

# How Variable Is Our Delivery of Information? Approaches to Patient Education About Oral Chemotherapy in the Pediatric Oncology Clinic

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**ABSTRACT**

In pediatric patients with acute lymphoblastic leukemia, adherence to oral chemotherapy relies largely on a parent's comprehension of the drug's indication and administration guidelines. We assessed how pediatric oncology providers educate families about oral chemotherapy. We conducted a cross-sectional survey of 68 physicians and nurses from 9 institutions in the Dana-Farber Cancer Institute Acute Lymphoblastic Leukemia Consortium. The inter-individual approach to patient education is variable and may consist of handouts, treatment calendars, and discussions. The extent of teaching often varies depending on a provider's subjective assessment of a family's needs. Twenty-five percent of providers suggested standardizing patient teaching. When developing educational models, care teams should consider approaches that (a) objectively identify families in need of extensive teaching, (b) designate allotted teaching time by nursing staff during clinic visits, and (c) maintain the variation and dynamism that informs a successful provider-patient relationship. *J Pediatr Health Care.* (2016) ■, ■-■.

**KEY WORDS**

Pediatric, leukemia, adherence, cancer care delivery, patient education

In the field of pediatric oncology today, the roles of health care providers continue to shift and evolve as treatment regimens include more oral chemotherapy agents (Place et al., 2015). Providers are responsible not only for writing prescriptions but for effectively educating patients and their caregivers about administration guidelines and treatment regimens. Based on this premise, the inherent challenge for providers is related to identifying the optimal way to deliver this critical information to each individual family.

Ensuring accurate adherence to prescribed treatment regimens is a challenge in every field of health care, including pediatric oncology, where oral chemotherapy delivered at home is incorporated into many treatment regimens. Administration of oral chemotherapy at home is a highly complex and often labor-intensive endeavor for patients and their caretakers. It is estimated that some children with cancer may take upward of 10 medications at home per day (Kondryn, Edmondson, Hill, & Eden, 2011). Standard treatment for pediatric acute lymphoblastic leukemia (ALL) requires 2 years of pharmacologic therapy. The continuation phase of therapy lasts 70 weeks and rests on a backbone of oral chemotherapeutics, including 6-mercaptopurine (6-MP) and dexamethasone. During this treatment phase, parents are responsible for administering 6-MP to their children for 14 consecutive days every 3 weeks, which can have a direct impact on the success or failure of the child's treatment. The potential impact of oral chemotherapy nonadherence on patient outcomes was demonstrated in a landmark study published by Bhatia et al. (2012). In this study, investigators assessed adherence to 6-MP in a large cohort of pediatric

patients with ALL who were being treated according to a Children's Oncology Group treatment protocol. Investigators observed that less than 95% adherence to 6-MP was associated with a 3.1-fold increase in relapse risk. Despite this finding, up to 30% of the study population was nonadherent to oral chemotherapy, thus highlighting both the danger and magnitude of this problem (Bhatia et al., 2012).

Published studies have identified medication administration errors in 10% to 40% of pediatric children younger than 18 years who are receiving oral chemotherapy at home (Taylor, Winter, Geyer, & Hawkins, 2006). In the medical literature, numerous studies link provider-patient teaching to therapy adherence, particularly with regard to oral chemotherapy (Pritchard, Butow, Stevens, & Duley, 2006; Tebbi, 1993). Accurate and consistent adherence to home medication regimes is influenced by patient-, provider-, and systems-related factors (Brown & Bussell, 2011). Health care providers are responsible for educating patient caregivers about both administration guidelines and the necessity of the medications prescribed. Without effective teaching, patient caregivers are at risk of erroneously administering home medications or of not administering them at all.

Here we report the results of a cross-sectional survey aimed at examining the way physicians (attending physicians and fellows), nurse practitioners (NPs), registered nurses (RNs), and physician assistants (PAs)—all working in a pediatric oncology clinic and with expertise in ALL—communicate and reinforce treatment information about oral medications to patients and families during the continuation phase of pediatric ALL therapy. We hypothesized that there would be high variability in the provider-driven education practices surrounding oral chemotherapy during the continuation phase treatment for ALL. We also hypothesized that care providers would suggest moving toward standardizing the educational approach as a means of improving the efficacy of our teaching and care delivery.

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**METHODS**

This study was approved by the Institutional Review Board at Columbia University Medical Center. We conducted a survey of health care providers directly involved in the care of children (ages 1 to 18 years) undergoing treatment for pediatric ALL. The study population included physicians, NPs, PAs, and RNs from

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