


**Precise Delivery of Education to Newly Diagnosed Pediatric Oncology Patients & Families:**

**A Quality Improvement Initiative**



Michelle Fritsch, LMSW-ACP

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Is our patient & family new diagnosis education sufficient?

What do the patient & families need to know???


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**Literature Review**

Medical Professional Think New Family Need: Education Prior to Initial Hospital D/C	What Parents reported was Taught Before D/C	What parents WANTED
Diagnosis	Emergency Phone #	How to give child oral meds
Fever	Fever	What to do if child vomits after oral med
Prognosis	Need to go to hospital if fever develops	Clinic Routine
Side Effects	Medications - schedule, dosing...	Needle size for port access
Who/How to call	How to administer injections	Precautions for Sibs
When/Why call	Not to give over the counter meds	Precautions for visitors at home
Clinical trials	Neutropenic Precautions	Diet precautions (wash fruit really well means?) Support Groups through social media and in person
Manage Medications	Thrombocytopenic precautions	
Central Line Care	Care of Central Line	
Care of Child at Home	Hygiene	
Supportive Care	Hand washing	
Health Team Members	Oral care and diet if mucositis develops	

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**What Medical Professionals Think Newly Diagnosed Families Need To Know:**

- Diagnosis
- Fever
- Prognosis
- Side effects
- Who/how to call
- When/why to call
- Clinical trials
- Manage medications
- Care of central line
- Care of child at home
- Supportive care
- Health team members



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**Families Report What Was Actually Taught:**

- Emergency phone #
- Fever
- Need to go to hospital if fever develops
- Medications - schedule, dosing,...
- How to administer injections
- Not to give over the counter meds
- Neutropenic precautions
- Thrombocytopenic precautions
- Care of central line
- Hygiene
- Hand washing
- Oral care and diet if mucositis develops



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**What Families Wanted to Know:**

- How to give child oral meds
- What to do if child vomits after oral med
- Clinic Routine
- Needle size for port access
- Precautions for sibs
- Precautions for visitors at home
- Diet precautions
- Support groups through social media and in person



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### Texas Children's Cancer & Hematology Faculty/Staff Polled

- What is the most important topics families MUST be taught in the first 4 – 6 weeks after diagnosis?
- Survey of all Texas Children's Cancer & Hematology Centers (TXCH) clinical staff to inquire top 5 topics for Safety and Coping.
  - 106 responded.
- 3 parents sent survey. Preliminary family review.



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### Top 5 Topics - Safety

- When and how to call
- Manage medicines
- Manage fever
- Who on treatment team
- Name, stage, diagnosis



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### Top 5 Topics - Coping

- Treatment plan
- Prognosis
- Know who to talk to about siblings, etc
- Pain management
- Activity restrictions



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### Communication Goals

**Patient-Provider Communication:  
What is it?**

<ul style="list-style-type: none"> <li>• <b>Goals for provider:</b> <ul style="list-style-type: none"> <li>- Gather history</li> <li>- Diagnose accurately</li> <li>- Counsel patient</li> <li>- Give medical advice and instruction</li> <li>- Address concerns</li> <li>- Establish caring relationship</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• <b>Goal for patient:</b> <ul style="list-style-type: none"> <li>- Feel as if emotions are validated</li> <li>- Comprehend medical information</li> <li>- Communicate needs and expectations</li> <li>- Make perceptions of care and condition clear</li> </ul> </li> </ul>
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**ULTIMATE GOALS:**

Improvement of health	Adherence to treatment plans
Patient comprehension	Patient satisfaction

Hs et al., Oschner/J 2010

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### Plan Do Study Act

Model for Improvement

What are we trying to accomplish?

How will we know that a change is an improvement?

What change can we make that will result in improvement?

adapted from The Institute for Health Care Improvement

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### PDSA

- **Setting Aims**  
The aim should be time-specific and measurable; it should also define the specific population of patients or other system that will be affected.
- **Establishing Measures**  
Teams use quantitative measures to determine if a specific change actually leads to an improvement.

