

AOSW 2026



Annual Conference

June 10-12, 2026

Portland Marriott Downtown Waterfront
Portland, Oregon USA

Pre-Conferences: June 9, 2026

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Emerging Adults and Advance Care Planning: How Social Workers Can Support What Matters Most

Devon Ciampa, DSW, LCSW-C

National Cancer Institute, National Institutes of Health



Background

“Being an AYA brings with it a unique view. You’re old enough to just be able to see the horizon of your life before your eyes, but young enough to not want to see the end just yet.”

-AYA cancer patient



Background and Purpose

Advance Care Planning (ACP) is a voluntary process of expressing and documenting medical preferences if a person cannot speak for themselves.

About 85,500 **adolescents and young adults (AYA)** between the ages of 15-39 were diagnosed with cancer in 2025 in the United States.
Over 9,000 of those patients died from their disease.

Within the AYA age range, about 30% are in the **emerging adult (EA)** population of 18-29 years, equaling around 25,650 EAs diagnosed with cancer each year.

Background and Purpose

Advance Care Planning (ACP) is a voluntary process of expressing and documenting medical preferences if a person cannot speak for themselves.

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Over 9,000 of those patients died from their disease.

Within the AYA age range, about 30% are in the **emerging adult (EA)** population of 18-29 years, equaling around 25,000 EAs diagnosed with cancer each year.

Few with advanced cancer have ACP conversations.

AYA barriers and challenges to care

Underdiagnosis or misdiagnosis

Few trained health care professionals knowledgeable and trained in AYA needs

Mistrust of health systems and limited understanding

Few organizations provide education or accessible information on AYA cancer incidence

Limited social support

Financial insecurity

AYA barriers and challenges to care

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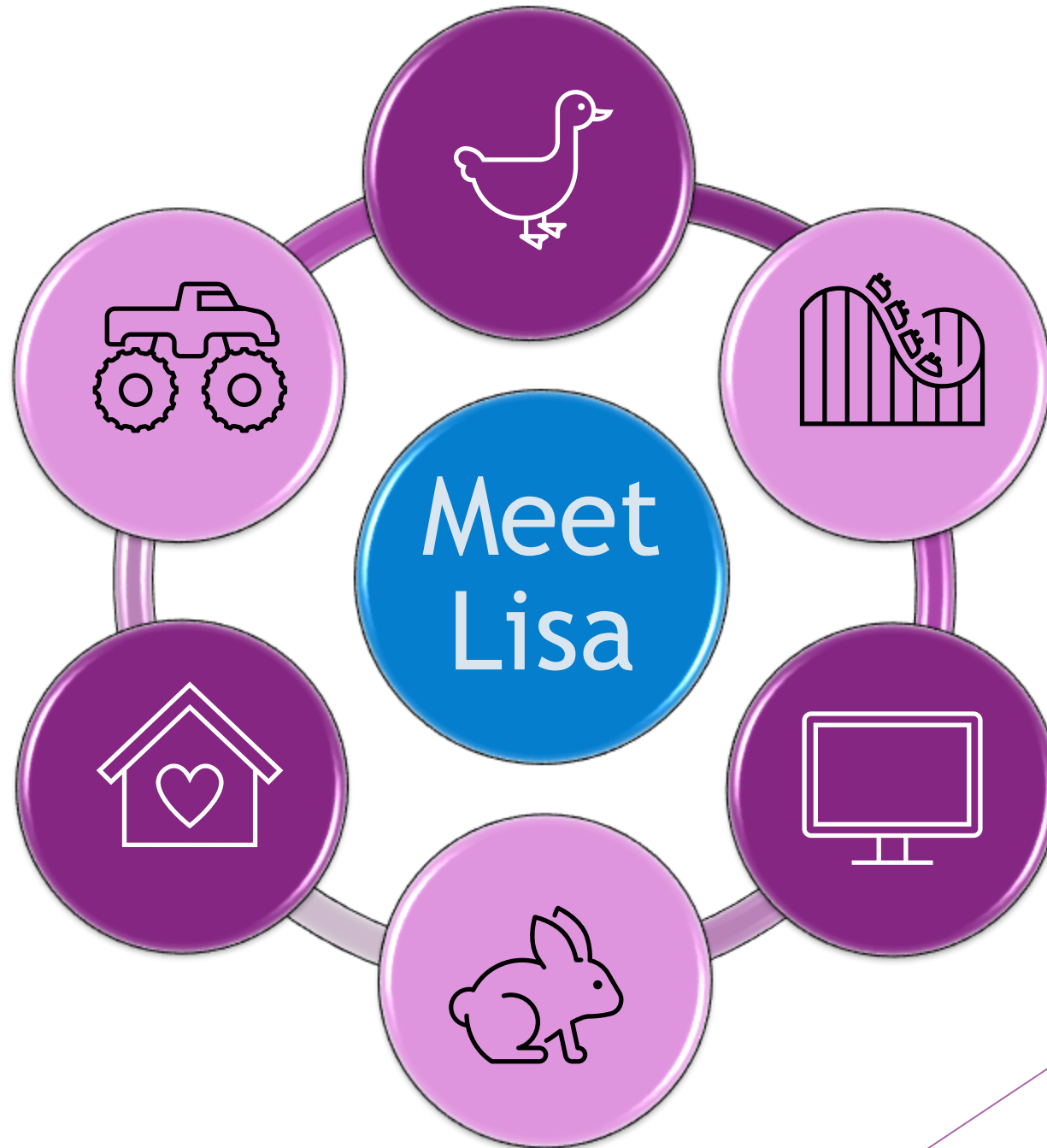
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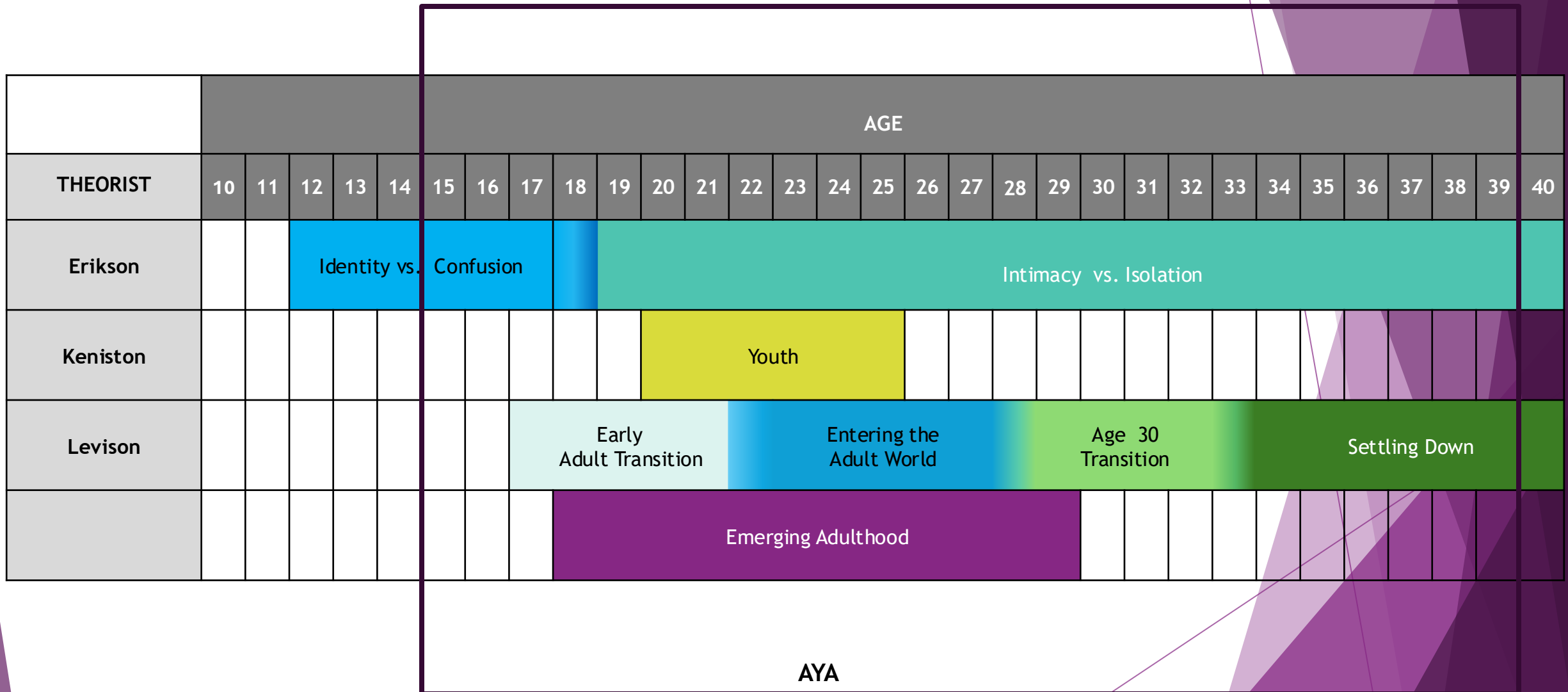


Meet Emerging Adults (EAs)

	AGE																																					
THEORIST	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40							
Erikson			Identity vs. Confusion						Intimacy vs. Isolation																													
Keniston										Youth																												
Levison								Early Adult Transition				Entering the Adult World					Age 30 Transition					Settling Down																
								Emerging Adulthood																														

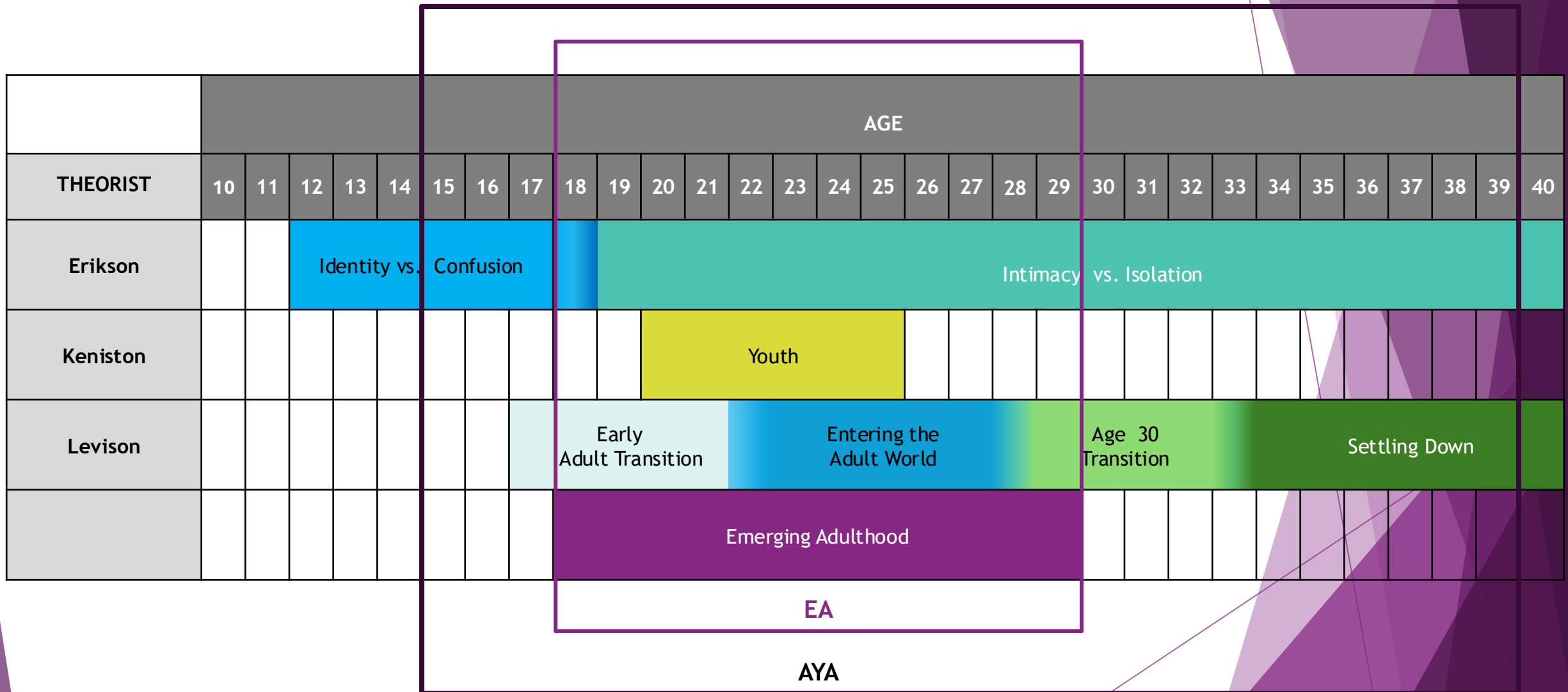
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- Emerging Adults (EA) = Ages 18 to 29

