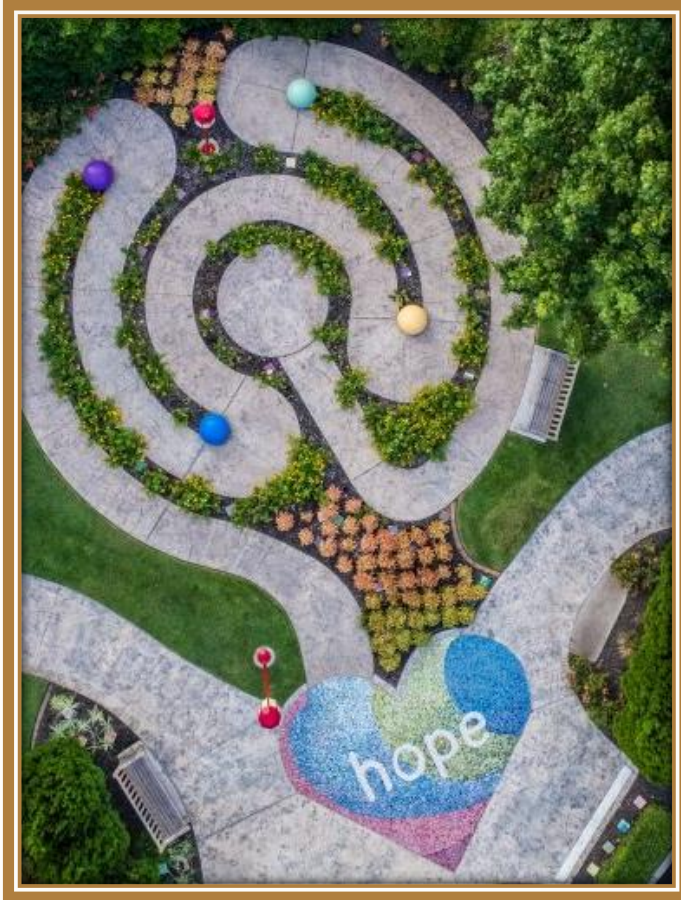


Changing Focus: Parents Reflecting on Hope during Hospice through Photovoice

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Background: Defining Hope



Desire for a possible but
uncertain goal.

How do parents define & describe
hope when their child is seriously
ill?

Background: Hope in Serious Illness



Hope Springs Eternal

Kaye et al.; St. Jude Quality of Life Steering Council. Bereaved Parents, Hope, and Realism. *Pediatrics*. 2020.

❖ Hopeful for...

- Cure
- Child to feel loved
- Quality of life
- Do all they could for the child

Sisk, Kang, & Mack. PBC. 2018.

❖ Hope persists, even if prognosis is poor.

Levine, Cuviallo, Nelson, et al. JCO. 2021.

❖ Parents may see 'hope' as essential to being a good parent.

Keene Reder & Serwint. JAMA Ped. 2009.

❖ Hope influences coping & decisions.

Feudtner, Carroll, Hexem, et al. JAMA Ped. 2010.

