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ADOLESCENT AND YOUNG ADULT (AYA) PATIENTS: WHAT ARE WE MISSING?

LEARNING OBJECTIVES



1

Identify disparities for AYA patients



2

Understand the three domains of concern for AYA patients



3

Understand the survivorship needs of AYA patients



4

Identify areas of improvement in the care continuum

THE AYA POPULATION

(SEER, 2024)

Patients
between the
ages of 15-39

Estimated
84,100 new
cases this
year

Only 4.2% of
all cancer
cases at any
age

Survival rate
increased
from
81%¹ (2000) to
88.6% (2016)

WHY DO WE CARE?

Leading cause of disease-related death among AYA patients

Need for supportive services differ from adult and pediatric needs

Higher concern for mental health issues

Difficulty transitioning into survivorship

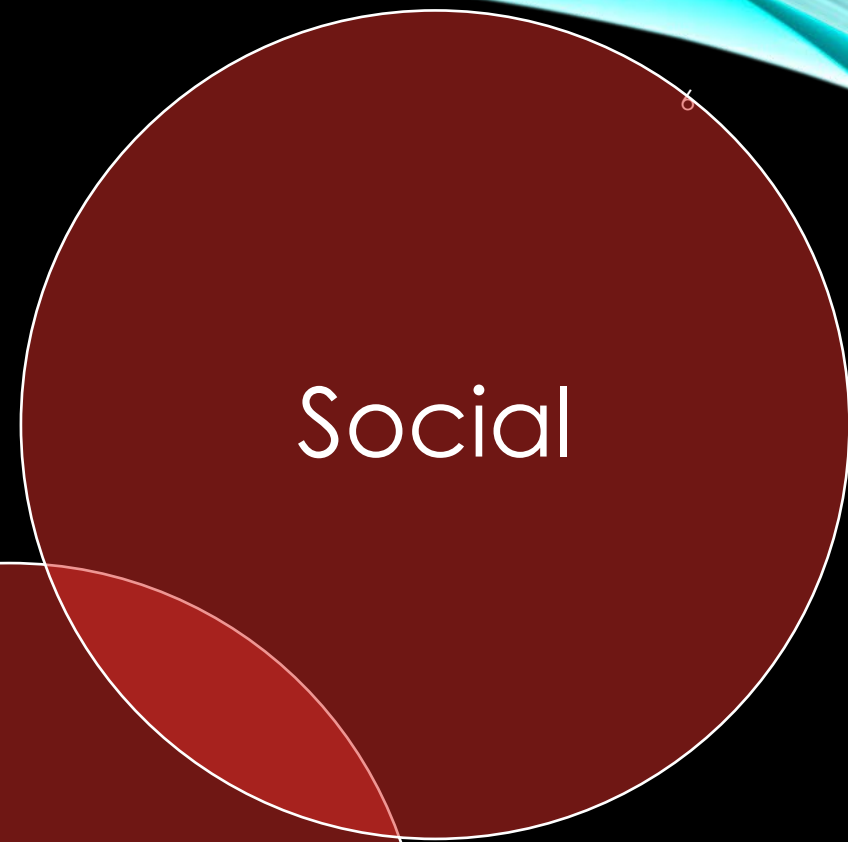
WHY DO WE CARE?

- Diagnosis happening during transitional milestones
- Cognitively mature enough to understand
- Emotional maturity not able to cope effectively
- Impacts the decision-making process



WHAT CAN BE IMPACTED BY CANCER AND ITS TREATMENT?