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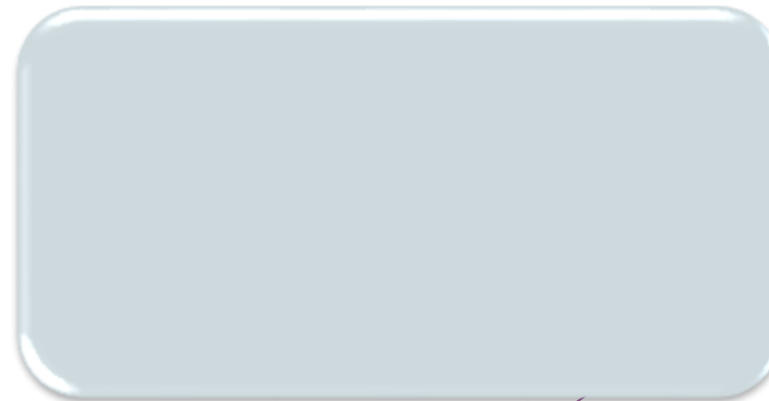


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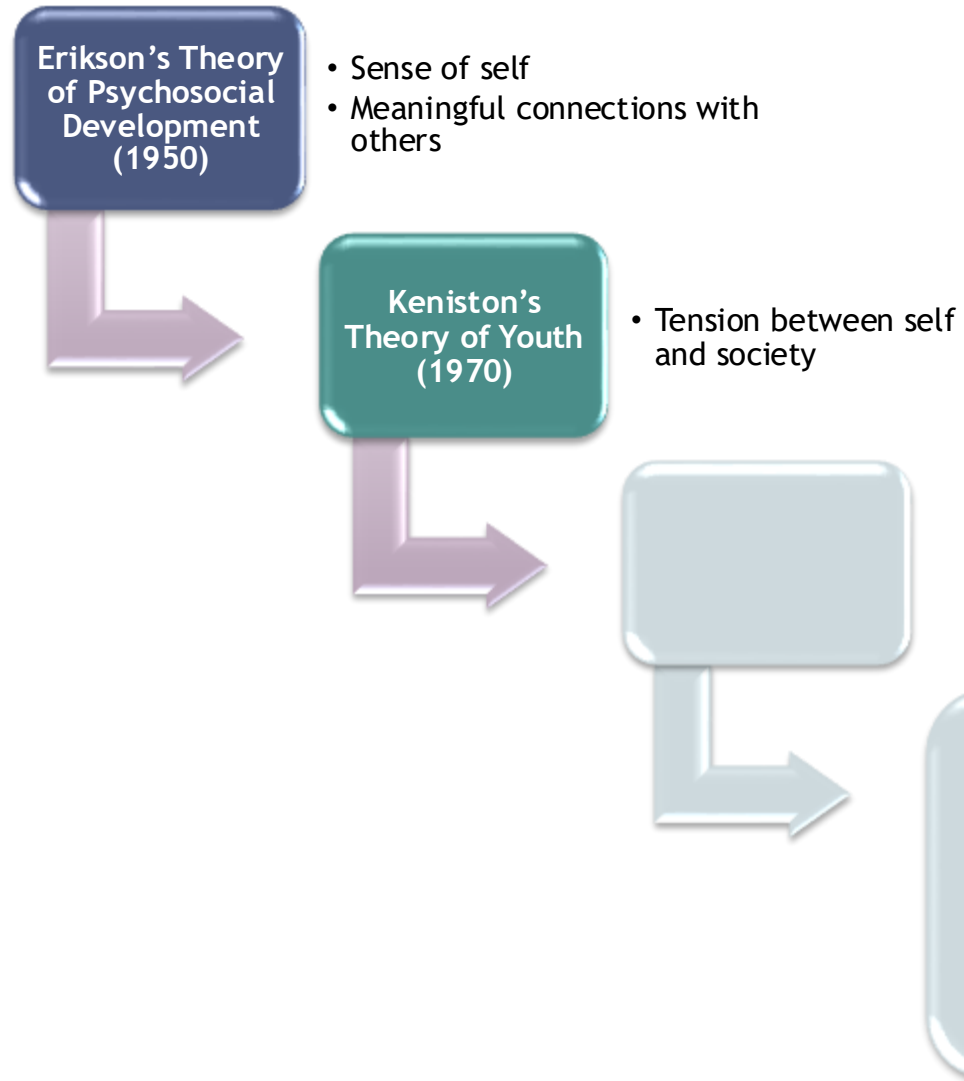
Emerging Adults (EAs)

Erikson's Theory
of Psychosocial
Development
(1950)

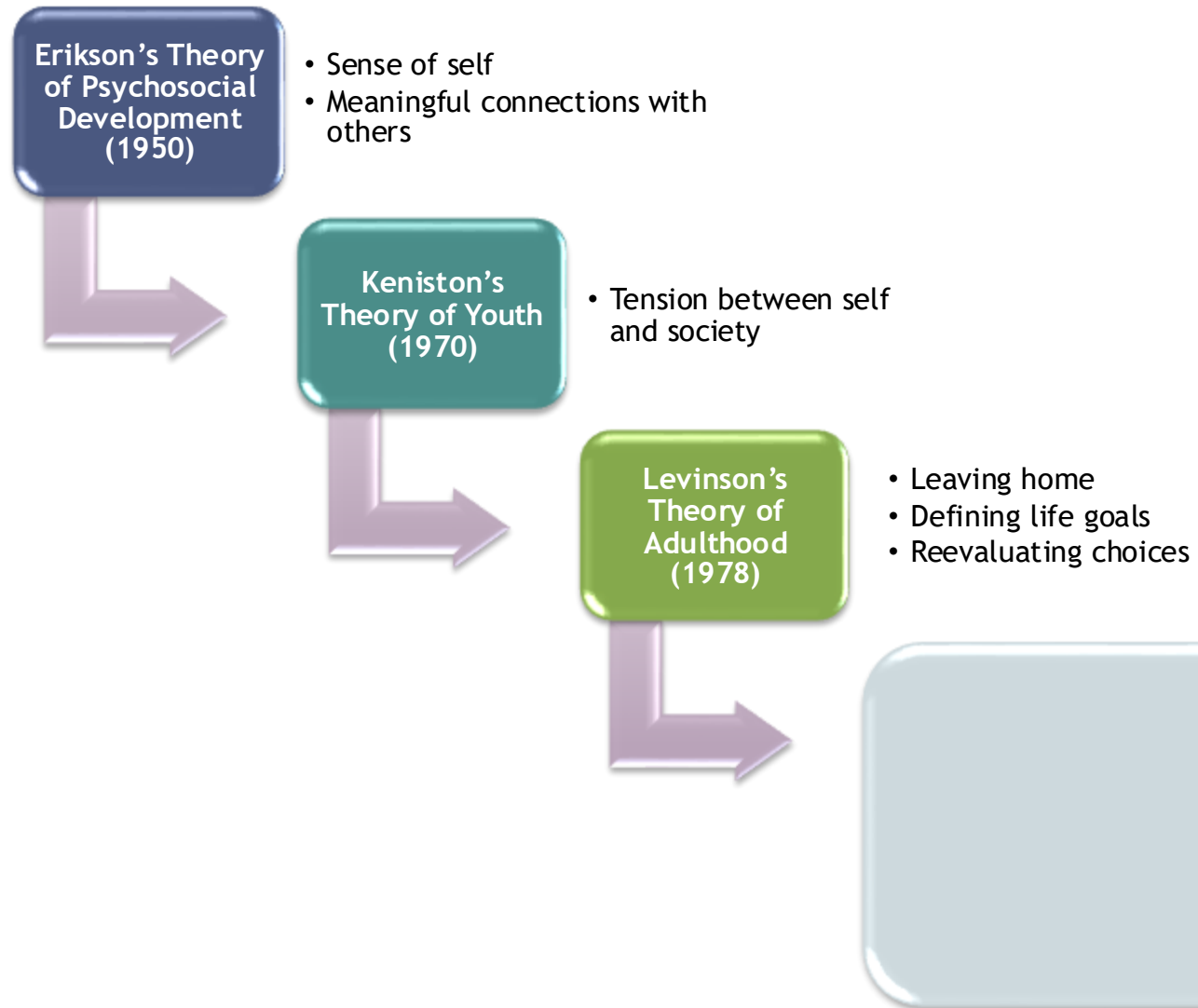
- Sense of self
- Meaningful connections with others



