

**DEVELOPMENTAL AND PSYCHOLOGICAL
STAGES AND DISRUPTIONS,
ROLE OF THE FAMILY
AND
OWNERSHIP OF ONE'S HEALTH**

**Karen Fasciano, Psy.D.
Dana-Farber Cancer Institute
Brigham and Women's Hospital
Harvard Medical School**

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Workshop on Addressing the Needs of Adolescents and Young Adults with Cancer
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OBJECTIVES

- Life stage: Adolescence and young adulthood (AYA)
- Life disruptions in AYA with cancer
- **Integration of a developmental understanding into AYA oncology care**

LISA'S VOICE

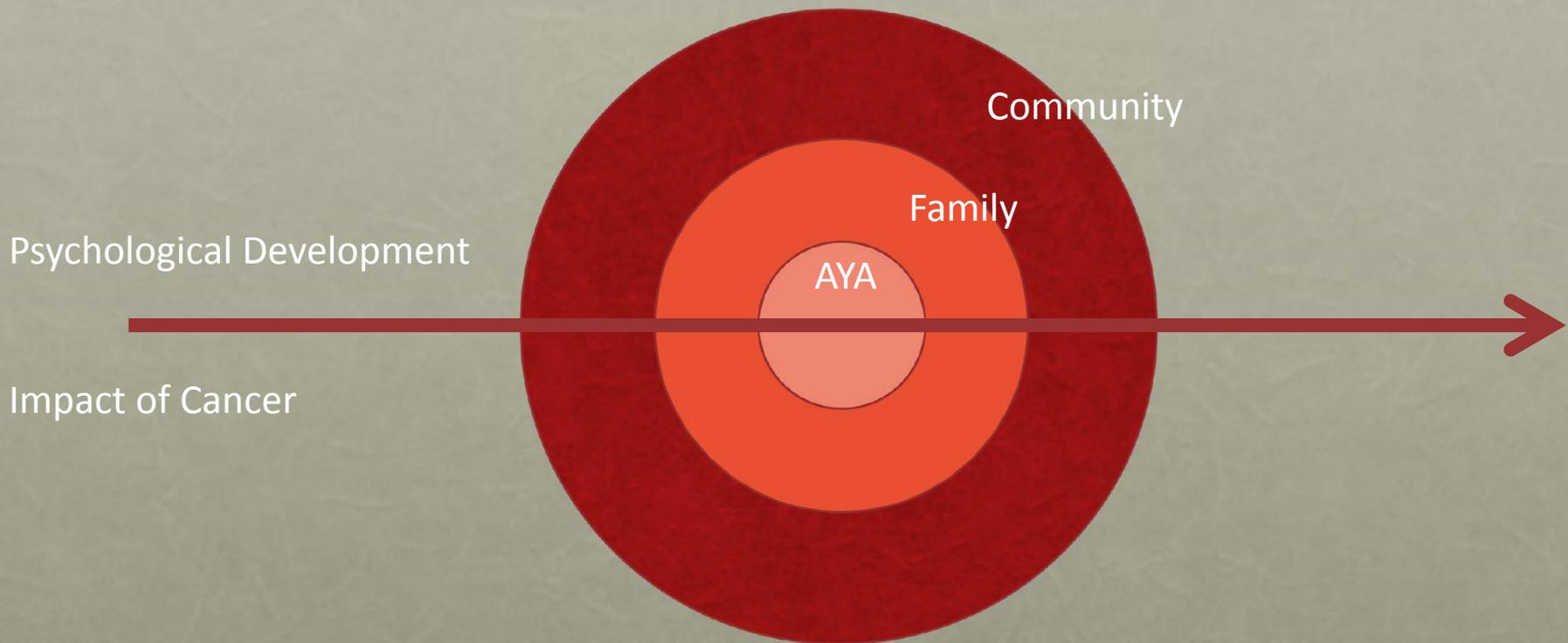
“My friends from college and home and my family, this isn't something they have experienced.

When you are a young adult, this is a turning point, when you are settling into a career, getting married, having a family. These are all issues that are normal and then you throw cancer into the mix, and you think what do I do now.