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### PDSA

- **Selecting Changes**  
Ideas for change may come from those who work in the system or from the experience of others who have successfully improved.
- **Testing Changes**  
The Plan-Do-Study-Act (PDSA) cycle is shorthand for testing a change in the real work setting — by planning it, trying it, observing the results, and acting on what is learned. This is the scientific method adapted for action-oriented learning.



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### Plan Do Study Act


- PDSA provides a straightforward approach to quality improvement.
- Framework is easy

What are we trying to accomplish

How will we know that a change is an improvement?

What changes can we make that will result in improvement?

Plan  
Do  
Study  
Act



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### PDSA

Plan: develop the initiative

Do: implement your plan

Study: check the results

Act: make further improvements



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**PDSA #1**

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Steps

1. Survey data
2. Develop questions



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**PDSA # 1 (June 1 – Oct 20, 2017)**

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Objectives

- Survey TXCH faculty/staff regarding their thoughts on what families should know post diagnosis (4 – 6 weeks after diagnosis).
- Develop questions that reflect the topics our staff determined were important for families to know post diagnosis.
- Revise survey based on 3 families validation and input.



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**Findings – PDSA #1**

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- We are able to develop questions that reflect the topics our staff determined were important for families to know post diagnosis.
- Families are willing and able to validate the survey for us.
- Survey can be translated by our translation department



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**PDSA Cycle #2**

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Steps

1. Revise questions
2. Identify & orient family advisors
3. Validate questions
4. Develop the process for identifying target participants



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**PDSA # 2 (Oct 20 – Dec 21, 2017)**

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Objectives

- Are their parents who will be willing to serve on our family advisor team?
- Can we orient them through our hospital's Family Centered Care Program?
- Will they be able to validate the questions/give feedback?
- Are we able to identify patients?
- Which patients were recently diagnosed?



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**Findings – PDSA #2**

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- Families are willing to participate.
- The sample strategy captured most newly diagnosed patients
- We can identify patients – with the help of the epidemiology group.
- We need someone designated to the collection of these questionnaires (staffing challenges)



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**PDSA Cycle #3**

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Steps

1. Approach and survey newly diagnosed families with leukemia



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**PDSA # 3 (Dec 21, 2017 - Present)**

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Objectives

- Are we able to administer the questionnaire?
- Begin with newly diagnosed leukemia patients
- Are we able to add another target population (diagnosis) to the research?



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**Findings - PDSA #3**

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- Families want more education.
- Families need more support.
- Families do not know how to identify their physician.



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### Demographics – PDSA Cycles

	Oct – Dec 2017 (PDSA #3)	Jan – March 2018 (PDSA #4)
# surveys	11	16
Diagnoses		
% Leukemia	100%	100%
% Brain tumors		
Who completed the survey?		
% Mother	100%	75%
% Father	0	25%
Location of survey		
% Hospital	18%	
% Clinic	45%	31%
% Phone	36%	69%
Location of diagnostic talk		
% Hospital	100%	81%
% Clinic	0	19%
Survey language		
% English	73%	88%
% Spanish	27%	12%




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### Do they know their medical team?

	Oct – Dec 2017 (PDSA #3)	Jan – March 2018 (PDSA #4)
# surveys	11	16
Who is your doctor?*		
Answered with an attending	1 (9%)	3 (44%)
Answered wrong (follow APP, first name only)	3	
I don't know?	3	7 (56%)
Who is your Nurse Coordinator?		
Answered with a NC for the appropriate team	6 (73%)	10 (62%)
Answered wrong (name that is not a NC or on the wrong team)	3	
I don't know / I don't have one	2	6 (38%)
Who is your Social Worker?		
Answered with a SW for the appropriate team	4 (36%)	6 (38%)
Answered wrong (name that is not a SW or a SW from the wrong team)	1	
I don't know / I don't have one	6	10 (62%)




