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# Precision Education for Newly Diagnosed Pediatric Oncology Patients and Families: A Quality Improvement Initiative

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## Background

Although the family of a child diagnosed with cancer needs comprehensive education, guidance, and support, there is little data available to guide methods, content and timing of education.

A quality improvement initiative was launched to evaluate and enhance the educational experience of newly diagnosed families. Assessment of family's understanding of their child's team members and their roles, their child's treatment plan, the management of home medications, emergencies, and support needs (i.e. educational materials, school reentry, siblings, support groups) were performed. In addition, a comprehensive review of existing family education materials and practices were simultaneously conducted.



## Project Aims

The primary outcome being measured is the family's understanding of target topics six weeks post-diagnosis measured by a 24 item survey. To design the questionnaire, a complete literature review to ascertain topics others have identified as important for newly diagnosed families.

Initial target audience for the first phase is families of children diagnosed with Acute Lymphoblastic Leukemia.

## Methods

Staff were interviewed via survey monkey and were asked to rank the topics in terms of importance.

The questionnaire was then designed and the Family Advisory Team vetted the questions before it was administered to newly diagnosed families. The final survey measured the following topics:

- Identifying team members and their roles
- Understanding the child's treatment plan
- Managing home medications
- Emergencies
- Support needs (educational materials, school reentry, siblings, support groups)

## Interventions

PDSA Cycle #1: Literature Review and Benchmark

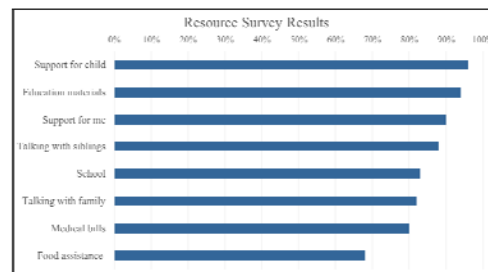
PDSA Cycle #2: Interview Staff and Families

PDSA Cycle #3: Survey

PDSA Cycle #4: Voting and Survey

Voted on:

- Style of binder
- General vs specific content
- Amount of disease specific information
- Online vs print of Beyond Diagnosis Book



## Interventions

PDSA Cycle #5: Information Display, Meet Your Team, and Survey



PDSA Cycle #6: Introduction of New Diagnosis Accordion, Survey

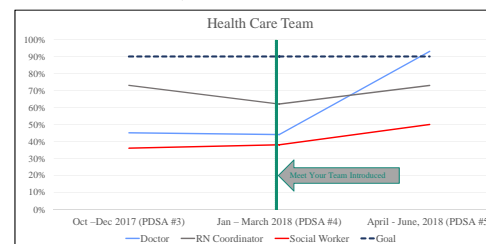


## Results

Preliminary results indicate families are comfortable with teaching about diagnosis, side effects, and roadmaps. They have indicated they do know when to call for fever and have an understanding of the child's treatment plan.

Families want more written publications, school reentry assistance, and knowledge of support services in the community.

Families are asking for more anticipatory guidance on likely discharge scenarios (i.e. redosing oral chemo after emesis, decrease food/fluid intake).



## Results