Can be broken down into 3 Domains



- **Sexual Health**
- **Fertility Risk and Preservation**
- **Reporting of symptoms**
- **Chronic disease**

BIOLOGICAL
DOMAIN



SEXUAL
HEALTH
INTERRUPTED

Exploring sexuality

Psychosexual identity

Preferences

Gender identity

Orientation

SEXUAL HEALTH CONSIDERATIONS

AYAs most likely will not initiate the discussion

Consider the presence of family members

Diagnosis of cancer does not stop sexual exploration

Sexual dysfunction can be an issue

Need for safe sex discussions

FERTILITY RISK AND PRESERVATION

Many haven't begun to think about family planning

Do not fully understand the potential effects on future fertility

Impacts quality of life

Increases distress

51% female patients have concerns

44% male patients have concerns

FERTILITY CONSIDERATIONS

Less than 50% of providers follow national guidelines

26% of providers address fertility

13% of patients referred to fertility specialists

Less than 25% of providers are aware of or distribute written materials

REPORTING OF SYMPTOMS

Underreport

Underreport symptoms experienced

Believe

Believe them to be “normal”

Believe

Believe nothing can be done

REPORTING
OF
SYMPTOMS
(N=575)

Pain: 66%

Hormonal/fertility: 66%

Sexual activity/function: 38%

Concentration/memory issues:
41%

Fatigue: 47%

CHRONIC DISEASE

Long term effects of treatment

Fatigue

Chronic pain

Cardiovascular

Respiratory

Arthritis/Osteoarthritis

PSYCHOLOGICAL
DOMAIN

Body Image

Survivorship Issues

Returning to Normalcy

End of Life

BODY IMAGE

- Response depends on perception prior to treatment
- Can change identity
- Negative reactions from others/peers
- Impact interpersonal relationships



SURVIVORSHIP ISSUES

Difficulty
returning to
“normal”

Limited
awareness of
support
available

Feelings of being
alone, confused,
and unprepared
for the transition

SURVIVORSHIP CONCERNS

44% of survivors report PTSD symptoms

31% report moderate to severe anxiety and depression

62% report a fear of recurrence

Distress symptoms may present as physical or behavioral concerns

END OF LIFE

AYA patients
want to talk
about death

88% prefer
honesty about
their prognosis

Only 50% report
an opportunity
to discuss

END OF LIFE: LACK OF DISCUSSION

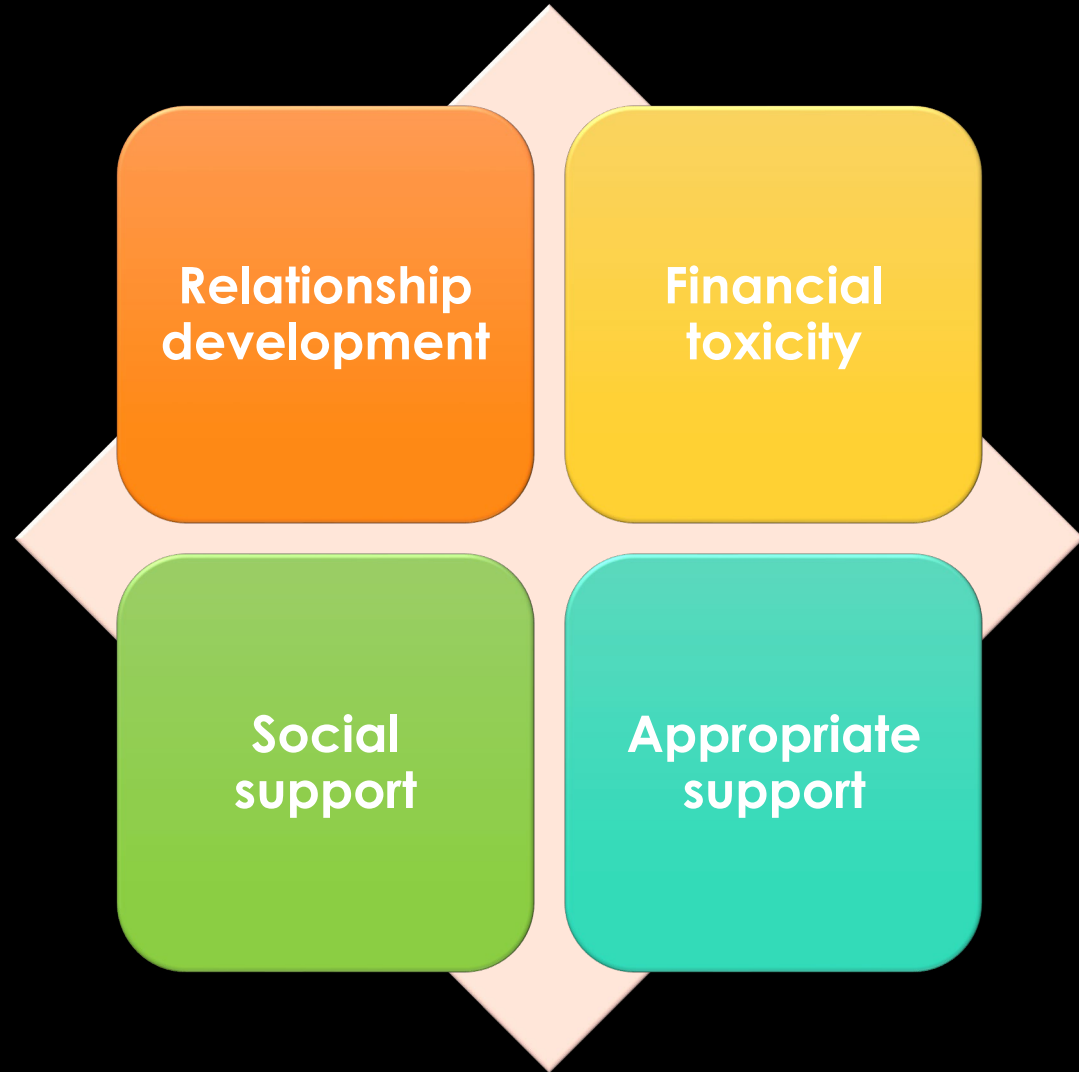
Leads to patients receiving treatments past the point of efficacy