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### Interactions with the medical team

	Oct – Dec 2017 (PDSA #3)	Jan – March 2018 (PDSA #4)
# surveys	11	16
Answered questions/concerns		
Yes, all or most	11 (100%)	16 (100%)
No, some or struggling		
None		
Know who to call	11 (100%)	16 (100%)
Yes, know who and when to call	8	13
Yes, sometimes	2	2
No, some or struggling		
None		
Had to reach team		
Yes	5	13 (81%)
Problems		
No problem		5
High person		2
Call back	1	1
Question		1
Email		
Did not help		2
Other		




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### Home Medications

	Oct -Dec 2017 (PDSA #3)	Jan - March 2018 (PDSA #4)
# surveys	11	16
Give medicine at home (yes)	11	15
Comfort with giving medication	11 (100%)	15 (94%)
Comfortable	5	10
Learning	5	4
Uncomfortable	0	1
Missed medications	4 (36%)	5 (30%)
Never missed or vomited	1	4
Comfortable with what to do	5	4
Uncertain	3 (40%)	3 (19%)
Confused	0	5 (31%)




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### Next Treatment Steps

	Oct -Dec 2017(PDSA #3)	Jan - March 2018 (PDSA #4)
# surveys	11	16
Comfort with what is happening next	9 (73%)	13 (81%)
Fully understand	4	13
Comfortable	4	13
Managing day to day	3	2
A lot of questions/completely confused	0	1




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### Pain

	Oct -Dec 2017 (PDSA #3)	Jan - March 2018 (PDSA #4)
# surveys	11	16
Did child have pain?	10 (91%)	8 (50%)
Yes	10	8
No	1	8
Adequately managed?	9 (82%)	6 (75%)
Yes	9	6
Some	1	1
No	0	1




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### Thermometer at Home

	Oct –Dec 2017 (PDSA #3)	Jan – March 2018 (PDSA #4)
# surveys	11	16
Do you have a thermometer at home?	10 (91%)	15 (100%)
Yes	10	15
No	1	





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### Food Insecurity / Money

	Oct –Dec 2017 (PDSA #3)	Jan – March 2018 (PDSA #4)
# surveys	11	16
Worried that won't be able to feed family?	4 (34%)	6 (38%)
Yes	4	6
No	7	10
Worried won't have enough money	6 (55%)	11 (69%)
Yes	6	11
No	5	5
Know who to talk to about not having enough food or money	0 (0%)	11 (69%)
Yes	0	11
No	11	5
Comfort with medical bills	6 (55%)	11 (69%)
Yes	6	11
No	5	5
Have questions	5	6
Uncomfortable	5	5
Comfortable	0	1
Who to talk to about medical bills	0 (0%)	6 (38%)
Yes	0	6
No	11	10



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### Educational Materials

	Oct –Dec 2017 (PDSA #3)	Jan – March 2018 (PDSA #4)
# surveys	11	16
Received COG handbook	1 (9%)	8 (50%)
Yes	1	8
No	7	8
I don't know	3	
Was COG handbook helpful		
Yes	1	5
No	0	1
Want future educational materials		
Paper	10	15
Internet	4	5
Phone	0	3



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### Support

	Oct -Dec 2017 (PDSA #3)	Jan - March 2018 (PDSA #4)
# surveys	11	16
Parking		
Wanted and received	5 (45%)	7 (44%)
Wanted and did NOT receive	6	9
Received but did not use	0	0
School		
Wanted and received	2 (33%)	4 (40%)
Wanted and did NOT receive	4	6
Received but did not use		
Support for other children		
Wanted and received	2 (50%)	3 (50%)
Wanted and did NOT receive	2	2
Received but did not use	0	1




