

# Partnering with Families to Validate Questionnaires Assessing Unmet Needs of Children, Adolescents, and Parents/Caregivers at the End of Cancer Treatment

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## BACKGROUND

### Ending cancer treatment & transitioning to survivorship:

- What are the needs?
- Are needs being met?
- What measures are available to determine needs?

### Coming off Therapy (COT) questionnaire (Nagel et.al, 2002)

- Parent survey only
- No reported validity/reliability

## PURPOSE

1. Adapt COT to End of Treatment (EOT) Questionnaires  
Children, AYAs, Parents/Caregivers
2. Validate Questionnaires

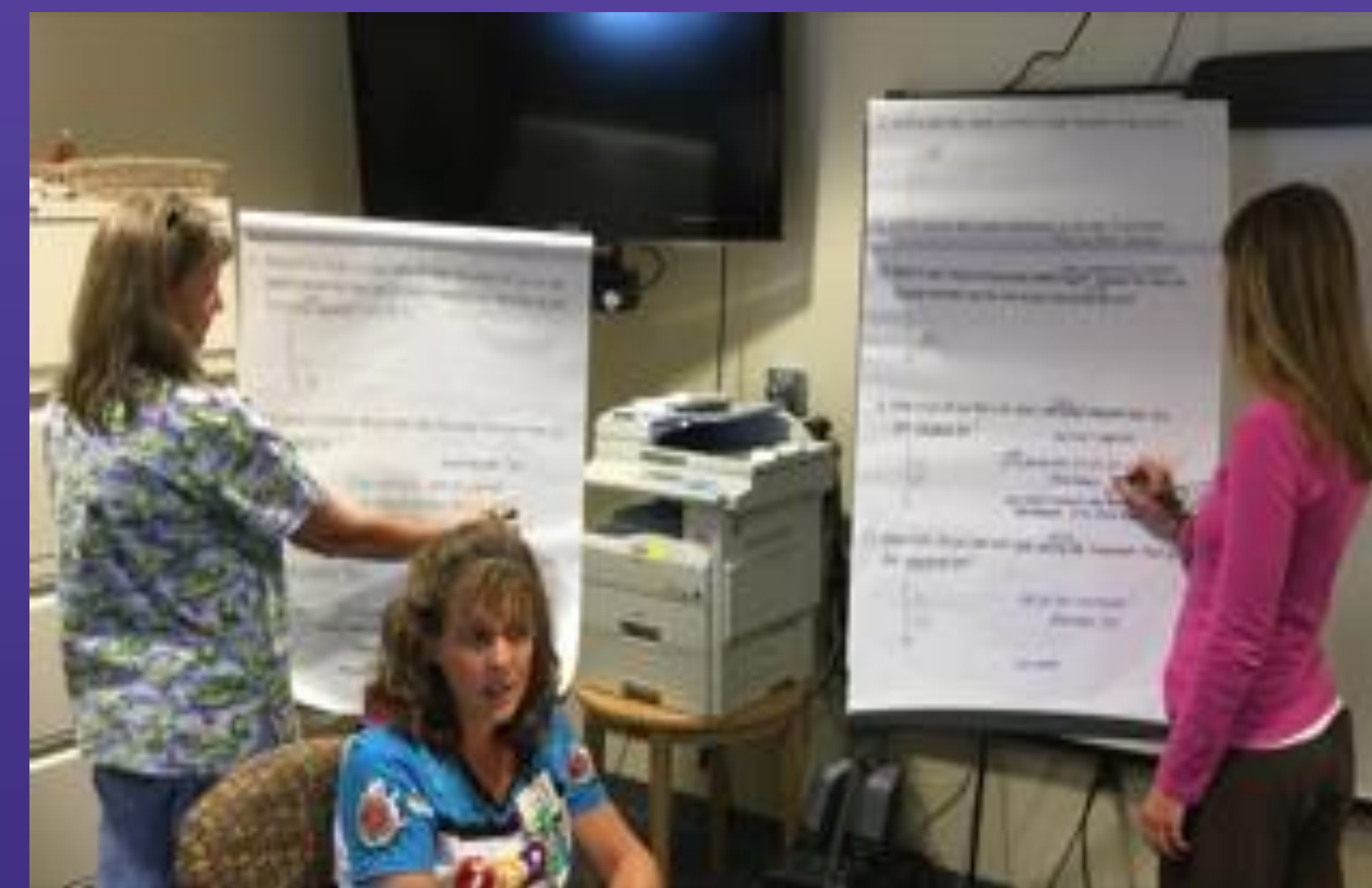
## METHODS

### Family Advisory Board members as experiential experts:

**Step 1:** Completed online survey to establish **face validity**

**Step 2:** Participated in focus groups to establish **content validity**

**Step 3:** Discussed and reworked each item until 100% consensus



## RESULTS

Face Validity					
Score	1	2	3	4	No consensus
Parents (n=68)	0%	0%	0%	42.6%	24%
Mixed 3/4:			33.8%		
Child/AYA (n=74)	0%	0%	0%	63.5%	17.6%
Mixed 3/4:			17.6%		

Content Validity: Preliminary Ratings					
Score	1	2	3	4	
Parent (n=78)		5%	21%	13%	45%
Mixed 2/3			4%		
Mixed 3/4				13%	
Child/AYA (n=80)		8%	6%	16%	36%
Mixed 3/4				33%	

## RESULTS

### COT Questionnaire

What information below would you have liked included in an off therapy review?

• Review of diagnosis and prognosis	yes/no
• Review of treatment(e.g., surgery, radiation, chemotherapy)	yes/no
• Review of side effects of treatment (e.g., hair loss, muscle pain, bone pain, low counts)	yes/no
• Plan for follow-up care at this center (e.g., scans, bloodwork, timing of follow-up visits)	yes/no
• The ongoing role of your family doctor	yes/no
• Provision of ongoing family emotional support/counseling	yes/no
• A discussion of family stress/anxiety coming off therapy	yes/no
• Genetic counseling	yes/no
• Hepatitis testing	yes/no

### EOT Questionnaire – Child Version

What information was included in your talk? (check all that apply):

Topic:	Yes	No	I don't know	I would have liked
Review of your diagnosis				
Review of your treatment (chemotherapy, radiation, surgery, etc.)				
Review of your side effects (weight gain, low counts, feeling tired, etc.)				
Plan for follow up at clinic (scans, blood work, etc.)				
Health topics you need to know (when to get vaccines, exercise do's and don'ts, etc.)				
School issues (learning, concentrating, making friends, etc.)				
Role of your pediatrician				
How to find support or counseling for you or your family				
Discussion of worries about finishing treatment				

## DISCUSSION/APPLICATIONS

- Through this process, our questionnaires were validated
- The questionnaires will lend integrity and relevance to future studies
- Plans:

1. Replicate process to develop EOT Questionnaire for healthcare professionals
2. Utilize questionnaires to study needs and gaps in services at EOT
3. Establish reliability of questionnaires through dissemination



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