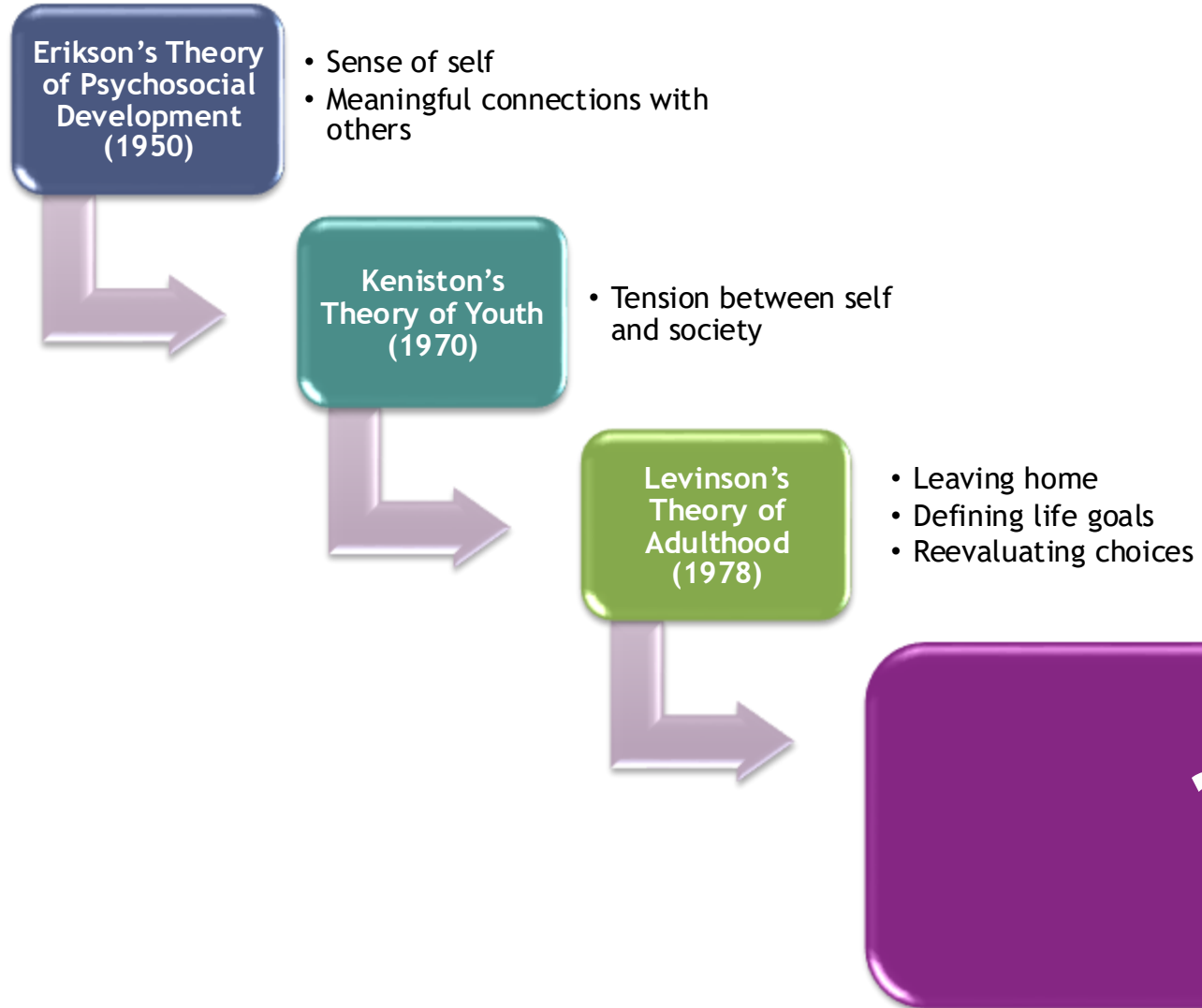
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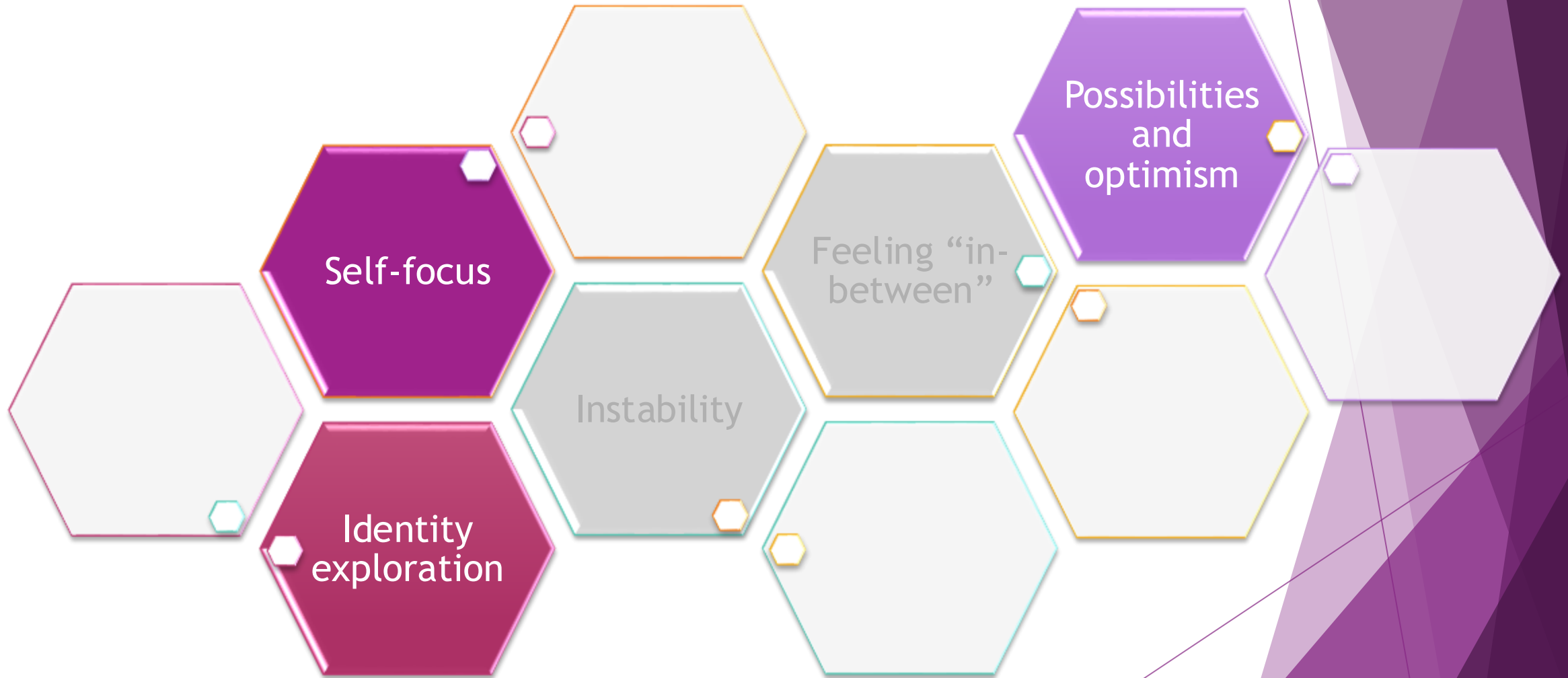


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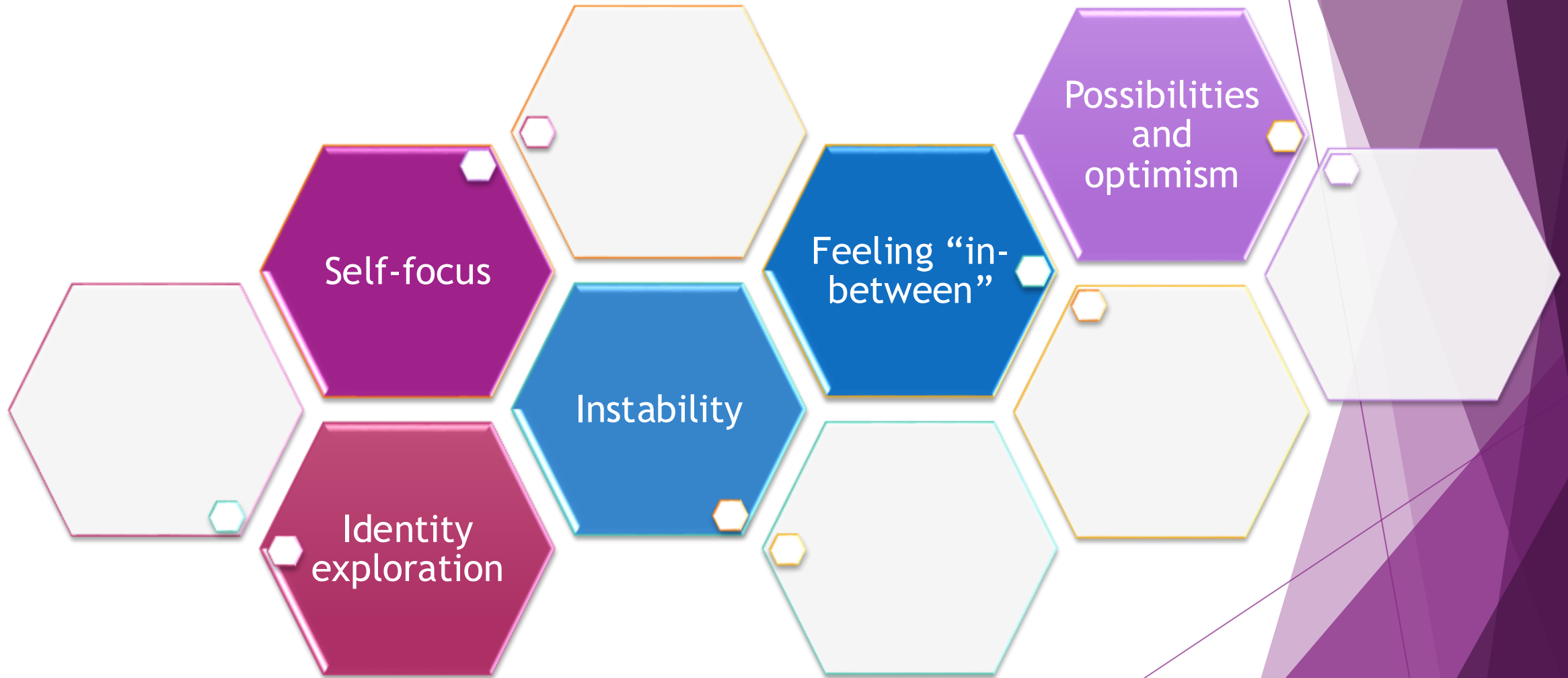
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Arnett's Theory of Emerging Adulthood