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### Support

	Oct -Dec 2017 (PDSA #3)	Jan - March 2018 (PDSA #4)
# surveys	11	16
Support for families		
Wanted and received	0 (0%)	2 (29%)
Wanted and did NOT receive	0	3
Received but did not use	0	2
Education		
Wanted and received	1 (9%)	1 (7%)
Wanted and did NOT receive	10	14
Received but did not use		1
Support for me		
Wanted and received	0 (0%)	3 (25%)
Wanted and did NOT receive	9	8
Received but did not use	0	1
Support for child		
Wanted and received	0 (0%)	1 (7%)
Wanted and did NOT receive	11	14
Received but did not use	0	1




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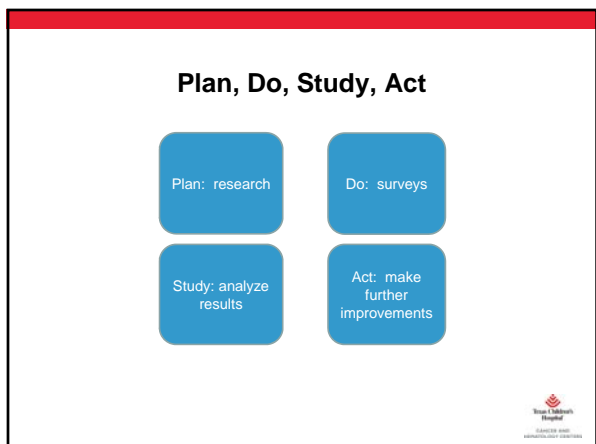
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**Discoveries**

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- Families need more support
- Families do not know how to identify their physician, team members
- Families want more education



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**Strategies for Improvement**

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- **Families need more support**
  - Social Work including support group information, supportive organization information at diagnosis
  - Provide support information in the clinic wall display
  - Advertise groups, organizations etc. in the infusion room and on inpatient setting



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**Strategies for Improvement**

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- **Families do not know how to identify their physician, team members**
  - Fact Sheets – “Meeting Your Team”
  - Fact Sheet on “Call Us”
  - Medical team must introduce self at each interaction; use name. Climate change ☺



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### Strategies for Improvement

- Families want more education
  - Include more education at diagnosis
  - Have libraries of educational materials and resource information at clinic pods and inpatient
  - Use wall display to showcase lots of materials/resources
  - Use nursing critical competencies time to showcase the educational materials so nursing is knowledgeable and able to provide the materials.
  - Identify family preferences for patient & family education



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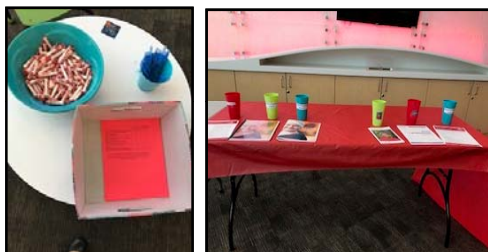
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### Educational Materials Showcase



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### Showcase Specifics

- Jelly bean voting
- Survey regarding support services
- 58 participants
- 3 separate days/times
- 5 parent advisor (volunteers)



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**Interactive Survey**

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- Text MICHELLEFRIT468 to 22333
- Text answers



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**Style of Binder**

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1. Vote for which style of binder you would prefer

