select all" list + other "fill-in")
- Caregiver education level if > HS

**Obtained via:**

- ✓ Extraction (manual) from the Electronic Medical Record
- ✓ Electronic Data Pull from electronic data warehouse (i.e., billing codes)
- ✓ Additional Survey items (professionally translated, backward/forward)



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**Study Results**

**Aim 1**  
Association between PSS and SDoH

**Aim 2**  
Explanatory model (predictors) of PSS for CMC family caregivers

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**Sample Characteristics**

**Caregiver Race/Ethnicity**

- Non-Hispanic White (n= 40, 44%)
- Non-Hispanic Black (n= 17, 18.7%)
- Hispanic or Latino (n= 26, 26.6%)
- Non-Hispanic Other (n=8, 8.8%)

Total= 91

**Household Information**

- Average household size= 4
- Many met FPL criteria (n= 29, 31.9%)

**Additional Characteristics:**

- 23-66 yrs
- White
- Female
- 40 yr
- College ≥ BS/BA
- 10 complexity dx's
- 4 medical devices
- 8 home meds
- 22% (n= 20) had approved Home Health (HH) RN hours
  - HH hours not filled for 60% (n=12)

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**Findings: Perceived Social Support**



- SPS scores: Mean = 79.86, SD = 12.04, Range = 56-96
- White, Non-Hispanic/Latino CMC Caregivers reported the highest perceived social support
- CMC caregivers from "Other" race-ethnicity groups reported the lowest perceived social support



*Image from [courageousparentsnetwork.org/library](http://courageousparentsnetwork.org/library)*

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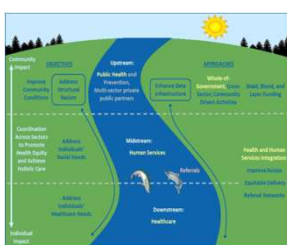
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### Findings: SDoH Risk

- Caregivers reported 3 (median) SDoH risks (range 0-22)
- 33% (n= 30) reported unmet needs
  - Child care (13.2%, n= 12)
  - Utilities (13.2%, n= 12)
- 12.1% (n= 11) were concerned about losing their housing

Figure from Health Affairs Blog, January 16, 2019 .

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### Perceived Social Support & SDoH Risk



|                           | Pearson Correlation | Sig. (2-tailed) | 95% Confidence Intervals (2-tailed) <sup>a</sup> |       |
|---------------------------|---------------------|-----------------|--|-------|
|                           |                     |                 | Lower  | Upper |
| sps_total - prap_total_sc | -.418               | <.001           | -.575  | -.232 |

**As SDoH Risks ↑, PSS ↓.**

Moderate negative correlation:  
( $r = -.418, p < .001$ )

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### Explanatory Model for PSS



**Predictor Pool** (9 variables)

- Child factors (4):  $p > .05$
- Caregiver Factors (4)
  - (stress, gender):  $p < .05$
  - SDoH Risk (total):  $p < .001$

**Final Model**

- $F(3, 87) = 12.53, p < .001$
- Explained 27.8% of the variance in PSS ( $R^2 = .302; R^2_{adjusted} = .278$ )

- Stress was independently associated with PSS ( $r = -.437, p < .001$ )
- Caregiver gender (Male) was associated with lower PSS
- SDoH Risk remained a significant independent predictor in the final model
- No child complexity variables predicted PSS

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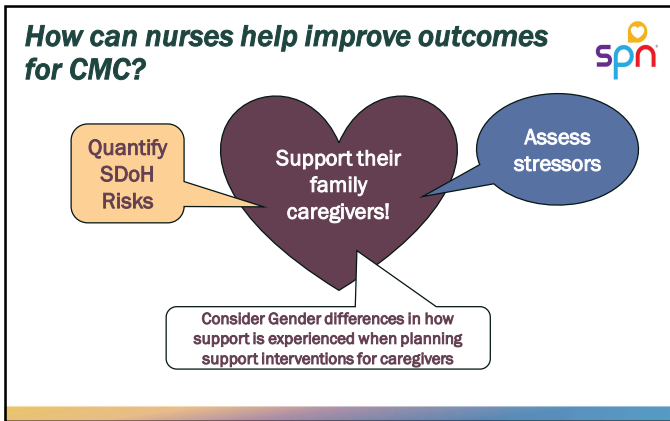
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**What next?**