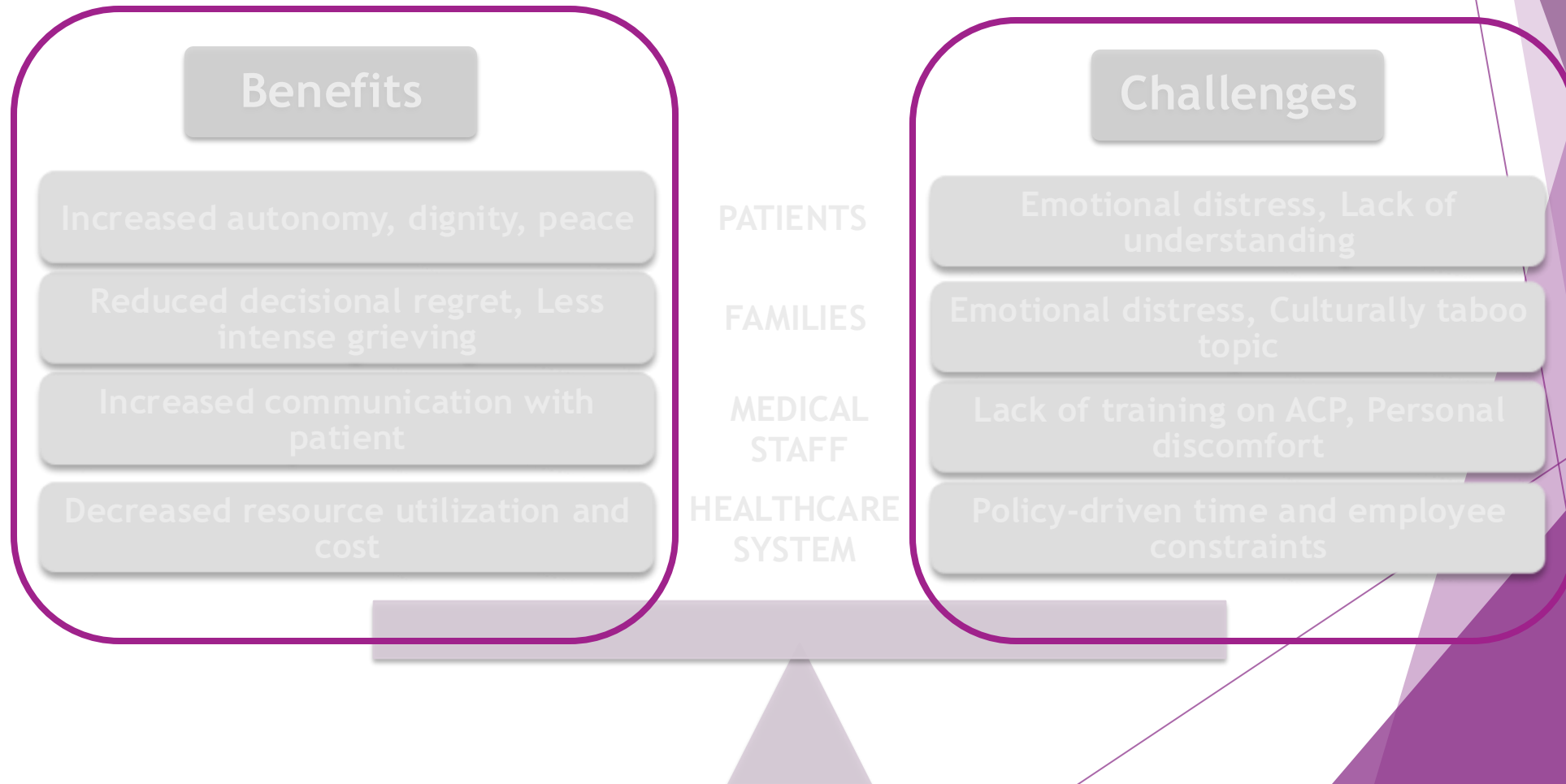


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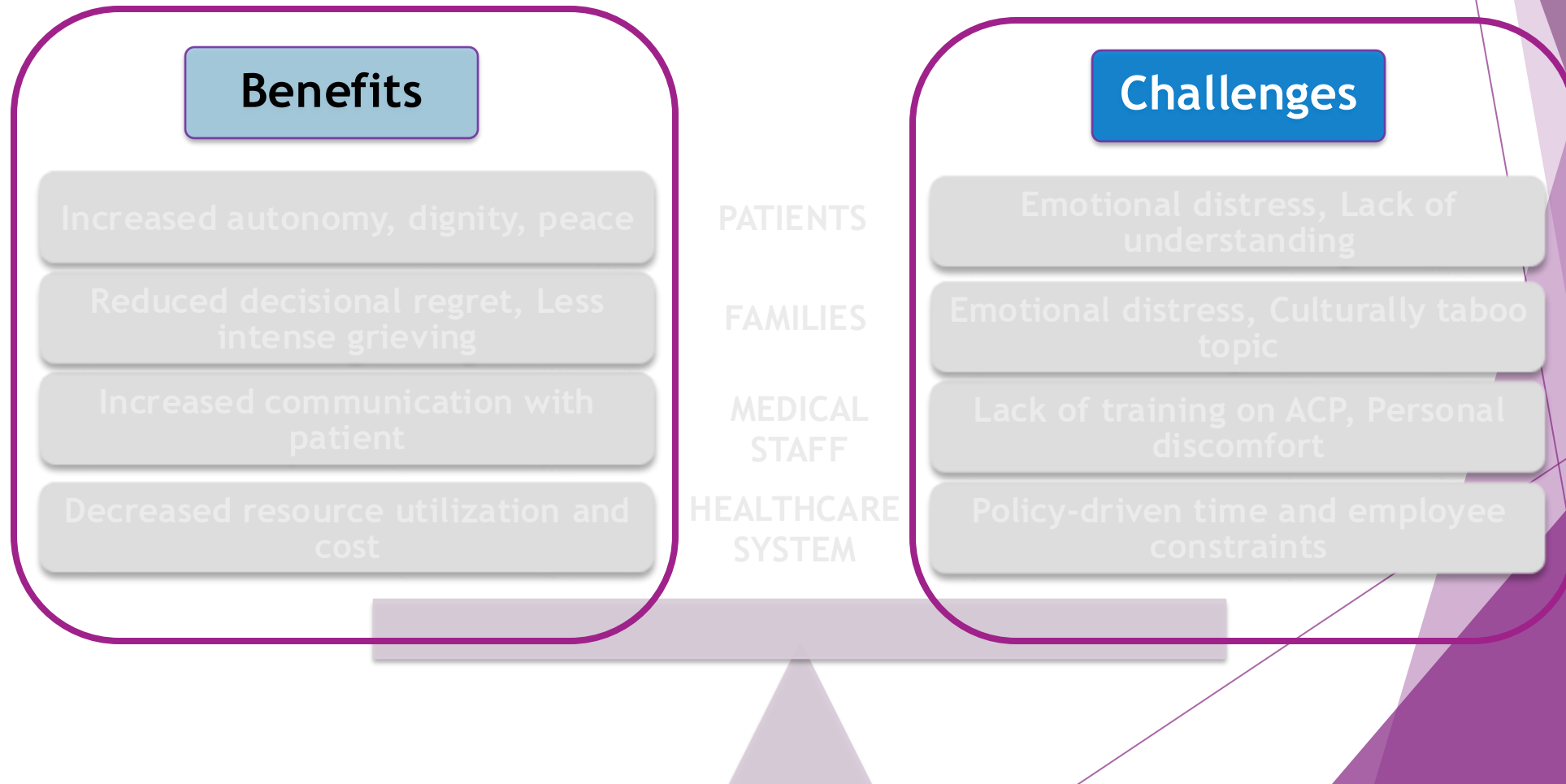
Defining Advance Care Planning (ACP)

- Preferences for medical decisions related to life-saving techniques
- Personal wishes that can ensure understanding of comfort and support needs as well as post-death requests
- Non-end-of-life needs