- a. Soft
- b. Hard
- c. Paper
- d. Accordion Style



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**Style of Binder**

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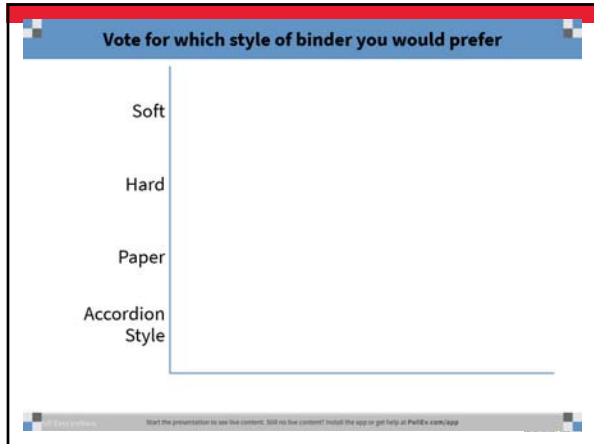
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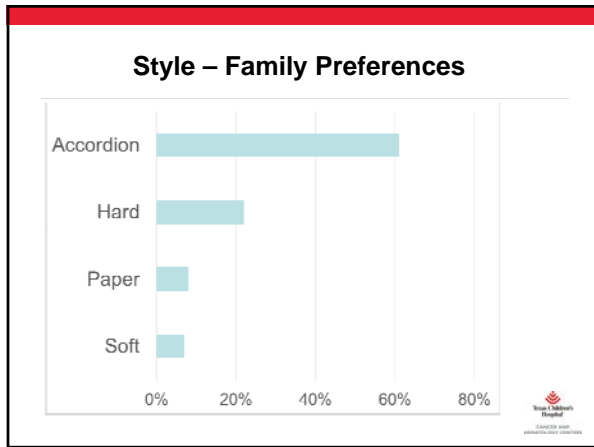
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**Content**

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2. Vote for which content you would prefer:

- a. General information about cancer
- b. Local information
- c. Both



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**Content**

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**Vote for which content you would prefer**

General information about cancer (COG binder)

Local information

Both

Start the presentation to see the content. Tell the presenter what the app or get help at PHEE's eLearning

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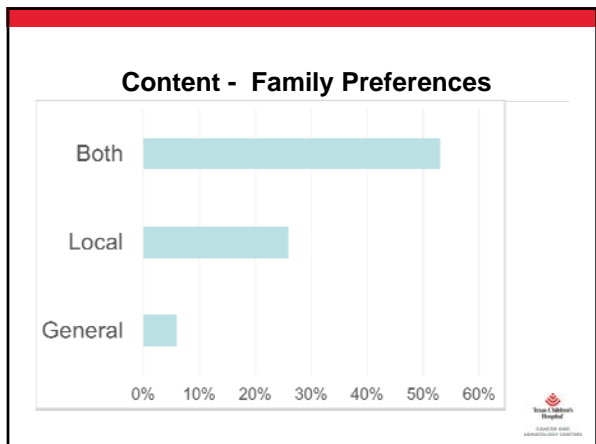
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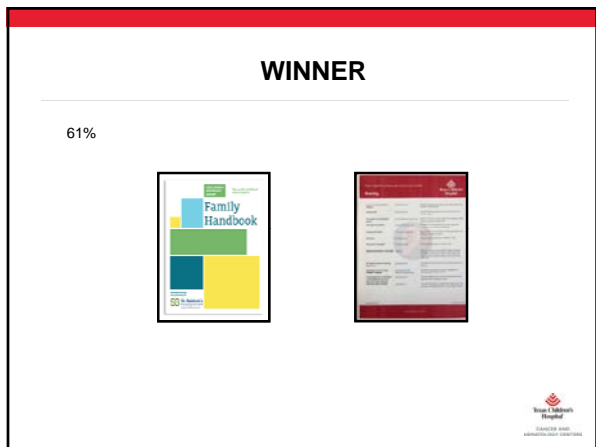
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### Style of Publication

3. Vote for which style of educational materials you would prefer:

- a. One page document (ex: leukemia)
- b. Publication put out by professional group
- c. APHON publication

Texas Children's Hospital  
COUNCIL AND  
ADMINISTRATIVE SERVICES

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### Style of Publication



The image shows three examples of educational materials. From left to right: a one-page document with a red header, a publication put out by a professional group (leukemia society) featuring a young girl's face, and an APHON document titled 'Acute Lymphoblastic Leukemia'.