They are still getting on with their life. All my friends are buying cars, getting new jobs and buying houses and I am at home and my mom is making me toast. You start to feel a little helpless and other people don't understand that.”



DEVELOPMENT MATTERS



ADOLESCENCE AND YOUNG ADULTHOOD: LIFE STAGE



ADOLESCENCE



EARLY YOUNG ADULTHOOD



LATER YOUNG ADULTHOOD



AYA DEVELOPMENT

- Impact of education, gender, trauma, race, ethnicity, sexual identity, temperament, family background, parenting style
 - Lack of studies on normative development for ethnically diverse populations
- Inconsistent across domains
- Mediated by emotional arousal

ADOLESCENT DEVELOPMENT

	Cognitive	Emotional	Social
Adolescence (15-18)	Abstract thinking Reasoning ability Moral reasoning ("black or white")	Identity (sexual, ethnic, values, goals) Self-esteem Emotion regulation Sensation seeking, invincibility	Independence Peer relationships Sexuality

EARLY YOUNG ADULT DEVELOPMENT

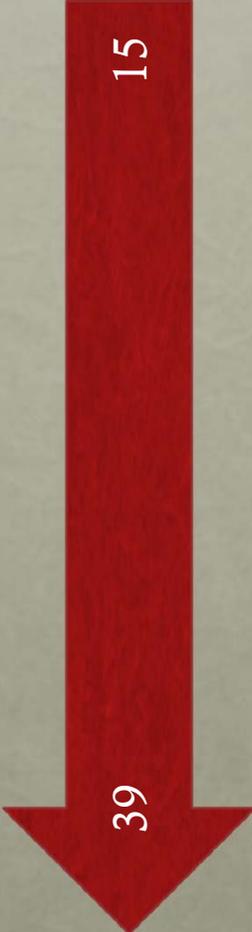
	Cognitive	Emotional	Social
Early young adult (19-mid 20's)	Critical thinking Future consequences	Empathy Language for emotion	Mutual relationships Appreciate differences Modulation of risky behaviors Mentors sought Financial responsibility Spiritual questioning

LATE YOUNG ADULT DEVELOPMENT

	Cognitive	Emotional	Social
Later young adult (mid 20 +)	Advanced complex thinking, decision making	Self evaluation Leadership capacity	Commitment to work, relationships, family

IT IS NORMAL....

- Be self-focused
- Disagree for the sake of disagreeing
- Jump to conclusions
- Find fault in the established position
- Take risks, challenge the rules and experiment
- Need control
- Seek peer role models
- Challenge professional boundaries
- Need identification of emotional responses
- Want to make a difference
- Be most concerned about their young children
- Feel responsible for work and family