**Theory Informed Nursing Interventions**

Critical Caring Theory

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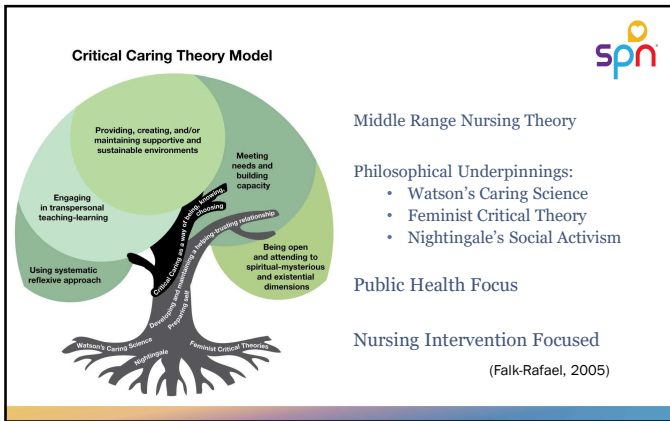
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## Intervention Planning

Supporting CMC Caregivers

- Providing Supportive, Caring Environment
- Meeting Needs & Building Capacity
- Engaging in Teaching & Learning
- Attending to Spiritual Dimensions
- Using a Systematic, Reflexive Approach

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## Providing Supportive, Caring Environment



**Reduce caregiver stress**  
ASK

- How stressed do you feel right now?
- What is causing you the most stress?

**Provide emotional support**  
ASK

- Do you have people in your life who you can talk to?
- Do you want me to connect you to social work or someone who you can talk to?
- I am here to help you. How can I help?

**Consider gender differences in expression of support needs and experience of social support.**



Image from <https://familylives.us/resources/recommended-study/>

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## Support Resources



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|--|---|
| <p><b>Courageous Parents Network</b></p>  <p>Resource for both families of CMC and health care providers</p> <p>Nonprofit 501(c)(3)</p> <p>Mission is to orient, equip and empower families and others caring for a child with a serious medical condition</p> <p><b>"PedIPals"</b></p> <p>Palliative care support (including siblings)</p> <p>+/- offered through Medicaid for CMC/ children with life-limiting conditions</p> | <p><b>Family Lives</b></p> <p>Provides home health care (HHC) in MA</p> <p>Funded through the Michael Brennan - Scotty Luce Foundation For Family Support</p> <p>Provides HHC service to people with serious and complex health and assists patients and their loved ones in the achievement of ordinary family lives and community lives, lives where they have both a spot at home with family and a place in the community with friends.</p>  |
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**Meeting Needs & Building Capacity** 



- Screen for SDoH risk or Health-related Social Needs
  - Recommend adopting an assessment tool that is valid AND can quantify a total score
- Make referrals to address the SDoH risks you can address
  - Social Work Consult
  - Case manager
- Provide resources to address health-related social needs
  - Health Insurance-based case manager
  - School resources
  - Mental Health Resources
  - Support Group information

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**Engaging in Teaching & Learning** 

- Provide disease-specific education (teach-back, demonstration/hands-on)
- Refer to educational resources

Examples:

- Epilepsy Foundation 
- National Organization of Rare Diseases 
- Congenital Heart Defect Families Association   
<https://www.heartsuniteglobe.com/>
- United Cerebral Palsy <https://ucp.org/> 

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**Attending to Spiritual Dimensions** 

**Aligns with the Medical Home Model**

- ✓ Goal of providing culturally effective care
- ✓ Part of providing CMC with a Comprehensive & Well-Functioning system of care

- Ask questions to understand cultural influences on decision making and goals of care for their child → incorporate into care plan
- Offer spiritual support (i.e., chaplain)
- Respect religious practices, if applicable
- Engage palliative care for CMC and children with life limiting condition
  - "PediPals"
    - Supports: case management, social work, spiritual care, child-life specialist, music therapy, massage therapy, art therapy
    - This team assists with legacy building of the child for parents and family

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**Using Systematic Reflexive Approach** 

- Implement evidence-based interventions
- Engage Family Advisory Councils (acute care) or Parent Engagement (school, community) for intervention ideas and feasibility
- Examine results of interventions
  - Quality Improvement → PDSA Cycles
  - Nursing Research → Test Interventions, Measure Outcomes
- Bring your results to Policy Makers
  - Ask for support (i.e., Nursing Organizations)
  - Letters to your legislators



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**Break into groups of 6 people—as many different badge reel colors in each group**

**Case Studies**

*Only when we partner can we SEE the WHOLE picture and find solutions that address the health care system these children and families experience.*

**Why?** To address gaps throughout the entire health care system we need to consult with nurses who work in different clinical settings.

