Journal of Pediatric Nursing (2015) **30**, 244–253

Coordination of Care Between Health and Education Systems for Patients With a Hematologic or Oncologic Diagnosis: A Time Study Analysis

Mary Kay Irwin EdD*, Megan P. Elam EdD*, Ashley L. Merianos PhDc, CHES

Cincinnati Children's Hospital Medical Center, Cancer and Blood Diseases Institute, Cincinnati, Ohio

Received 8 January 2014; revised 8 July 2014; accepted 10 July 2014

Key words:
Hospital–School liaison;
School intervention;
School reentry;
School advocacy;
Chronic illness;
Chronic medical conditions;
Time study

Given the increasing emphasis on care coordination between healthcare and schools, hospital–school liaison services are increasing in demand. Limited research examines hospital–school liaison programs that focus on educational journeys of school-age patients with a chronic illness. Thus, this initiative aimed to determine the time needed to support the educational needs of these patients. Liaisons tracked time spent per patient, and per specific task category, to support school-age patients (N = 419) using work-sampling and time-and-motion methods. Findings may be useful for hospital-based programs seeking to establish or increase staff dedicated to the coordination of care between school and healthcare systems.

AS PEDIATRIC MEDICAL conditions formerly categorized as terminal or fatal are increasingly being cured and redefined as chronic, quality of life has progressively become an important focus for the individuals surviving these conditions (van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). Because health status and school performance are directly linked to overall short-term and long-term quality of life outcomes for pediatric patients with a chronic medical condition (Forrest, Bevans, Riley, Crespo, & Louis, 2011), efforts dedicated to addressing quality of life issues for these children and adolescents must include education. Multiple stakeholders are responsible for supporting the educational needs of students with a chronic medical condition, including the caregivers/family members, educators and school personnel, and healthcare providers.

Challenges exist for each stakeholder group relative to providing school support for students with a chronic illness. Within their respective systems, educators experience challenges trying to provide optimal support for students with a chronic medical condition, as they must work within the limitations of a system that is not equipped to support the needs of these students; teachers lack the resources needed to provide adequate support; they must work within policies and rules that are often not conducive to address the unique needs of this student population; they share widespread misunderstandings about students with a chronic medical condition; and they admittedly lack the training needed to understand the needs of these students (Irwin & Elam, 2011). Healthcare personnel struggle to provide optimal school-related support for their patients whom they are treating for a chronic condition due to time constraints, as medical appointments typically demand a focus on acute and urgent medical issues; they often lack the expertise and know-how to navigate the educational system and its policies; and clinical demands prevent them from communicating directly or comprehensively with school providers (Moore, Kaffenberger, Goldberg, Mi Oh, & Hudspeth, 2009). Parents of children and adolescents with a chronic medical condition are often caught in between the health care and educational sectors, trying to achieve a balance in supporting the demands of two competing systems (Olson, Seidler, Goodman, Gaelic, & Nordgren, 2004; Thies, 1999); they are charged with communicating pertinent information to school about medical needs, and communicating school concerns to the healthcare team, all while trying to ensure optimal health and safety plus academic success for their child.

---

* Corresponding author: Mary Kay Irwin, EdD; Megan P. Elam, EdD.
E-mail addresses: marykay.irwin@cchmc.org, megan.elam1@cchmc.org.

http://dx.doi.org/10.1016/j.pedn.2014.07.003
0882-5963/

Ultimately, what results from each of these barriers is fragmented care in which delivery systems (such as schools) are not included in care coordination, and the efforts of each system working in isolation "can impose a great burden on families" (Catalyst Center, 2010). Consequently, this often creates a delay in access to appropriate services and accommodations in schools.