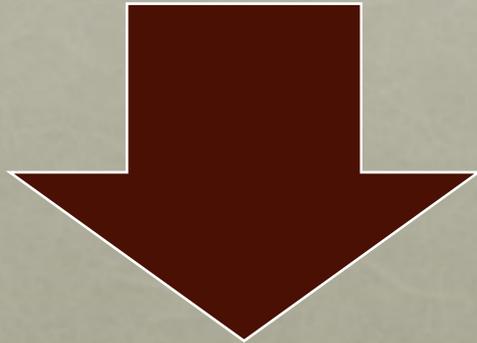


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OPPOSING DEMANDS

Demands of Illness

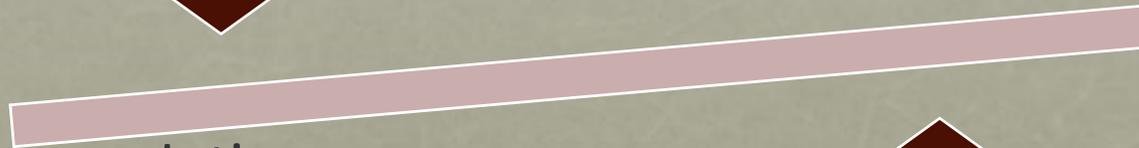


Isolation

Vulnerability

Dependence

Uncertainty

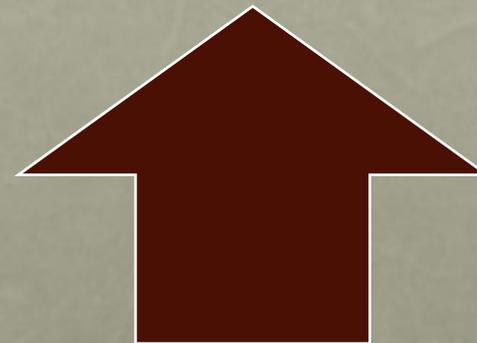


Intimacy

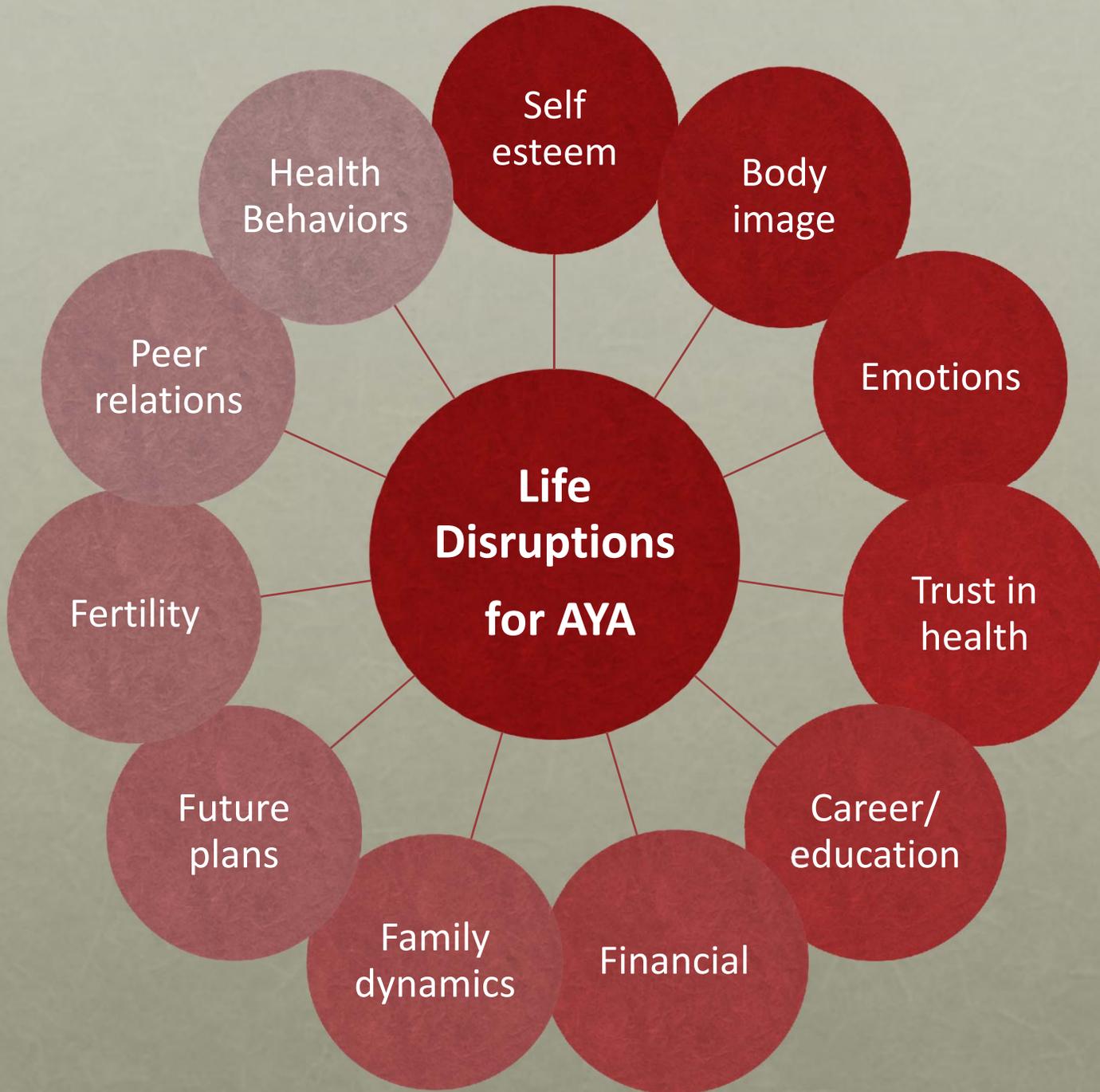
Invulnerability

Independence

Control



Demands of Life Cycle



POSSIBLE LIFE DISRUPTIONS

IMPACT OF CANCER FOR AYAS

Negative impact

- Financial
- Body image
- Control over life
- Work plans
- Relationship with partner
- Plans for having children

Positive impact

- Relationships
- Future goals/plans
- Health competence

FAMILY CONTEXT

Development

- Tension between independence and dependence
- Oscillation: in and out of the family of origin
- Maturing relationships in family of origin
- Experimentation and definition of new chosen family

AYA Cancer

- Family members' (role) perspectives contribute to distress
- Family support and cohesiveness important to adjustment
- Higher family functioning associated with less distress