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**Case 1: Annie** 

Annie is a 12yo F with pMhx explosive onset epilepsy, Was re-admitted 3 times within the first 2 months after diagnosis. During her current 8-mo admission, she spent 2 mos in the ICU managing status epilepticus and weaning/optimizing anti-epileptic meds.

- could not extubate and underwent tracheostomy
- experienced a complication and has left sided hemiparesis
- failed a swallow evaluation and underwent G-tube placement
- working with PT, but cannot ambulate or sit without support

Her multidisciplinary team has searched for rehab placement but no rehab will accept her because she cannot tolerate more than brief PT sessions

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**Annie's Discharge Options are limited** 

- Home with skilled nursing services and in-home PT/OT

OR

- Long-term acute care

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**Due to no LTAC within 2 hours of her home, parents decide they want to bring her home** 

- The family primarily speaks Spanish and an interpreter has been used for all medical updates throughout the admission
- The father recently lost his job after missing extensive time due to his daughter's illness and the mother stays at home to care for her children
- Annie's insurance is State Medicaid through the Children's Health Insurance Program (CHIP)

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**Discuss Interventions Annie Case 1** 

- What other information do you need to plan interventions?
  - Consider what you learned from the literature presented and research study results in the interventions you plan
  - Frame interventions using a Critical Caring Theory perspective



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**Case 1** 



**Share your plans with everyone**

- Need volunteers from 2 groups
- Choose a speaker from your group to present a brief summary of your discussion

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**Case 2: Bobby** 

Bobby is 16yo and has a complex medical hx, including prematurity s/p VP shunt due to an IVH, epilepsy, neuromuscular scoliosis, spastic quadriplegic cerebral palsy, central sleep apnea & chronic respiratory failure requiring night-time ventilation via a tracheostomy tube, and oropharyngeal dysphagia and recurrent aspiration s/p G-tube.

Recently Bobby has spent little time at home due to frequent illness. Each time he is admitted he requires the ICU because of his ventilator needs. He lives at home with his Dad who is his sole care provider. Because of the frequent hospitalizations, all the overnight home care nurses have left.

Dad works part-time as a postal carrier but has been out of work because of a back injury.

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**Case 2 continued** 

Bobby has recently gained a fair amount of weight and his scoliosis and contractures have worsened making it very difficult for Dad to get him in and out of his wheelchair. Because he has been sick so much, Bobby has rarely been able to go to school in the past 3 months.

You are the High School nurse who coordinates with the nurse who joins him at school. The personal nurse at school confides in you that Dad expressed feeling like he just can't do it any more. He admits that he has exhausted Bobby's respite hours and he brought Bobby into the hospital last week because he needed a break. He does not know what he is going to do when school is out in 2 months.

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**Discussion Case 2:**  
**Bobby's Dad's Support Needs**



- What needs can you identify & what other information would you want to have before planning interventions?
- What referrals might you make? Or who do you think might be able to help?
  - Consider who else may be a part of Bobby's care that you could partner with
  - Frame your approach according to at least 1 aspect of Critical Caring Theory
- Choose 1 intervention to offer Bobby & his Dad
  - How did you decide on this intervention?
  - What will it take to implement this intervention?

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**Case 2**



**Time to Share**

- Need volunteers from 2 groups
- Choose a speaker from your group to present a brief summary of your discussion




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**Summary**



- CMC Caregivers are in need of social support-based interventions
- The main predictors of perceived social support for CMC family caregivers are SDoH Risk and Stress
- More research is needed to better understand gender differences in PSS for CMC family caregivers
- Using theory and evidence to guide family-centered nursing interventions promotes a structured approach to caring for CMC that includes assessment of both the caregiver and child needs and consideration of the entire system of care
- Collaboration is key to ensure a comprehensive system of care for CMC that fills the gaps in care

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**Thank You** 


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My husband, Adam, & children Brendan, Declan, & Caleb. The greatest support system anyone could ask for!



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**References** 



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**Questions?**



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