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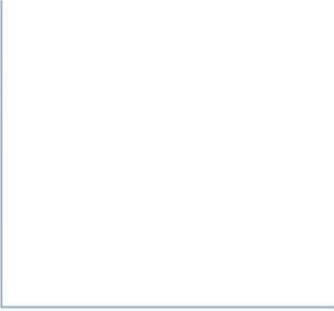
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### Which style of educational materials do you prefer?

- One page document
- Publication put out by professional group (leukemia society)
- Association of Pediatric Oncology Nurses document



Start the presentation to see live content. Still no live content? Visit the app or get help at [PHOEx.com/app](http://PHOEx.com/app)

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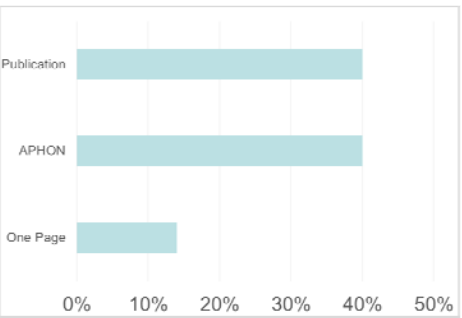
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### Publication – Family Preferences



Style	Percentage
Publication	40%
APHON	40%
One Page	15%



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### Style of Publication - WINNER

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40% 40%





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### Beyond Diagnosis

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4. Beyond Diagnosis

- a. Beyond Diagnosis Guidebook (bound)
- b. Beyond Diagnosis Guidebook (spiral)
- c. Fact Sheets
- d. Online Version



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### Beyond Diagnosis

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[Free download](#)



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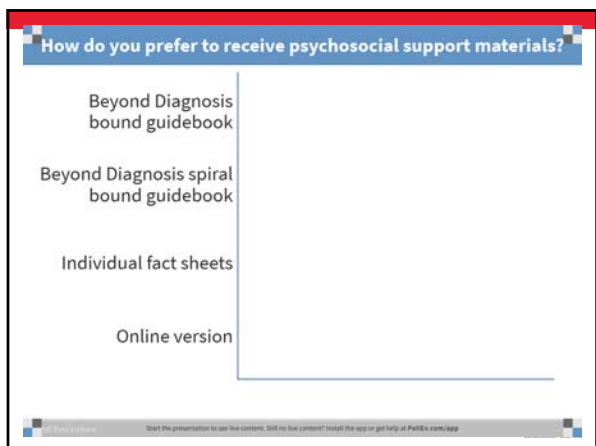
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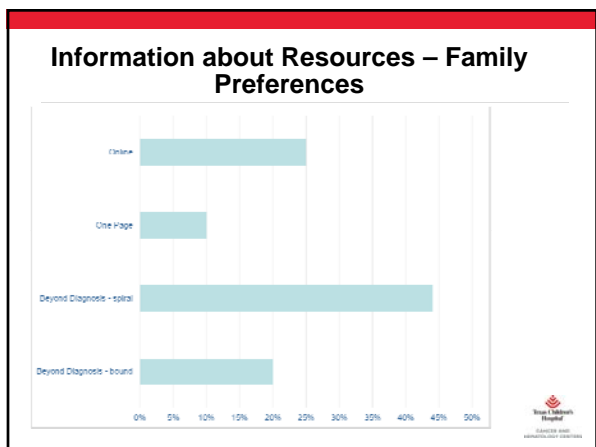
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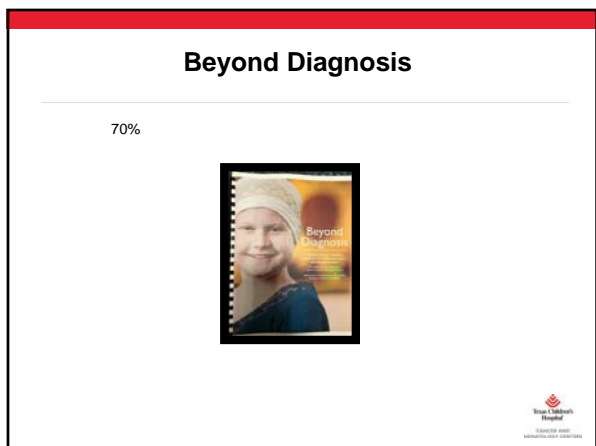
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	Would like information	Would NOT want
School coordination/information about services	<input type="radio"/>	<input type="radio"/>
Educational materials regarding diagnosis, general medical topics	<input type="radio"/>	<input type="radio"/>
Talking with my other children about my child's medical condition	<input type="radio"/>	<input type="radio"/>
Talking with my other family members about my child's medical condition	<input type="radio"/>	<input type="radio"/>
Connection to support & resources for me (support groups, counseling, etc)	<input type="radio"/>	<input type="radio"/>
Connection to support for my child (camps, social events)	<input type="radio"/>	<input type="radio"/>
Information about food assistance programs	<input type="radio"/>	<input type="radio"/>
Information about how to manage medical bills	<input type="radio"/>	<input type="radio"/>