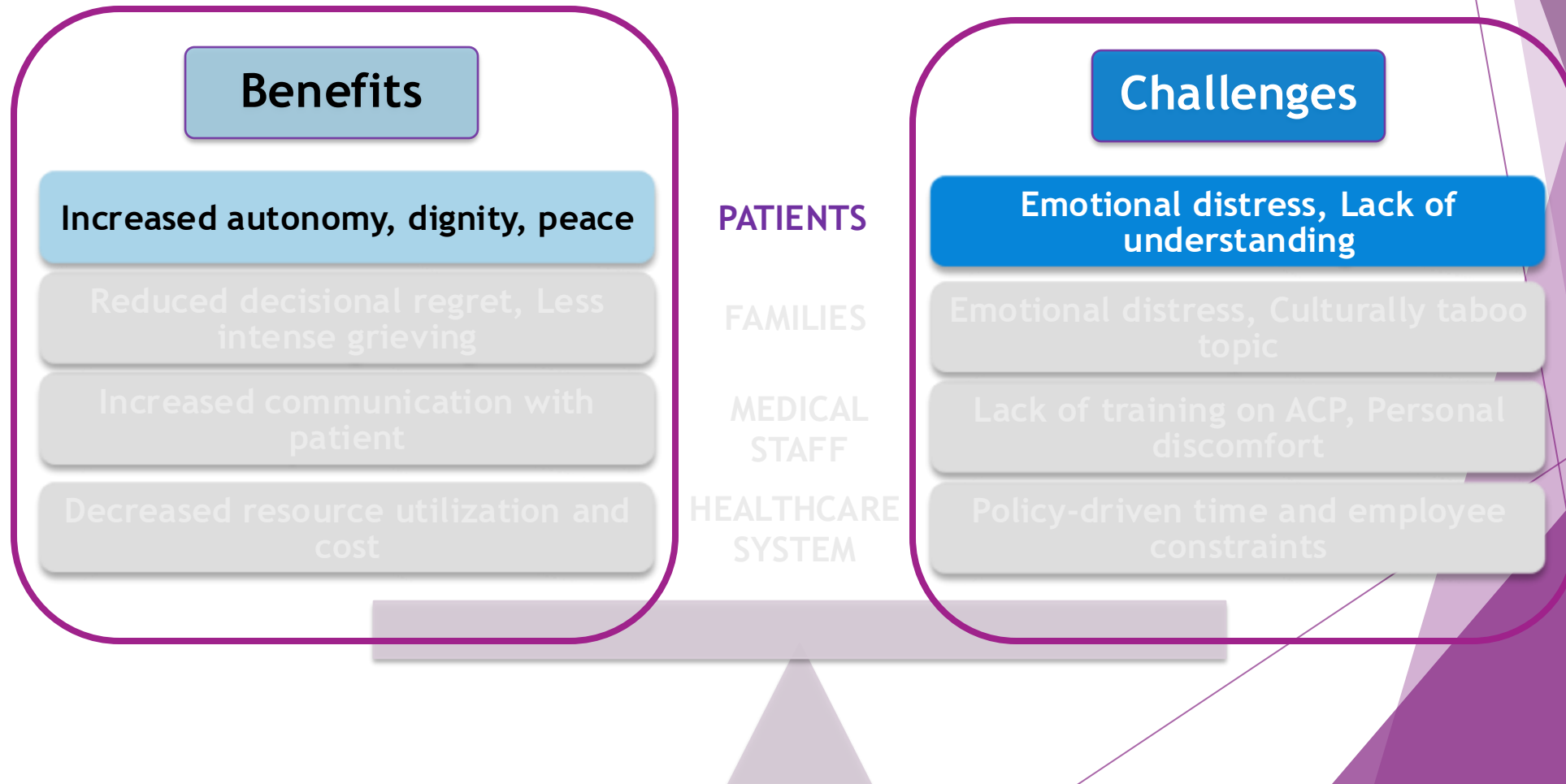
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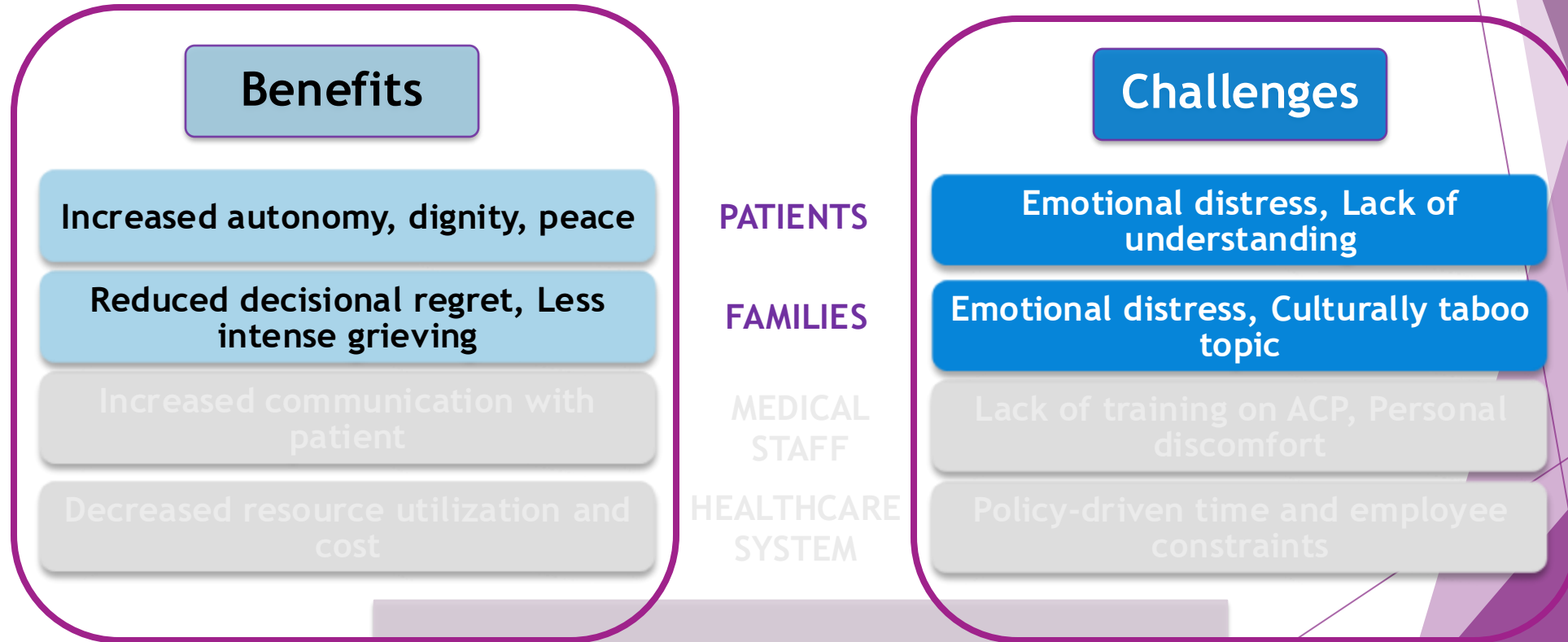
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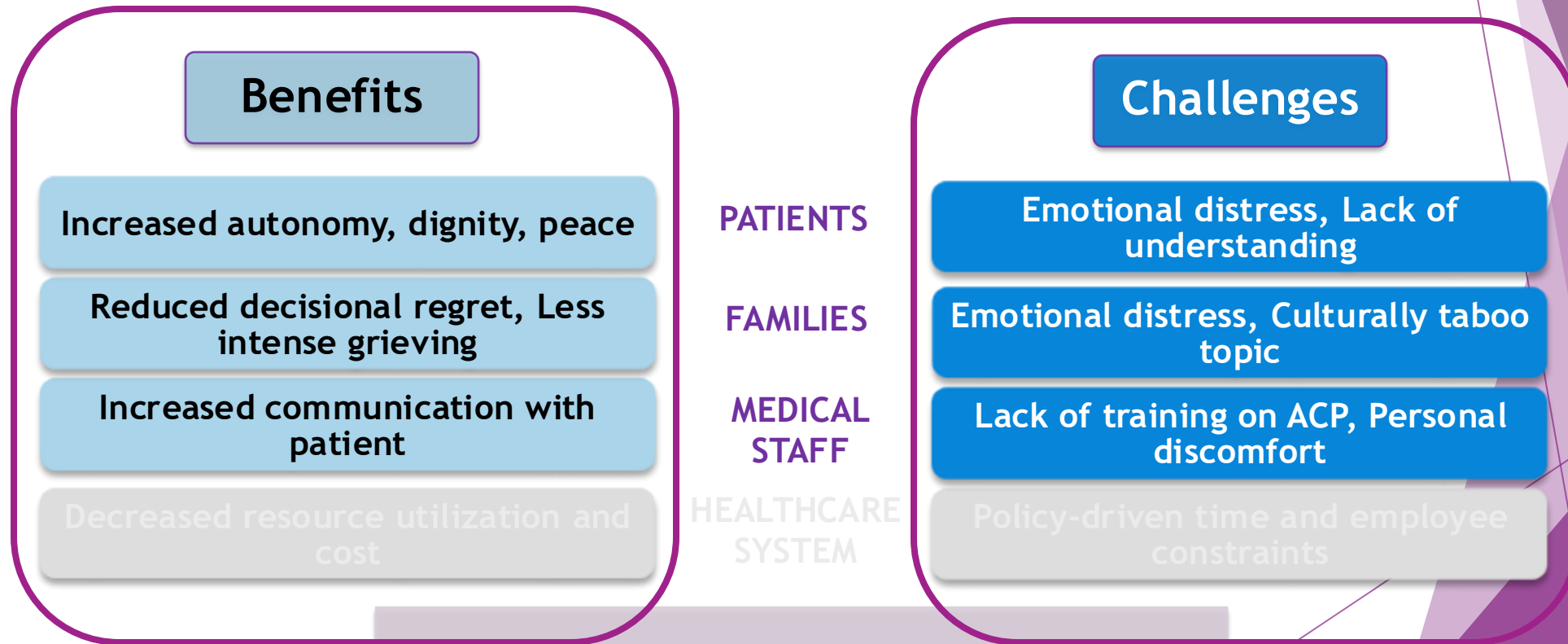
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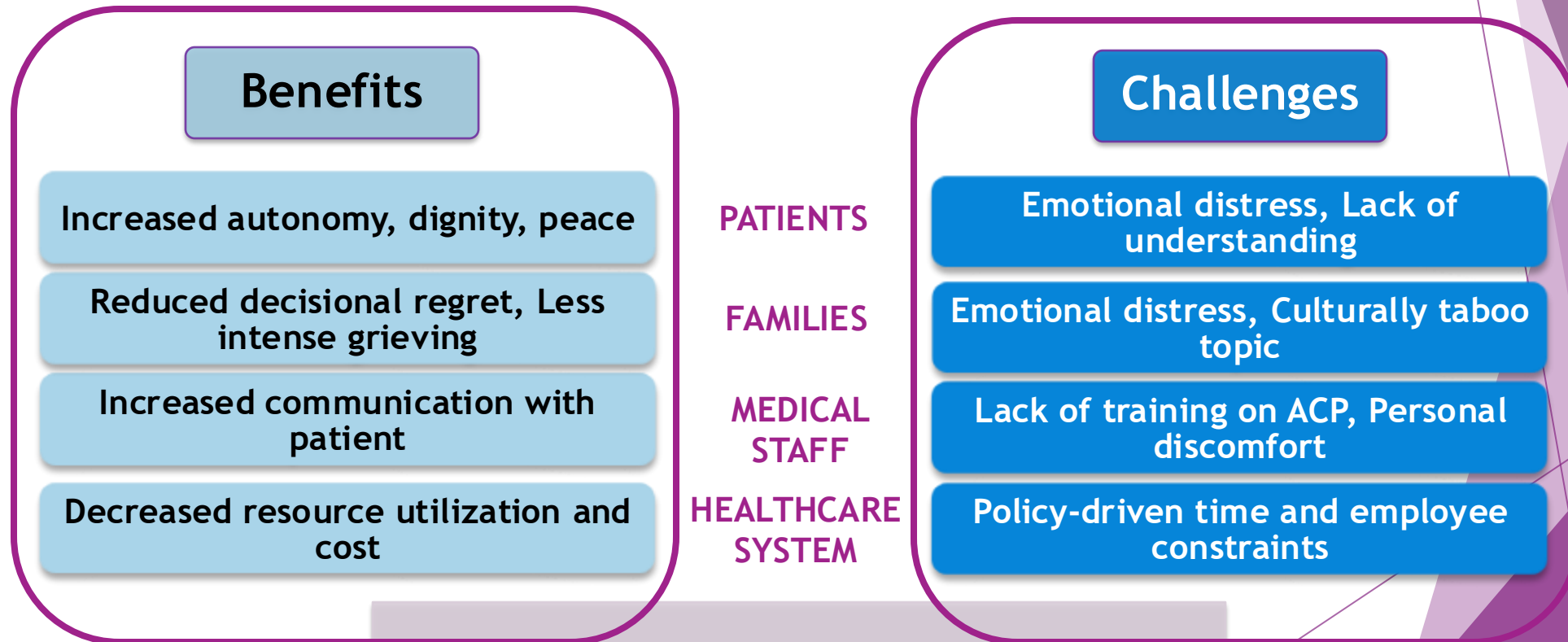
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ACP across the life cycle

ACP and children

- **Children:** Focused on feelings, parent/guardian is primary decision-maker, prioritizing both child and family well-being
- **Puberty:** Can handle larger concepts of life and death, make basic medical decisions
- **Adolescence:** Awareness of self and others, usually can play a larger role in ACP conversations

ACP and young adults

- Relationships as a primary focus - both inside and outside of family unit, worry for dependents
- Can comprehend larger medical concepts and consequences
- Legal factors put young adults in charge of decision-making at start of adulthood

ACP with older adults

- Coming to terms with met and unmet life goals
- Creating a will for any accumulated possessions and wealth
- Relationship with doctor might be well-established
- Prior experience with health problems and the medical system

CONSIDERATIONS AT ANY AGE

- Emotional & cognitive ability
- Access to resources and support
- Culture
- Legal factors

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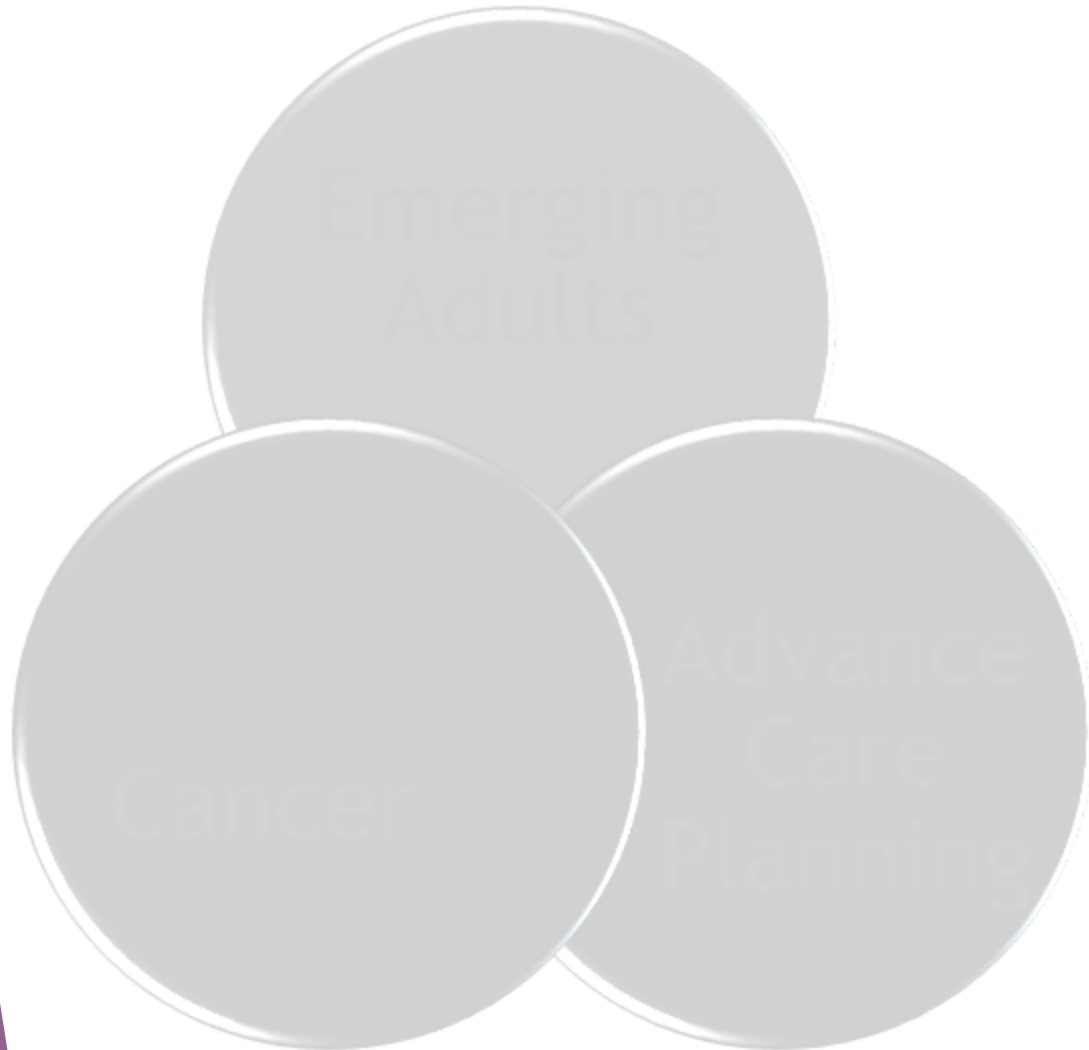
Statement of the problem

- ❖ **Research on emerging adults and advance care planning is scarce**
- ❖ Tension exists between emerging adult developmental tasks and restrictions caused by serious illness