Background: Gaps

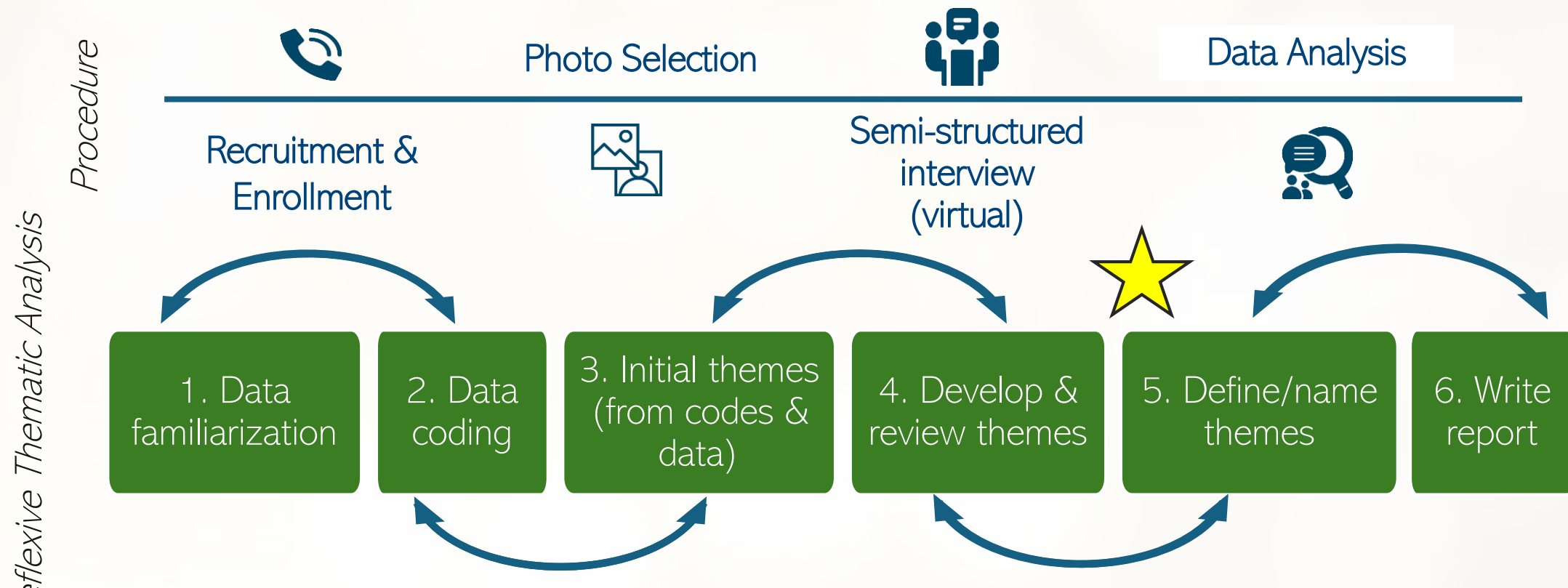
- ❖ Hope is understudied in pediatric cancer, especially in hospice.
- ❖ Hope during hospice is difficult to study...
 - Complex, abstract topic
 - Emotionally & logistically complex setting

Photovoice



Methods

- *Design:* Qualitative participant-generated photo-elicitation interview study.
- *Participants:* Parents of children who died on hospice 6-24 months prior.
 - English or Spanish speaking
- *Setting:* Comprehensive pediatric hem-onc center in the southeast U.S.



Results

❖ 19 parents of children who died from cancer were interviewed.

			n (%) or Median (Range)
Demographic & Clinical Characteristics	Gender	Female	8 (42%)
		Male	11 (58%)
	Race & Ethnicity	African American/Black	3 (16%)
		Asian	2 (11%)
		White (may select multiple)	16 (84%)
		Hispanic	4 (21%)
		Age	At diagnosis At death
	Diagnoses	Brain/CNS Tumor	6 (32%)
		Leukemia/Lymphoma	5 (26%)
		Solid Tumor	8 (42%)
Died at Home		10 (56%)	

			n (%) or Median (Range)
B) Parent Characteristics	Gender	Female	15 (79%)
		Male	4 (21%)
	Race, Ethnicity, Language	African American/Black	2 (11%)
		Asian	1 (5%)
		White	16 (84%)
		Hispanic	4 (21%)
		English	16 (84%)
		Spanish	3 (16%)
	Religion Geography	Midwest U.S.	3 (16%)
		Southeast U.S.	13 (68%)
Southwest U.S.		2 (11%)	
Central America		1 (5%)	
Religion	Christian	13 (68%)	
	Catholic	4 (21%)	
	Hindu	1 (5%)	
	None	1 (5%)	
	Months Bereaved	14m (7m -	

