Sample Abstract-Poster Track B

Title
Primary Care for Children with Medical Complexity

Summary and Learning Objectives
Outpatient pediatric services in the U.S. often are not designed to provide holistic care. A primary care practice designed to fit the needs of children with medical complexity provides comprehensive care in a medical home setting. The practice addresses the medical and social-emotional care of these patients, their siblings, and families.

Attendees will be able to:

- Discuss national research and a local family survey that demonstrates the need for a comprehensive primary care clinic for Children with Medical Complexity (CMC).
- Explain a multidisciplinary clinic model developed to provide comprehensive family-centered care and coordination for CMC.
- Describe the child life role within this alternative setting that addresses CMC.
- List the initial responses of families and children to this clinic model.

Domain
3 Professional Responsibility

Presentation Level
Intermediate

Abstract
Introduction:
Advances in medical technology and more effective treatment for life-limiting illness have allowed Children with Medical Complexity (CMC) to survive not only the neonatal-period, but also their adolescent years, with an ever-increasing number living well into adulthood (Hjern, Lindbald, & Boman, 2007) (Thompson et al., 2003). Unfortunately, CMC are often ill-served in the present system. Outpatient pediatric health care services in the U.S. are designed primarily for episodic diagnosis and treatment of acute diseases, and not to provide coordinated, comprehensive, family-centered care. As a result, care is often fragmented, redundant, inefficient, and costly—despite their small number (1-3%), this population accounts for a grossly disproportionate amount of the costs within pediatric medicine. Furthermore, services are not comprehensive, overlooking areas such as pain-management, sleep-management, palliative care, and psychosocial and behavioral interventions (including transition to adult medicine, counseling, and child life support), which are often inconsistently accessible or non-existent. Four areas define complexity in the pediatric population: Needs, Chronic Conditions, Functional Limitations, and Health Care Use. Needs, the least described domain for this population, includes heightened health care service needs and increased presence of psychosocial and child emotional needs (Cohen, et al., 2011). These contextual needs are often the result of greater stress on family due to caregiving, care coordination, financial impact, and overall impact on family of illness (Antonelli, Stille, & Antonelli, 2008). Research has shown that caring for children in medical homes and using interdisciplinary approaches offer quality patient care (National Academy of Sciences, 2004) (Rosenstein & O’Daniel, 2005), better outcomes (Homer, et al., 2008), and decreased costs (National Joint Practice Commission, 1981) (Schmalenberg, et al., 2005).

A local survey of parents of CMC affirms national findings on the need for comprehensive services that include sibling and family counseling, sibling support, and care-coordination services (Name Withheld, Pediatric Palliative Care, 2010). Child life specialists and services continue to move into alternative settings and broaden the scope of practice (Child Life Council, Inc., 2008). This innovative model allows for integrated
and comprehensive care with CMC, and the use of a multidisciplinary team incorporating a high level of family-centered care.

Description:
The AAP defines a Medical Home as “primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective to all children and youth, including children and youth with special health care needs.” For CMC, these principles are especially important. In the below described clinic, these areas are addressed in the format of a pediatric medical home that uses an interdisciplinary team of three physicians, two nurse practitioners, an RN case manager, a social worker, and a child life specialist. This clinic offers integrative care through direct, in-clinic access to specialists intrinsic to the care of this population—psychology, psychiatry, and physical medicine and rehab. Case review includes the entire team, including family input. Foundational to this approach is the understanding that in pediatric care, contextual needs are as important as physical needs, remembering that a child lives in the context of family—to support the family, is to support the child.

Outcome:
The design of this clinic results in accessibility to a more comprehensive model of care, meeting one of the criteria for a Medical Home. Interdisciplinary care allows each child and family the opportunity to discuss relevant medical and social-emotional information. This type of care requires the extensive use of child life in many traditional roles as well as new and innovative roles. Family support from the psychosocial team is a key element of this program and families are reporting great appreciation for this support. Initial results of family satisfaction are high.

Relevance to Child Life Practice:
A focus of this model, contextual needs incorporate the values and practice of child life and broaden them to an alternative setting. Child life’s focus on family-centered care is an asset and resource to a multidisciplinary approach for primary care focused on CMC. The child life specialist in this clinic uses a standardized tool to assess the developmental and behavioral functioning of the patient, assists parents in addressing the needs of the siblings, provides patient and sibling emotional support, and collaborates with the school system on behalf of the patient and family.

Organization of Presentation
The layout of this poster will consist of highlighted educational sections including presentation of the background and research supporting the need for this clinic model, a description of the clinic model, information detailing the multidisciplinary team, information regarding the family centered care approach, and a section describing the child life role with other disciplines, the patient and family. The poster will include pictures of children from the clinic. The poster will also include quotes from families and siblings displaying the effect this clinic has had on their coping and managing of medical care for their child and family. The poster will also include quotes from the multidisciplinary team regarding the value of child life to the clinic.

References

