Clinical Practice Guideline for Support of Families of Children with Chronic Conditions

INTRODUCTION/PROBLEM STATEMENT

Pediatric nurses in all settings play an important role in the assessment of family caregiving burden and identification of resources to optimally support family functioning. This clinical practice guideline identifies four domains of family functioning for assessment and intervention: (1) physical and mental health, (2) social, (3) financial, and (4) caregiving.

DEFINITION(S)

**Children with chronic conditions:** “An ongoing health condition that: (1) Has a biologic, psychological, or cognitive basis, and (2) Has lasted or is virtually certain to last for at least 1 year, and (3) Produces one or more of the following sequelae: (a) Limitation of function, activities, or social role in comparison with healthy age peers in the general areas of physical, cognitive, emotional, and social growth and development. (b) Dependency on one of the following to compensate for or minimize limitation of function, activities, or social role: (i) Medications (ii) Special diet (iii) Medical technology (iv) Assistive device (v) Personal assistance (c) Need for medical care or related services, psychological services or educational services over and above the usual for the child’s age or for special ongoing treatments, interventions, or accommodations at home or in school.” This term was chosen over the more-widely used “children with special health care needs” because it describes a narrower group of children with more extensive needs and heavier healthcare utilization.

**Respite care:** Respite care is a formal support service designed to give family members temporary, short term relief from the care of a child with chronic illness or disability.

RATIONALE AND SUPPORTING INFORMATION

Family functioning and family caregiving burden are important considerations for supporting children with chronic conditions. Family functioning and caregiving burden are generally conceptualized as multidimensional with various frameworks and sub-domains articulated in the literature. This guideline addresses four domains: (1) physical and mental health (such as physical and emotional care provided by families), (2) social, (3) financial, and (4) caregiving.

Physical and mental health. Studies have shown that caregivers experience increased fatigue and are at risk for poor sleep quality, which has been associated with poor physical and emotional functioning. Similarly, families of children with chronic conditions may also be at higher risk for mental health conditions such as depression and anxiety.

Social. The importance of the social impacts of family caregiving has received significant attention in the literature. For example, families of children with chronic conditions are at risk for social isolation. When social support has been provided for families, it has been associated with decreased stress, enhanced resilience and coping, as well as strengthened ability by the family to manage their child’s chronic condition.
Financial. Financial resources are a frequent concern for families of children with chronic conditions.\textsuperscript{18,19} These families are more likely to experience a financial burden than families of healthy children, with greater than 50\% of families reporting financial problems and a reduction in household employment to accommodate their child’s care.\textsuperscript{20} Family out-of-pocket costs may include co-payments for medical office visits, medications, hospitalizations, equipment and supply costs not covered by insurance, and adaptations to the home or vehicle to provide a safe environment for the child. Families are in need of financial support and should be connected to federal, state, and local programs that can help to alleviate this burden.\textsuperscript{21} Programs and the resources they provide will vary by state and locality.

Caregiving. Families must also be equipped with the knowledge, skills, and support necessary to engage in self-management of the child’s condition.\textsuperscript{22-24} Family members will require different teaching and support strategies to assume caregiver responsibilities within the home.\textsuperscript{25,26} The family’s health literacy level should be assessed and incorporated into teaching strategies so as to ensure understanding of the content being taught.\textsuperscript{27,28} Nurses and their interprofessional colleagues should also have an understanding of the distribution and burden of caregiving responsibilities and, when possible, identify supportive caregiving interventions that can help to minimize the family’s burden.\textsuperscript{29-31}

Respite care is an example of a supportive caregiving intervention. Most of the research specifically on the effects of respite was conducted in the 1970s and 1980s in the wake of widespread consent decrees that led to the deinstitutionalization of care for children and adults. Recent studies involving children with chronic illness and disabilities have described respite care as an important service to offer parents to provide temporary relief from the demands of the child’s care, to attend to the needs of other family members, to maintain their social relationships, and for improved marital quality.\textsuperscript{3,32-39} Teenaged children with a chronic condition have described respite care as benefiting them as well by giving them a break from their parent’s constant care.\textsuperscript{40} More than a theoretical support, respite care has been associated with a decrease in the odds of the child being hospitalized in the succeeding 60 days, leading to eventual cost savings to the family and society.\textsuperscript{41}