Thematic Analysis

Theme 1: Hope Changes Focus

Theme 2: Hope is Shown by the Child's Radiance

Theme 3: Awareness of Loss Casts a Shadow

Theme 4: Beliefs, Spirituality, & Values are a Lens through which Hope is Seen

Theme 5: Supportive Clinicians Hear, See, and Honor Families Outlook

Theme 1: Hope Changes Focus



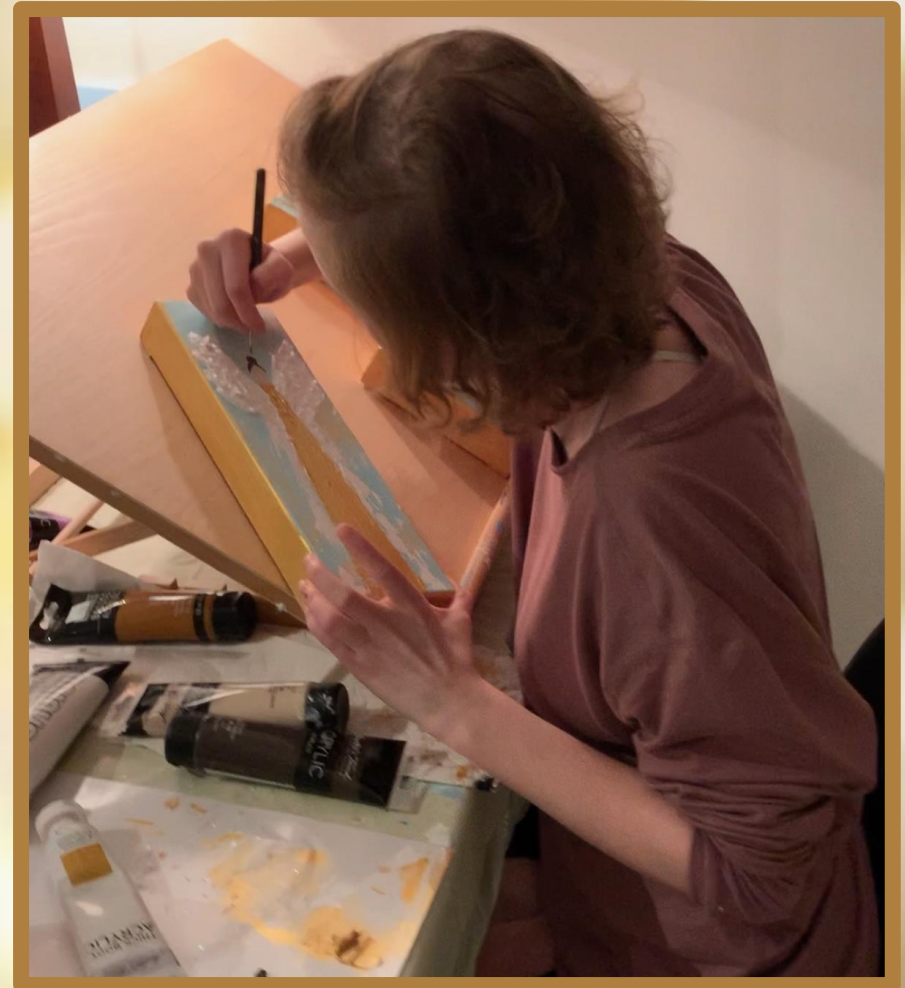
“I think there’s a point in time in treatment and in the life of it that your hope don’t diminish. It just changes focus.”