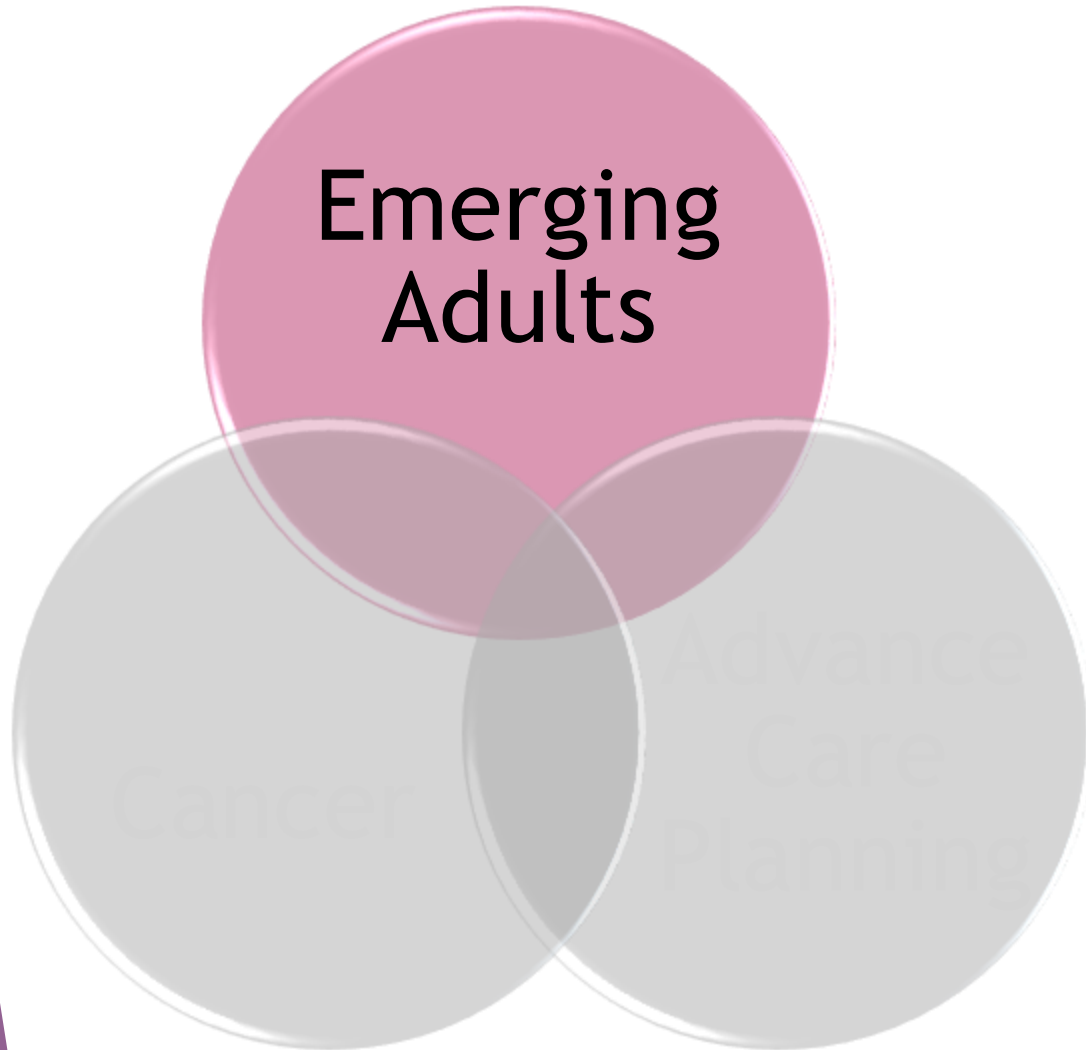
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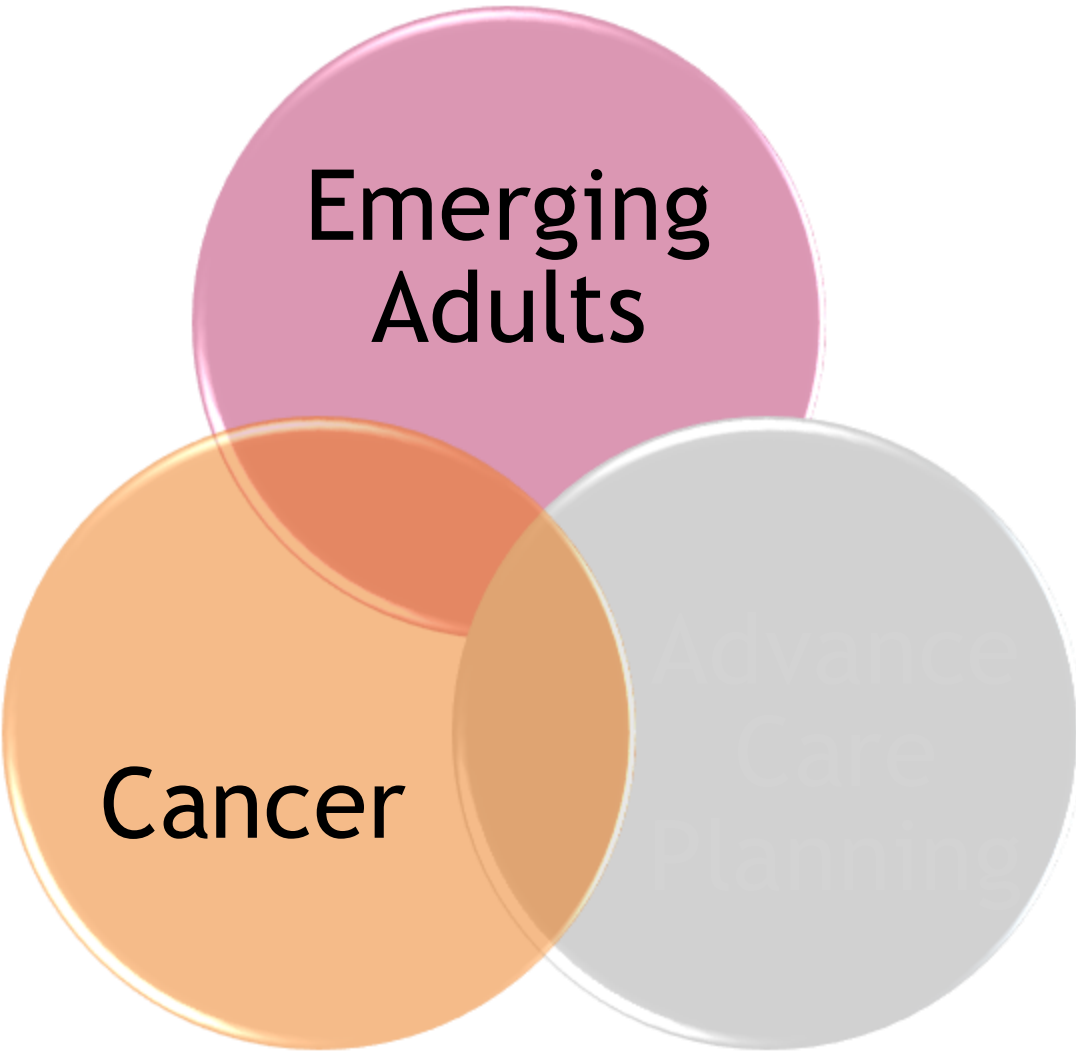
The question...



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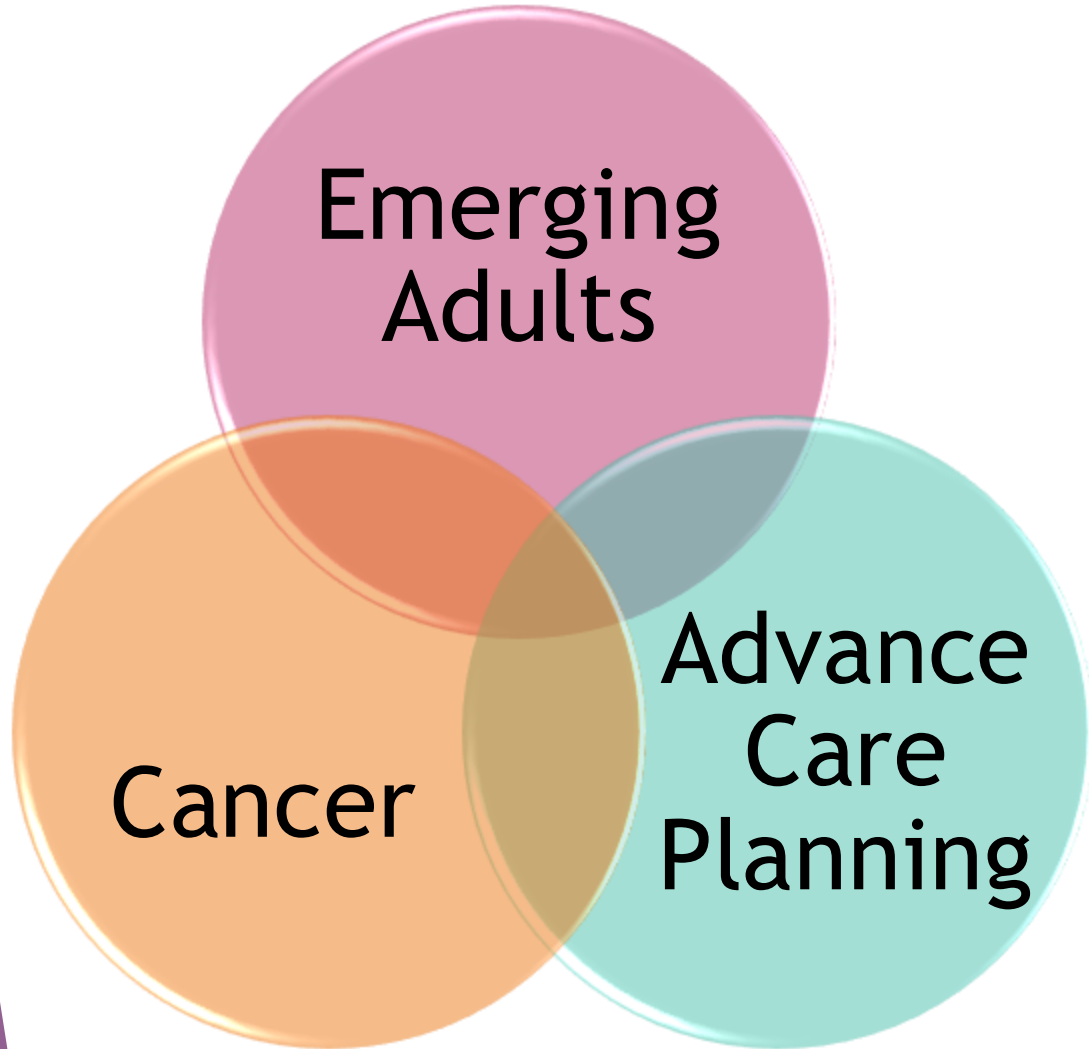