Texas Children's Hospital  
CANCER AND HEMATOLOGY CENTER

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**Pick the top three services/topics the parents requested.**

School coordination/information about services  
information about how to manage medical bills

Information about food assistance programs

Educational materials regarding diagnosis

Talking with my other children about my child's medical condition

Talking with my other family members about my child's medical condition

Connection to support & resources for me

Connection to support for my child (camps, social events)

Information about how to manage medical bills

Texas Children's Hospital  
CANCER AND HEMATOLOGY CENTER

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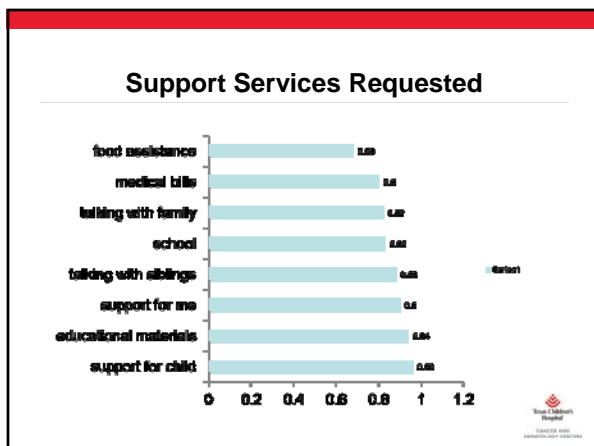
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### Patient and Family Education Nook



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### Patient and Family Education Nook



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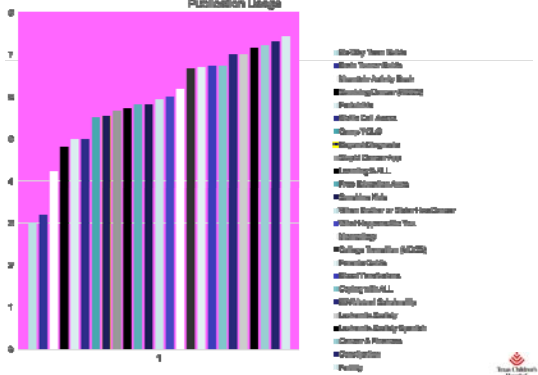
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Publication Usage



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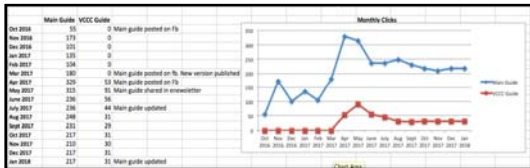
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### Beyond Diagnosis Usage




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### References

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- Hockenberry, M.; Rodgers, C. "Understanding effective delivery of patient and family education in pediatric oncology: a systematic review from the children's oncology group." 2016. APHON; 33 (6).
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### Comments/Questions




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