Theme 2: Hope is Shown by the Child's Radiance



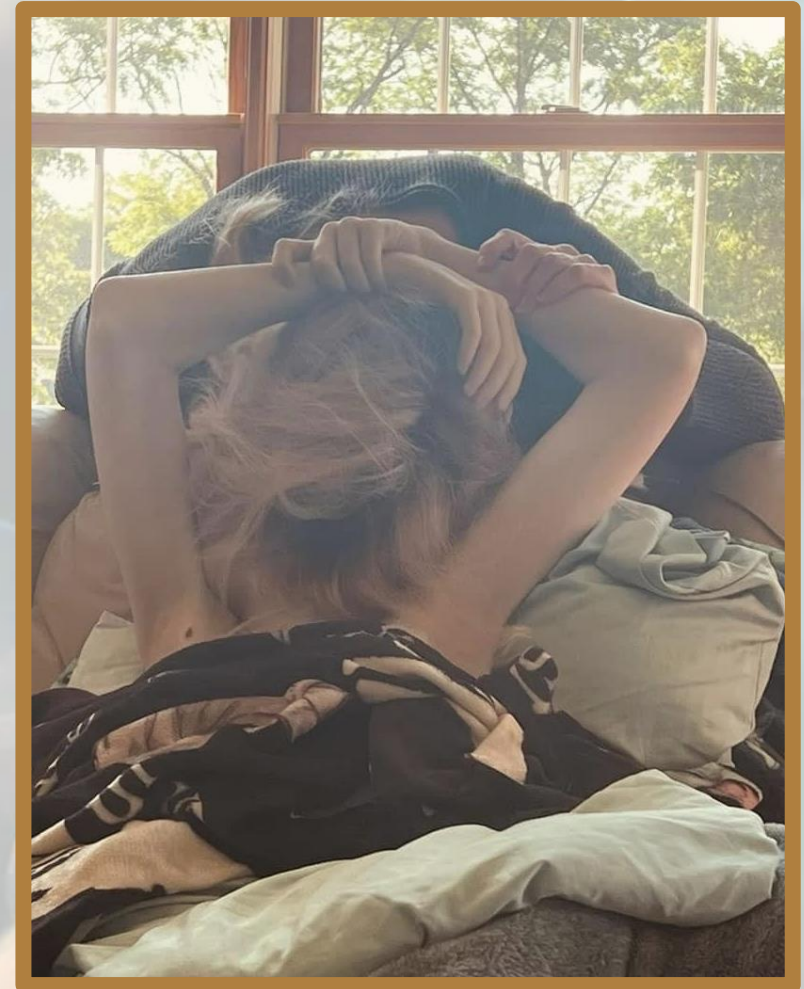
“She was a joy-filled little girl. She found happiness in the darkest times.”



Theme 3: Awareness of Loss Casts a Shadow



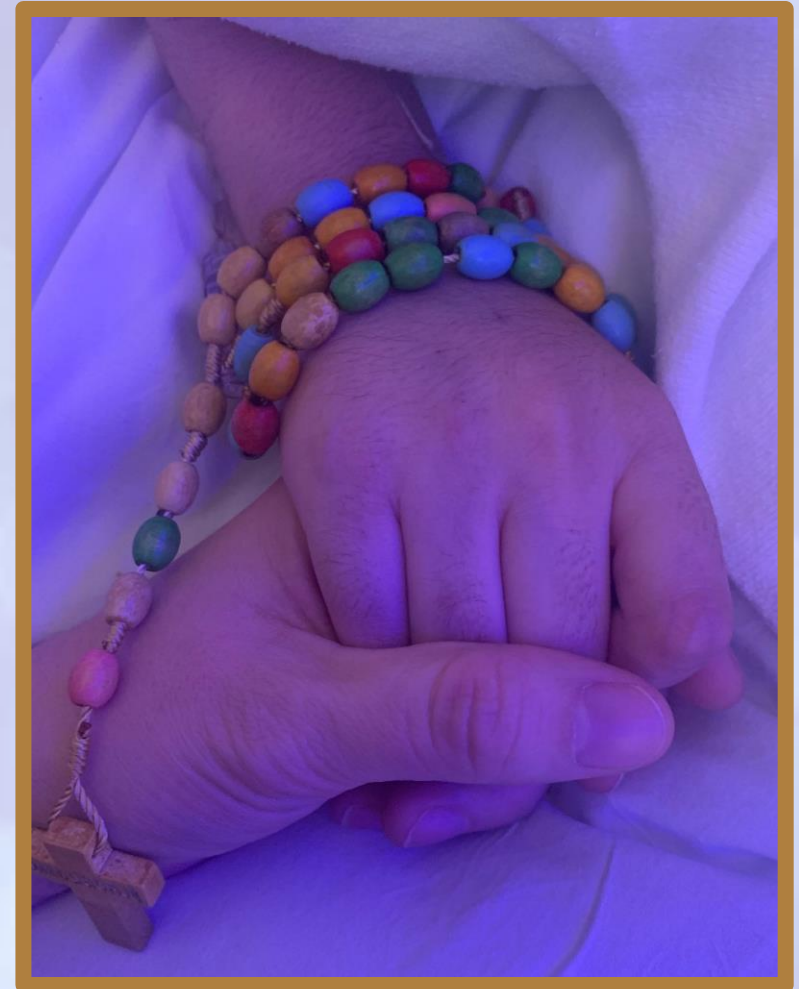
“When you know they might die at any moment...you’ve got that kind of dark cloud hanging over you.”