Emerging
Adults

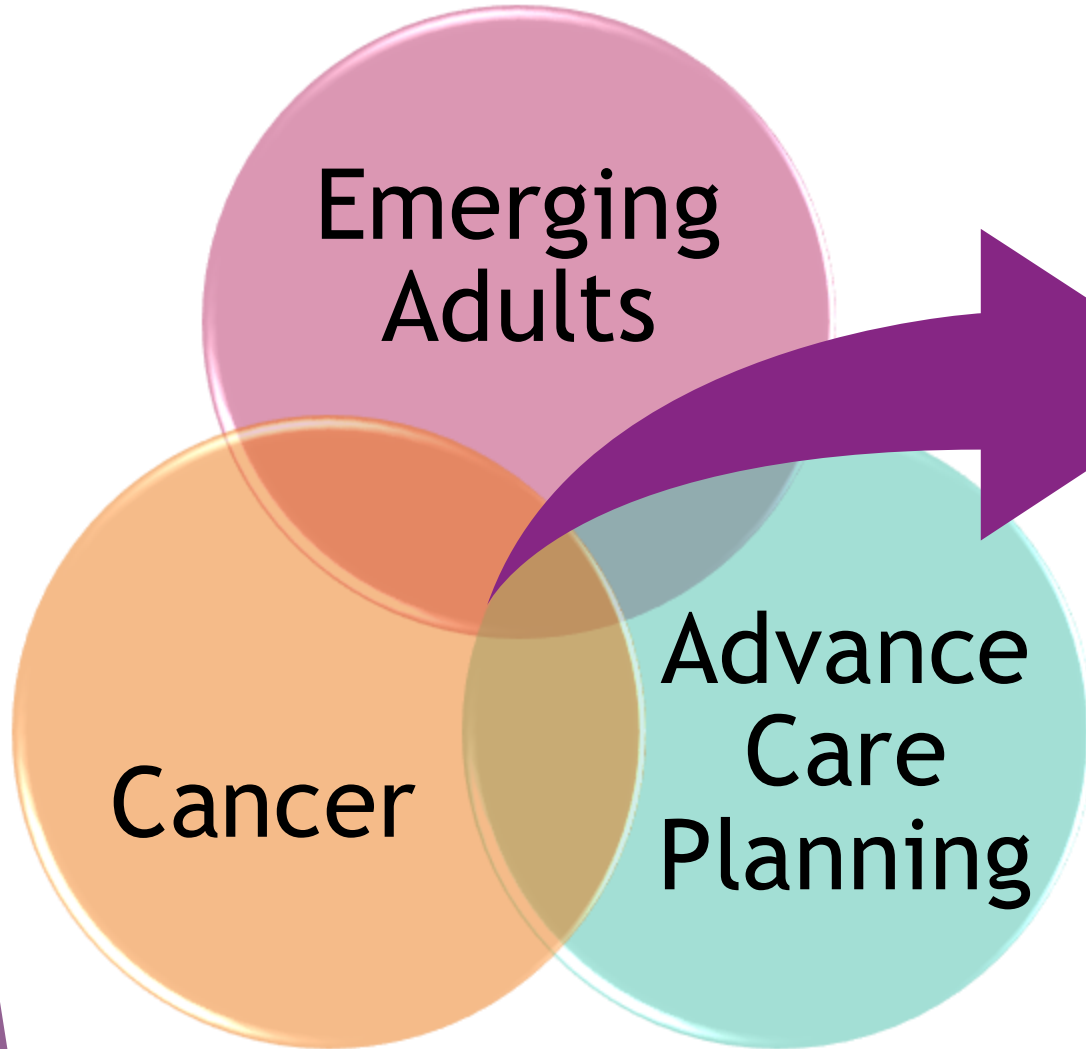
Cancer

Advance
Care
Planning

The question...



The question...



**What do EAs
facing cancer
need to engage
with ACP?**

Methods

“Everyone’s cancer journey is different. And yet, everyone’s begins the same. One minute, you’re a person. The next, you’re a patient.”

-AYA cancer patient



Research questions

This study sought to demonstrate that the ACP process is not only critical to patient care but developmentally significant for EA patients and their families.

Specifically, the study answered the following questions:

What do EAs want to focus on in ACP?

What are the benefits and barriers to ACP with EAs?

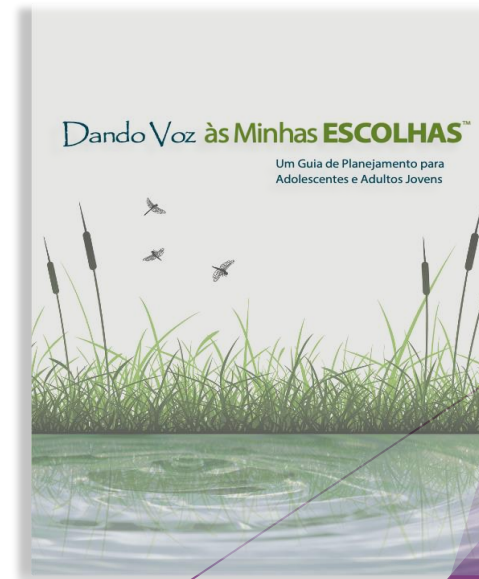
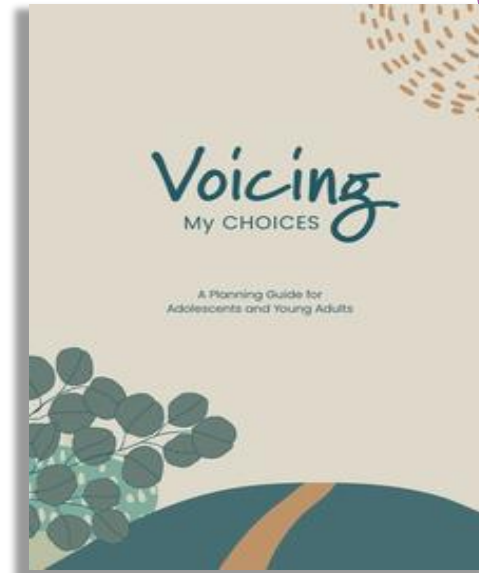
How can Voicing My CHOICES assist EAs in ACP conversations?

Voicing My CHOICES

Communication guide for AYA patients and their loved ones on the topic of advance care planning

“(Voicing My CHOICES) allows AYAs to play an active role in their medical decision making. This can be empowering for the patient and provide clarity for their caregivers.”

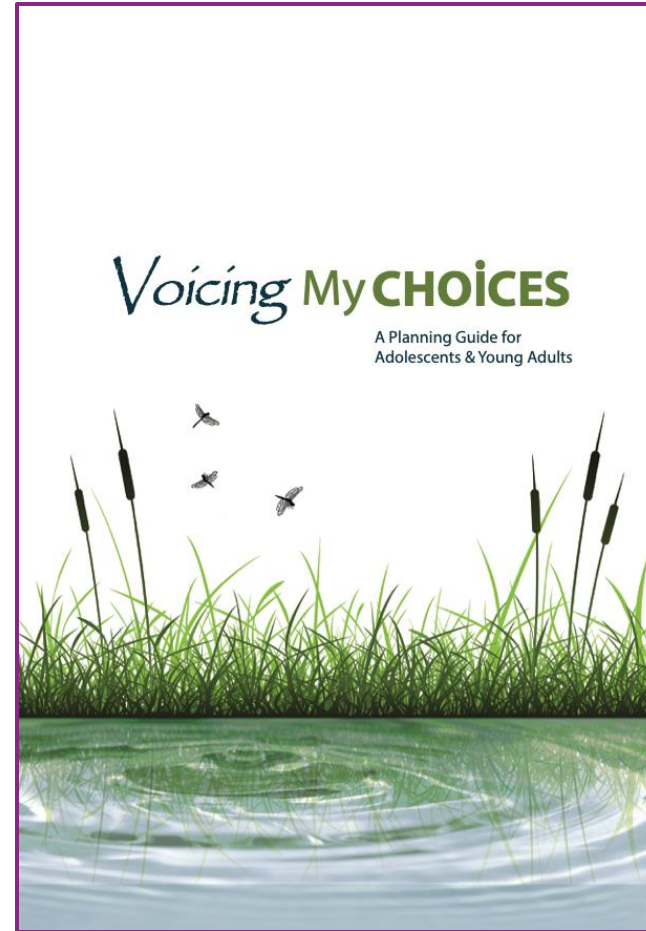
(Bedoya, Wiener, Ciampa, et al, 2025)



Lisa

and

Voicing My CHOICES



The EA Study

The EA Study used data from The Parent Study:

“Voicing My CHOICES as a Tool for Advance Care Planning for Young Adults with Cancer”

THE PARENT STUDY

RECRUITMENT

- Four US medical centers
- Convenience sampling
- Inpatient and outpatient
- Eligibility:
 - English-speaking
 - Current treatment
 - Ages 18-39 years

DATA COLLECTION

- Pre-interview questions included ACP experiences with family, friends and providers
- Interviews compared two versions of VMC
- Post-interview questions included how to improve VMC

PARTICIPANT DEMOGRAPHICS

$N = 67$
Mean age = 24.5
Male = 56.7%
Caucasian = 70.8%
Cancer diagnosis = 80.6%

THE EA STUDY

DATA INCLUSION

- The Johns Hopkins Hospital and The National Institutes of Health
- Participants aged 18-29 years
- $N = 39$ participants
 - 29 participants from NIH
 - 10 participants from Hopkins

ANALYSIS

Thematic Content Analysis

The EA Study

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ANALYSIS

Thematic Content Analysis



Findings

“(With cancer) You feel so powerless...You are less capable to do things yourself. You have to ask for help all the time, and you depend on others for a lot of things. It’s just like that. You can’t avoid it. You are a child again.”

- (Belpame et al, 2016)

RQ 3:

How can VMC assist EAs in the ACP process?

1

Emphasizing
Choice and
Control

2

Supporting
Loved Ones

3

Highlighting
Developmentally
Appropriate
Aspects

37 out of 39 participants
stated they would use VMC
for themselves

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Choice and Control: *Supporting Emerging Autonomy*

Exercising Autonomy (100%)

- ▶ Maintaining control over body, personal space, appearance and legacy was most important
- ▶ Reflection of self-determination and identity - both in care selections and remembrance

“(I would like) a box stating ‘if I ask for your idea or opinion (give it). Otherwise, I would like my decisions to be respected and not judged.’ ”

“It is important to me that my friends and family respect my wishes, decisions and choices even if they don’t agree with them.”

Increasing Knowledge (56%)

- ▶ Educational components helped them understand options within domains of care
- ▶ Learning new information previously not thought of

“More options that I hadn’t thought about.”

“The glossary is so helpful, so I can understand.”

Space to explain or justify preferences (44%)

- ▶ Documenting preferences and ensuring those preferences would be honored were two distinct but equally important factors

“Having more space to write in personal answers is important.”

“I like being able to explain (my decisions).”

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“I want to be remembered in a happy way.”

“There may be special ways that someone wants to distribute their belongings and be remembered especially on certain days such as a birthday.”

“(Add) ‘Things I would like people to do to keep my memory alive (fill in option)’.”

“(Add) ‘If I have participated in fertility preservation, and I am unable to use the collected eggs/sperm, I would like (fill in option)’.”

“(Add) ‘If I have hurt or upset any of my friends, family, or others, I wish to be forgiven for (fill in option)’.”

“Keep the part about making sure I look ok (at my funeral).”

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- ▶ **Importance of joy (36%)**

“One more line - what makes me happy or brings joy.”

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Support for Loved Ones: *Prioritizing Others*

Providing and Receiving Guidance (82%)

- ▶ Providing direction to loved ones was equally important as receiving direction from VMC

“I like the prompts. I wouldn’t know what to write otherwise.”

“It helps with knowing how to phrase hard statements with family.”

“Allows you to feel comfort, reflect, feel supported, and to have everyone on the same page.”

Helpful for loved ones - both during the ACP process and after death (77%)

- ▶ Supports loved ones’ coping and decisional challenges
- ▶ Reduces decisional regret

“I said no matter what happens I know I will be ok, But I want to make sure my loved ones are OK too.”

“(I would like) a checkbox for spiritual/religious support for my family. Family needs peace after.”

Defining Loved Ones (18%)

- ▶ Distinguishing between family and friends was not wanted - simply use “loved ones”

“Sometimes friends are like family in terms of making decisions.”

