

Children with Chronic Conditions: Impact on Families Teaching Strategy

Overview of Teaching Strategy

Chronic medical conditions in children can cause challenges for families, communities, schools, and the health care system. Chronic condition is a broad term, and usually refers to a health problem that lasts over three months, affects a child's normal activities, and may require frequent hospitalizations, medical visits, or home health care. Chronic conditions may affect a child's physical, emotional, or intellectual well-being and include asthma, epilepsy, and sickle cell disease, as well as such conditions as obesity, autism, and developmental disabilities.

Parents, siblings, and caregivers often find it stressful to live with and care for a child with a chronic condition. The financial drain related to cost of care and therapies may be extensive. Family dynamics can be disrupted when the child requires more time than the other children and special equipment, medications, and other adaptations. Parents may find their relationships with each other are strained, and siblings may feel they are being neglected or left out. On the other hand, families may also find that the child brings special contributions to the family that enrich their lives and strengthen family bonds.

This teaching strategy is designed to help students understand the impact caring for a child with a chronic condition has on family members and family life. Students can refer to one of the pediatric simulation cases, or to families encountered in an inpatient or community clinical experience. If students are unfamiliar with the simulation cases, and have not had appropriate clinical experiences with children with chronic conditions, an alternative option would be to refer to a family they have read about in a book or seen in a movie. (Examples of books include *Wonder* by R.J. Palacio, *The Baking Life of Amelie Day* by Vanessa Curtis, and *House Rules* by Jodi Picoult; suggested films include *The Fault in Our Stars*, *Lorenzo's Oil*, and *My Sister's Keeper*.)

Students will be required to engage in the literature on children with chronic conditions and investigate online resources available to families with specific problems and needs. Students can use these resources to complete this teaching strategy (faculty may choose one or both activities, depending on learners' needs):

1. Demonstrate an understanding of the impact of a chronic illness or chronic condition on the child and family by creating an original story told from the perspective of the child, sibling, parent, or other family member. This story could be in the form of a monologue, play, poem, or video – or other format the student prefers.
2. Discuss the ways the nurse could intervene and assist this family, considering the family's social and economic background and the role of an interprofessional team.

Learning Objectives

Students will:

- Develop an understanding of a selected chronic illness or condition.
- Investigate treatments and resources pertinent to this condition.
- Recognize the impact of the condition on the patient and other family members.
- Consider how this condition may be similar or different from other chronic conditions.
- Create a story from the patient or family member's perspective.
- Identify how nursing can play a role in improving outcomes for the child and family.
- Identify how social determinants of health impact outcomes for families managing chronic conditions.

Learner Pre-Work

The three pediatric simulation cases are Thomas Sykes, age 17 (obesity and depression), Mia, age 4 (severe dental caries), and Damon McAdam, age 2½ (autism). Each case includes a parent monologue along with three simulation scenarios. Students should read a monologue to understand how to write from a family member's perspective. If they chose one of these children for this learning strategy, they can write their story using the voice of a different family member.

Whether a simulation case, a clinical case, or a fictional or "real" case from a book or movie is chosen, students should research and become familiar with the chronic condition or illness and possible treatments. Family support groups, both in-person and online, should be investigated. Websites for parents and children specific to the condition should also be examined and critiqued. Students can explore how the condition affects the child's education, mobility, communication, activities, and other aspects of life.

Faculty may instruct students to research and understand the condition or illness they have selected and share their findings with colleagues.

The following resources are provided to facilitate the student's prep work:

[Damon McAdam unfolding case](#)

[Mia Jones unfolding case](#)

[Thomas Sykes unfolding case](#)

healthychildren.org (American Academy of Pediatrics):

“How Chronic Illness or Disability Affects a Family”

<https://www.healthychildren.org/English/health-issues/conditions/chronic/Pages/How%20Chronic-Illness-Affects-the-Family.aspx>

Social Determinants of Health

<https://health.gov/healthypeople/priority-areas/social-determinants-health>

M. Mattison, August 21, 2017

Raising the Extraordinary blog: The Isolation of Special Needs Parents

<http://raisingtheextraordinary.com/isolation-special-needs-parenting/>

Exceptional Lives: Empowering Families, Accelerating Success blog

https://exceptionallives.org/parent-child-disability-tired-care-blog/?gclid=CjwKCAjw-6bWBRBiEiwA_K1ZDcprD1AtyEL_0L8RPitxsB_XmkysGAIv6BMMBkC7se5n93LmTtshoC6f8QAvD_BwE

Suggested Learning Activities

1. Demonstrate an understanding of the impact of a chronic illness or chronic condition on the child and family by creating an original story told from the perspective of the child, sibling, parent, or other family member.
 - a. This assignment could be a written monologue, screenplay, poem, or any format the student prefers.
 - b. Students could audiotape an interview, monologue, or dialogue from the family perspective.
 - c. Students could create a video of a play or interview.
 - d. Possible problems to be portrayed could include spousal stress, anger, or disagreement about treatment, sibling rivalry or expression of distress at increased responsibility, or child's anger at being overprotected due to the chronic condition
 - e. Students may be encouraged to include discussion of the positive impact the child with the illness or condition has on the family, or recognize the child's contributions and the gifts the child brings to the family.
2. Discuss the ways the nurse could intervene and assist this family, considering the problem or issue depicted in the story. Students should include recognition of the

family's social and economic background and its impact on health and treatments.

Inclusion of the role of an interprofessional team in helping the family is also encouraged.

- a. Students can discuss the role of the nurse in a primary care setting, inpatient setting, or community or school setting.
- b. The roles of interprofessional team members and their contributions to the family's or child's care can be explained.
- c. Students can be encouraged to investigate local clinics, support groups for the child and family members, camps, respite care sites, and other options available in their own area.

Suggested Reading

Depending on the curriculum and level of the students, the following articles may be helpful as faculty resources or for students' research:

AAP Council on Community Pediatrics. (2016). Poverty and child health in the United States. *Pediatrics*, 137(4), e20160339

Bitsko, R. H., Holbrook, J. R., Robinson, L. R., Kaminski, J. W., Reem, G., Smith, C., & Peacock, G. (2016, March 11). Health care, family, and community factors associated with mental, behavioral, and developmental disorders in early childhood — United States, 2011–2012. *MMWR*, 65(9). Retrieved from <https://www.cdc.gov/mmwr/volumes/65/wr/mm6509a1.htm>

Perrin, J. M., Anderson, L. E., & Van Cleave, J. (2014). The rise in chronic conditions among infants, children, and youth can be met with continued health system innovations. *Health Affairs*, 33(12), 2099-2105. doi: 10.1377/hlthaff.2014.0832

Murphy, N.A., Carbone, P.S., & Council on Children with Disabilities. (2011). Parent-provider-community partnerships: optimizing outcomes for children with disabilities [Clinical Report]. *Pediatrics*, 128(4). Retrieved from <https://pdfs.semanticscholar.org/d2d2/a1fcb90257d2a2bbd3c668fa9a29f9d9eee9.pdf>
doi:10.1542/peds.2011-1467

Smith, J., Cheater, F., & Bekker, H. (2013). Parents' experiences of living with a child with a long-term condition: A rapid structured review of the literature. *Health Expectations*, 18, 452-474.
doi: 10.1111/hex.12040



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