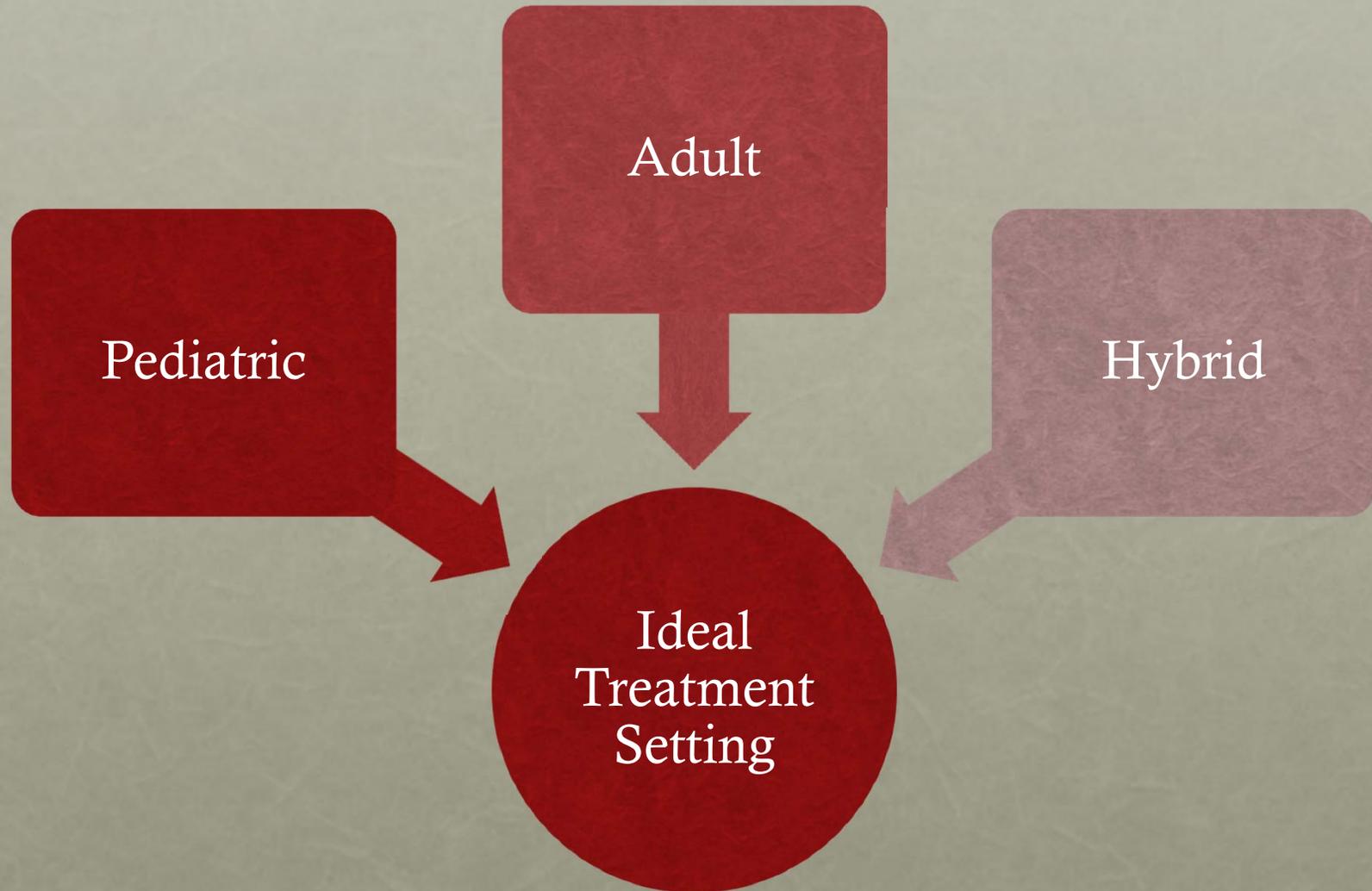
LISA'S VOICE

“Don’t compare the beginning of your journey to the middle of someone else's and don’t feel like you are behind on anything or set back, because you haven’t taken a step back. You have moved onto a different path. Your life is different now.”

INTEGRATION OF DEVELOPMENTAL UNDERSTANDING INTO AYA ONCOLOGY CARE

- Pediatric v adult medical setting
- Illness phases
- Responsibility for health care
- Information needs
- Communication

AYA ONCOLOGY CARE



DEVELOPMENTAL CONSIDERATIONS DURING THE ILLNESS CONTINUUM

Diagnosis

- Difficulty comprehending information and emotion
- Feeling impact on normality/anticipating disruptions
- Lacking skill to explain illness

Treatment

- Challenge to coping strategies
- Discomfort with dependence
- Challenge in balance of illness and life demands

Post treatment

- Less established life for reintegration
- Choices re-evaluated (peers, career, goals)
- Integration of uncertainty into future planning

End of life

- Identity formation in the face of death
- Meaning making with less skill/ experience
- Unfulfilled legacy, overwhelming grief

DEVELOPMENTALLY INFORMED CARE: RESPONSIBILITY

AYA

- **What kind of responsibility do I want?**
- **What responsibility do I give to others?**
- What kind of privacy do I want?
- Who is in charge?

Family

- **What is my responsibility?**
- What support do they need to take responsibility?

Provider

- **Assess and promote self efficacy**
- **Define who has responsibility for what**
- **Discuss responsibilities of defined family**
- Define what is in the patient's control

DEVELOPMENTALLY INFORMED CARE: INFORMATION NEEDS

AYA

- **What do I need to know?**
- **How does it relate to me?**
- **How do I like to receive information?**

Family