Across the country, widespread efforts are underway to increase the coordination of care across systems (McDonald et al., 2007). As far back as 1999, the American Academy of Pediatrics emphasized that care coordination is an essential component of ensuring optimal outcomes for pediatric patients. More recently, the Framework for High-Performing Pediatric Care Coordination developed through the Commonwealth Fund, defined coordination of care as follows:

> Pediatric care coordination is a patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes. (Antonelli, McAllister, & Popp, 2009, p. vii)

Recommendations for improved coordination of care are not limited to the healthcare sector; leaders in education are reinforcing this need, as well. The call for comprehensive programs that support the educational needs of students with a chronic medical condition is highlighted in prominent national education organization policies. For example, the Council of Chief State School Officers ([CCSSO]), 2004) propose that the educational system is responsible for looking beyond setting typical standards and systems, and joining with multiple healthcare providers to address chronic medical conditions that inhibit student learning and healthy transitions into adulthood. Additionally, they promote that a coordinated, comprehensive approach to developing healthy schools can provide a helpful framework for creating and implementing policies and practices to address chronic medical conditions that interfere with student learning and success. The CCSSO contends that a comprehensive approach must include parents, schools, and communities who work together to address their shared objective of promoting academic success and quality of life.

Leaders from the National School Boards Association (2013) echo these sentiments, encouraging school boards to "recognize that health and learning are integrally linked and […] to collaborate with community partners to maximize resources for achieving a coordinated school health program" (p. 35).

These initiatives from both the education and healthcare sectors acknowledge the critical role of their respective contributions to increase the quality of life and academic success of students with a chronic illness. Because the prevalence of children and adolescents living with chronic conditions has increased considerably over the past 40 years (Perrin, Bloom, & Gortmaker, 2007), the emphasis of hospital–school coordination should be meeting the educational needs of these students by minimizing academic difficulties and health complications, both simultaneously and collaboratively (Engelke, Guttu, Warren, & Swanson, 2008). The use of a hospital–school liaison may play a critical role in improving the coordination of care between school and medical treatment facilities, thus improving the overall short-term and long-term outcomes for students with a chronic medical condition. Consequently, there is an increasing demand for comprehensive, hospital–school liaison programs and for qualified professionals who provide hospital–school liaison support for these students.

The school intervention program (SIP) at Cincinnati Children's Hospital Medical Center (CCHMC) has received national and international recognition since 1979 for its efforts in helping sensitize schools to the needs of school-age patients with chronic illnesses. The CCHMC SIP was initially a small program that has expanded over time, most significantly within the past decade, from a relatively small program dedicated to supporting the school needs of patients with an oncologic diagnosis to a robust program providing support to patients with a variety of chronic conditions. Today, liaison support is provided for patients both during and after treatment, inclusive of ongoing school intervention support for long-term disease survivors who experience physical, cognitive, social, psychological, and other late effects of treatment that impact school success.

The CCHMC SIP has a longstanding reputation for success, much of which can be attributed to the program's commitment to employing highly qualified and experienced educators who are dedicated to supporting the school needs of patients, but also the needs of the stakeholders in each patient's education, including the caregivers, educators, and healthcare personnel. While national certification does not currently exist for hospital–school liaisons, and many hospitals fill this role in a variety of ways (e.g., physicians, nurses, social workers, psychologists), the CCHMC SIP has rigorous standards for individuals who fill this role. For example, all hospital–school liaisons must have a minimum of 4 years of classroom or related experience, they must maintain their teaching license, and a graduate degree is highly preferred. The program utilizes a referral-based system to ensure that support is allocated to those patients specifically in need of school-related interventions. Services are individualized for each patient's level of need, which allows CCHMC SIP liaisons to meet the unique demands of the various stages of treatment, from diagnosis to survivorship. While supporting the educational needs of the patient remains the focus of liaison support, establishing and maintaining longstanding relationships with community partners in the local school districts has been critical with respect to the success of the program.

School professionals value the link to the hospital provided by SIP liaisons, and appreciate the student-specific information that is shared regarding the patient's medical experience. These relationships are invaluable to the