Theme 4: Beliefs, Spirituality, & Values are a Lens for Hope



“[She] took her last breath in that room. But she is not there. Jesus literally parted the sea as we were all standing there around her bed.”



Theme 5: Supportive Clinicians Hear, See, and Honor the Family's Outlook

Facilitators

- Holistic understanding of child & family dynamics over time
- Palliative Care
- Child life
- Psychosocial/spiritual support



“The [hospital staff] were able to find the hope when there was no hope to be found. In that picture, I remember losing all hope. But a smile, a hug, a ‘they remembered me,’ helped take those bad thoughts away for a bit.”

Barriers

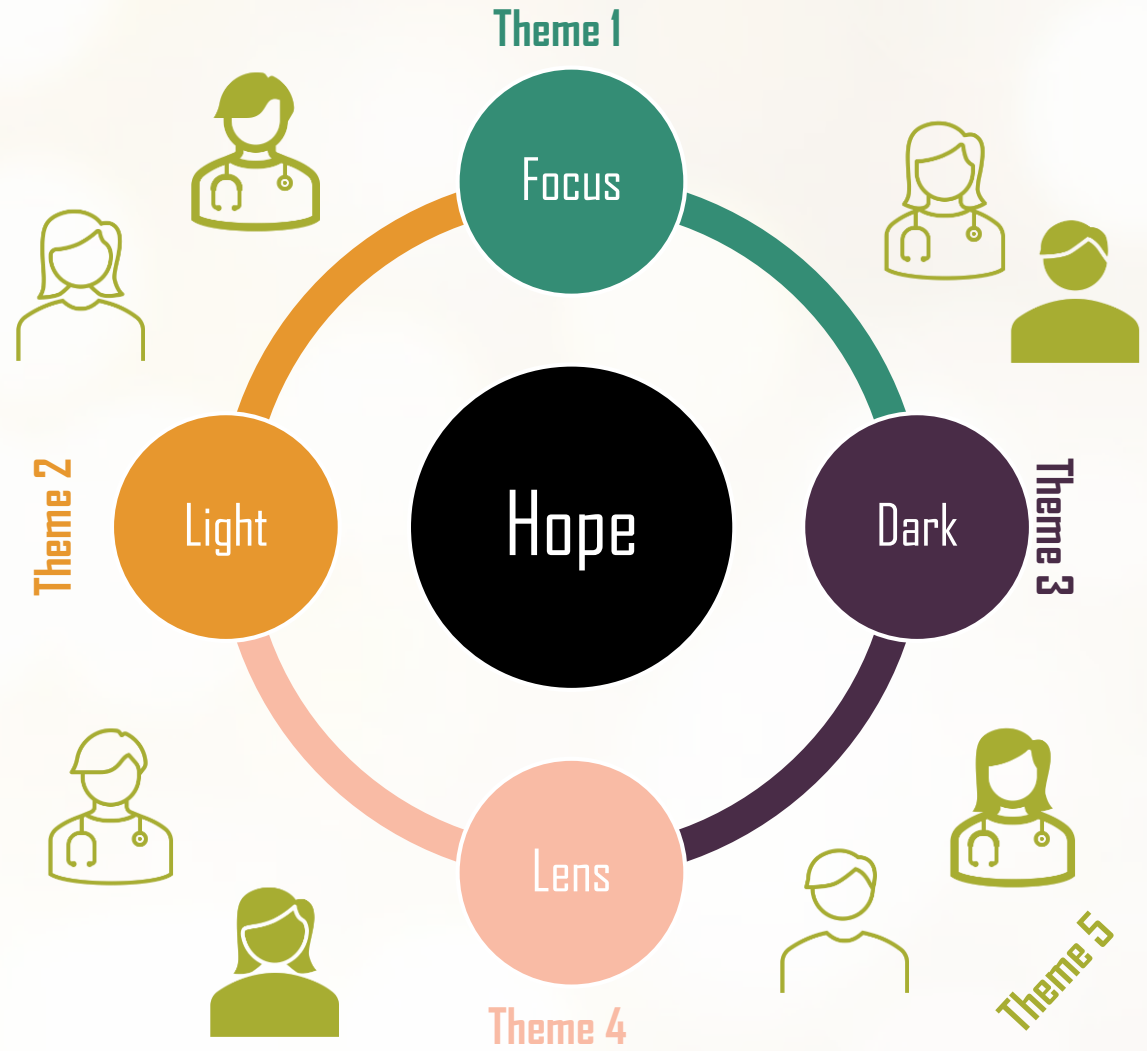
- Misunderstood hopes
- Poor communication
- Hospice inexperienced with children.
- Gaps in hospice care