- **How is the information I need the same or different?**

Provider

- **Understand cognitive style and capacity**
- **Present information in life context**
- **Provide places for reliable information**
- **Present information in useful format**
- **Offer information from peers**

DEVELOPMENTALLY INFORMED CARE: COMMUNICATION

AYA

- **How do I communicate what is most important to me?**
- **How do I want others to communicate with me?**
- How can I advocate for myself?
- How do I communicate with others to help me make important decisions?

Family

- **How do I communicate with the provider?**
- Do I do this independent of the AYA?
- How do I communicate with my AYA?

Provider

- **Discuss communication with parents/spouse**
- **Ask what is most important**
- Ask about ways to communicate (provide examples)
- Propose shared decision making
- Balance support and with challenges

CONCLUSIONS

- Development and the experience of cancer are both stressors
- Development in ethnically diverse populations and implications for oncology care need further research
- Demands of illness and life cycle can be opposing
- Life disruptions can have both positive and negative impact
- Family cohesiveness can impact adjustment
- Challenges to providing appropriate treatment settings are ongoing
- Unique developmental needs during different illness phases
- Patient and family concerns often reflect developmental task and life stage
- Developmentally appropriate AYA oncology care matters

Franklin's illness gave him the strength and courage he had not had before. He had to think out the fundamentals of living and learn the greatest of all lessons- infinite patience and never ending persistence.

Eleanor Roosevelt
FDR Memorial, Washington, DC



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