In studies of parents’ support needs, respite care is listed as their greatest unmet need,\textsuperscript{42} and there is a consistent theme of not being able to get information about respite care on their own.\textsuperscript{43} Parents have different definitions of what constitutes a “break” from their child’s care.\textsuperscript{33} The process for applying for respite care and the models that exist in different areas of the country vary as does the availability of respite resources at any given time. Models of respite care include in-home respite care, designated respite care centers, and respite camps. Parents must have a role in deciding which respite model best suits their needs along with the needs of their child.\textsuperscript{40,44}

Siblings. Siblings of children with chronic illness are also in need of supportive measures to ensure optimal mental health and quality of life. Up to 50\% of siblings have emotional and behavioral difficulties;\textsuperscript{45} social support is a predictor of lower depressive symptoms in siblings of children with chronic illness.\textsuperscript{46,47} Parent proxy reports of sibling quality of life are generally higher than sibling self-report thereby supporting the self-assessment of the sibling population to determine their support needs.\textsuperscript{48-50} Support programs, such as camp programs, illness education, and enhancing control through cognitive coping strategies, are associated with better sibling mental health.\textsuperscript{51-54} It is particularly important to provide education about the diagnosis to the sibling and to address the sibling’s questions about the condition to reduce anxiety and fear.\textsuperscript{55,56}
CLINICAL PRACTICE RECOMMENDATIONS

Physical and Mental Health Domain:

Pediatric nurses should:
Assess family/caregiver physical and mental health, especially levels of sleep, fatigue, or signs and symptoms of depression or anxiety, and encourage consultation with adult-oriented services as necessary.7-12 [level C]
Assess family/caregiver spirituality and coping strategies.13,17,57,58 [level C]
Assess mental health needs of siblings of children with chronic illness.48-50 [level C]
Refer siblings to appropriate physical and mental health care providers.45-47 [level C]
Encourage parents to engage in self-care activities to ensure that they are able to care for their child.9,34,59 [level C]
Help parents to develop a self-care plan.59 [level C]

Social Domain:

Pediatric nurses should:
Assess family members’ social relationships and social support networks.6,13-17 [level C]
Assess individual parent/caregiver understandings of their child’s condition and goals of care.16 [level C]
Provide families with information about formal and informal parent peer support programs.61,62 [level E]
Advocate for sibling involvement in social support programs for siblings, such as sibling camp programs.50-53 [level C]

**Financial Domain:**

Pediatric nurses should:
Assess the financial burden of the child’s care needs and family access to financial resources.18-20 [level C]
Refer families or generate a consult to support staff members who can connect families with financial resources, such as a social worker or case manager.21 [level C]

**Caregiving Domain:**

Pediatric nurses should:
Assess the family’s knowledge of management of the child’s condition.14 [level C]
Assess individual family members’ health literacy skills.27,28 [level D]
Assess the time burden through an understanding of individual family members’ caregiving responsibilities.29-31 [level C]
Discuss respite resources with the family early and often, including before every hospital discharge. This discussion should include types of respite available and suitability for the family and child patient.35,36,38,39,44 [level C]
Continue to assess parent/caregiver need for respite once the child is home, as need and readiness for the service will vary.7,37-39,42 [level C]
Evaluate the effects of respite care on caregivers and siblings.52,33,44,45 [level C]
Provide education and information about the diagnosis to siblings of child.52-56 [level C]

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<th>Level</th>
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<td>Level A</td>
<td>Meta-analysis of multiple controlled studies or meta-synthesis of qualitative studies with results that consistently support a specific action, intervention or treatment</td>
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<tr>
<td>Level B</td>
<td>Well-designed controlled studies, both randomized and nonrandomized, with results that consistently support a specific action, intervention or treatment</td>
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<td>Level C</td>
<td>Qualitative studies, descriptive or correlational studies, integrative reviews, systematic reviews, or randomized controlled trials with inconsistent results</td>
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<td>Level D</td>
<td>Peer reviewed professional organizational standards, with clinical studies to support the recommendations</td>
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<td>Level E</td>
<td>Theory-based evidence from expert opinion or multiple case reports</td>
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<td>Level M</td>
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This Clinical Practice Guideline is authored by the SPN Chronic Conditions CPG Taskforce:

Jennifer Baird, PhD, MPH, MSW, RN, CPN
Laura H. Hays, MSN, APRN, CPNP-PC
Elizabeth Straus, MN, RN
Nancy M. Terres, PhD, RN
Lori Jean Williams, DNP, RNC-NIC, CCRN, NNP-BC
REFERENCES


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