Support for Loved Ones: *Prioritizing Others*

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- ▶ **Advance care planning is emotionally difficult**

- ▶ 68% mentioned emotional distress for themselves
- ▶ 44% mentioned emotional distress for loved ones
 - ▶ Words used to describe this distress was **“upsetting”**, **“hurtful”**, and **“scary”**
 - ▶ **“I don't know how to talk about this. I don't think they would understand. We would just be upset.”**
- ▶ For those who had not previously had advance care planning discussions:
 - The conversation would be upsetting to family (43%)
 - It would be bad luck (39%)
 - The conversation would be upsetting to me (17%)
 - The doctor will decide when it was time to have conversations (4%)

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Support for Loved Ones: *Prioritizing Others*

Helpful for loved ones - both during the ACP process and after death (77%)

- ▶ Supports loved ones' coping and decisional challenges
- ▶ Reduces decisional regret

“I said no matter what happens I know I will be ok, But I want to make sure my loved ones are OK too.”

“(I would like) a checkbox for spiritual/religious support for my family. Family needs peace after.”

- ▶ **Advance care planning is emotionally difficult**

- ▶ 68% mentioned anticipated or experienced emotional distress for themselves
- ▶ 44% mentioned anticipated or experienced emotional distress for loved ones
 - ▶ Words used to describe this distress was “upsetting”, “hurtful”, “scary”, and “felt numb”
 - ▶ “I don’t know how to talk about this. I don’t think they would understand. We would just be upset.”
- ▶ For those had not previously had advance care planning discussions:
 - **The conversation would be upsetting to family (43%)**
 - It would be bad luck (39%)
 - **The conversation would be upsetting to me (17%)**
 - The doctor will decide when it was time to have conversations (4%)

Support for Loved Ones: *Prioritizing Others*

Providing and Receiving Guidance (82%)

- ▶ Providing direction to loved ones was equally important as receiving direction from VMC

“I like the prompts. I wouldn’t know what to write otherwise.”

“It helps with knowing how to phrase hard statements with family.”

“Allows you to feel comfort, reflect, feel supported, and to have everyone on the same page.”

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Defining Loved Ones (18%)

- ▶ Distinguishing between family and friends was not wanted - simply use “loved ones”

“Sometimes friends are like family in terms of making decisions.”

RQ 3:

How can VMC assist EAs in the ACP process?

1

Emphasizing
Choice and
Control

2

Making
Information
Approachable

3

Highlighting
Developmentally
Appropriate
Aspects

Age-Appropriate: *Making information developmentally relevant and accessible*

Importance of formatting and presentation of document (100%)

- ▶ Appreciated aesthetic differences between VMC and traditional medical documents including clear formatting and intuitive design

Words used to describe VMC = “less intimidating”, “less overwhelming”, “warm”, “inviting”

Importance of language (90%)

- ▶ Appreciated intentional age-appropriate language in VMC
“This speaks more to how I think.”
- ▶ Acts as a reminder that EAs are not alone
“I didn’t know others thought about these things.”
- ▶ Appreciated directness - desire for honesty and truth
“Things we have to, but don’t tend to think or talk about.”

Improving accessibility (56%)

- ▶ Noted the need for an online version for a “digital generation”, ease of updating, and to allow young adults anywhere to access it (and share it)
“Being able to make changes anytime is important”
“Take pressure off of my shoulders to think of what I need to do and tell everyone.”

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Age-Appropriate: *Making information developmentally relevant and accessible*

Importance of formatting and presentation of document (100%)

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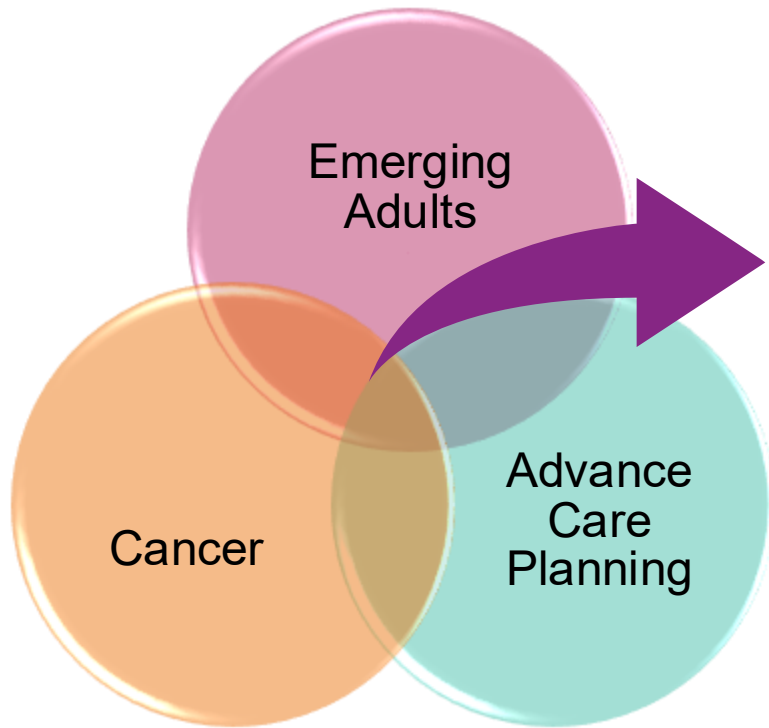


Discussion

“The physical side effects of cancer treatment are often discussed, but the mental and emotional burden is just as significant, if not more so.”

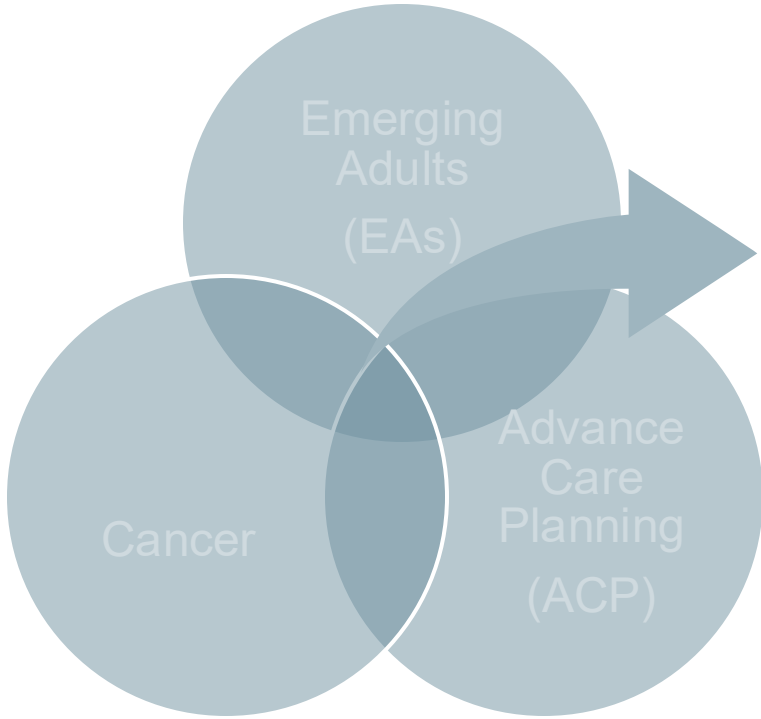
-Teen Cancer America community member

Back to the question...



What do EAs facing cancer need to engage with ACP?

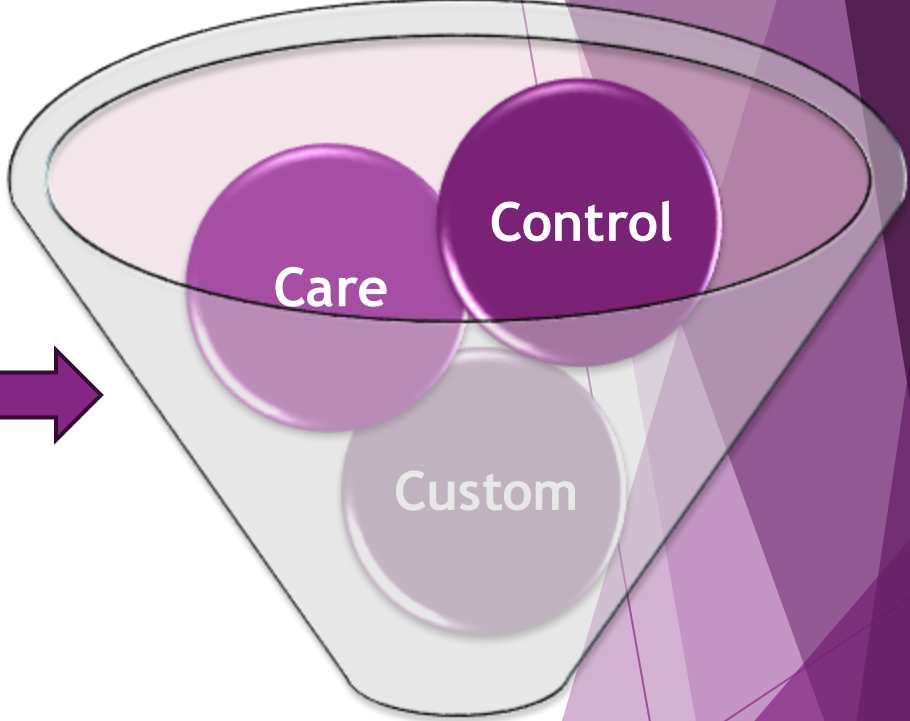
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What do EAs facing cancer need to engage with ACP?



Three C's



ACP with EAs

What do EAs need?

Exercise autonomy in ACP

ACP can offer *continuous control*

EAs see themselves in the *future* whether they are present or not

Balance their needs with the needs of others

Secure care of loved ones both during ACP and *in the future*

ACP can increase support *from* others and *for* others

A living document that is unique to them

What EAs want is *equally* important as what they don't want

How information is presented is just as important as *what* is presented

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Implications for Practice

- ❖ **ACP is emotionally complex**
 - ❖ Experienced as both distressing and meaningful by patients
 - ❖ Requires space for fear, hope, and connection
- ❖ Clinician-initiated, developmentally attuned ACP is essential
 - ❖ Normalize ACP as part of comprehensive care, not just end-of-life
 - ❖ Use age-appropriate communication and education
- ❖ Critical role of mental health professionals
 - ❖ Support emotional processing
 - ❖ Facilitate family communication and reduce avoidance
 - ❖ Help patients maintain agency and developmental integrity
- ❖ Training needed across disciplines
 - ❖ Address clinician discomfort
 - ❖ Build shared language across disciplines
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Lisa's wishes are honored due to ACP conversations and VMC



What I Would Like My Family and Friends to Know

My Choice

It is important to me that my family/friends:

- Get along
- Take care of themselves
- Take care of one another
- Get counseling or find a support group for themselves and/or my siblings if they are having a hard time
- Pursue the things that bring them comfort and joy

My Voice

I want my family to know that I am especially thankful for:

I want my friends to know that I am especially thankful for:

If I have hurt or upset any of my friends, family, or others, I want them to know:

If I have been hurt or upset by my family, friends, or others, I want them to know:

The things I value most in my life include:

Further considerations

- ▶ *How should we navigate situations where the patient's wishes differ from their caregivers'?*
- ▶ *What are the biggest barriers you might encounter when engaging emerging adults in advance care planning? - Are there any systemic or institutional challenges that might make these conversations more difficult in your setting?*
- ▶ *How do you think cultural, spiritual, or socioeconomic factors show up in these conversations?*
- ▶ *How should we assess patient readiness for these discussions?*
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Acknowledgments

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This study is dedicated to young people who are facing the unimaginable possibility of a life cut short by disease as well as their loved ones and providers who travel the complicated and often heartbreaking cancer journey alongside them.

Voicing My CHOICES



**For further information:
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