78% of patients receive high-intensity treatment in the last month of life

75% would prefer to focus on comfort in the last month

Advanced care planning leads to decreased levels of stress

SOCIAL DOMAIN



RELATIONSHIP DEVELOPMENT

- AYA patients are beginning to define their identity
- Learning to build meaningful relationships
- Develop a sense of autonomy





IMPACT ON RELATIONSHIP DEVELOPMENT

Loss of control

Loss of former identity

Lack of understanding from family and friends

Unrealistic expectations

Difficulty finding where cancer fits

Can lead to isolation

EFFECTS OF SOCIAL SUPPORT



Positive

Promotion of normality
Visits from friends/family
Gifts
Support from AYA survivors



Negative

Avoidance
Dismissal of the experience
Inappropriate
comments/laughter
Overprotective parents

SOCIAL SUPPORT

Impacts
adherence to
treatment

Impacts
perspective
of the journey

Impacts
quality of life

FINANCIAL TOXICITY

15–25-year-olds
experience less
financial toxicity
on average

26-39-year-olds
experience
increased burden
on average

Lack experience
with medical
billing, health care
system, and
insurance

CONCERNS RELATED TO COST



Afraid that insurance eligibility/coverage may impact provider's decisions



Lack financial security prior to diagnosis



Interferes with the ability to work/attend school



Cost of additional services like oncofertility

AYA PROGRAMS IN INDIANA

Riley Children's Hospital and IU Health is the
ONLY program in Indiana

Louisville, KY

Chicago, IL

HOW CAN WE IMPROVE

- Educate ourselves on the resources available in our areas
- Create partnerships with local resources
- Identify at-risk patients
- Early financial navigation



ONLINE RESOURCES

- Moffitt Cancer Center www.moffitt.org/patient-family/programs-support-services/aya-adolescent-young-adult-program/learn/
- Memorial Sloan Kettering <https://www.mskcc.org/cancer-care/patient-education/adolescent-and-young-adult-support-resources>
- Cactus Cancer Society www.cactuscancer.org
- Elephants and Tea www.elephantsandtea.org
- Imerman Angels www.imermanangels.org
- Stupid Cancer www.stupidcancer.org



HOW CAN WE IMPROVE

Improve access to age-appropriate information and resources

Reapproach topics more often throughout the care continuum

Discuss post-treatment care and expectations

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THANK YOU