Discussion

- ❖ Promote clinician understanding
- ❖ Develop supportive interventions

Discussion



Discussion



Discussion

What is the focus of this parent's hope right now?

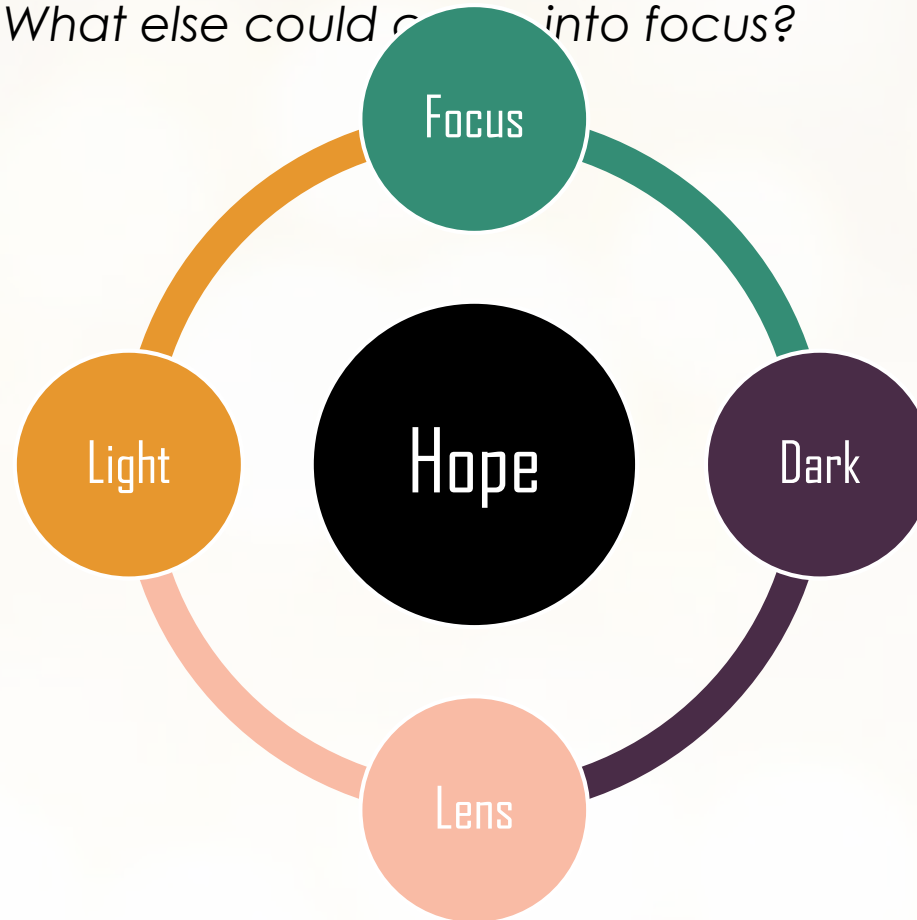
What else could come into focus?

Where does this parent see glimmers of hope?

How can I align with parents in celebration of the good?

What is casting shadows?

How can I recognize or grieve the darkness with families?



What values, beliefs, and worldviews are coloring a family's outlook on hope?

Conclusion

Hospice is a time where hope is complex & evolving.

Seeking to understand the dimensions to a family's hope may help clinicians better support families.

Thank you!

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