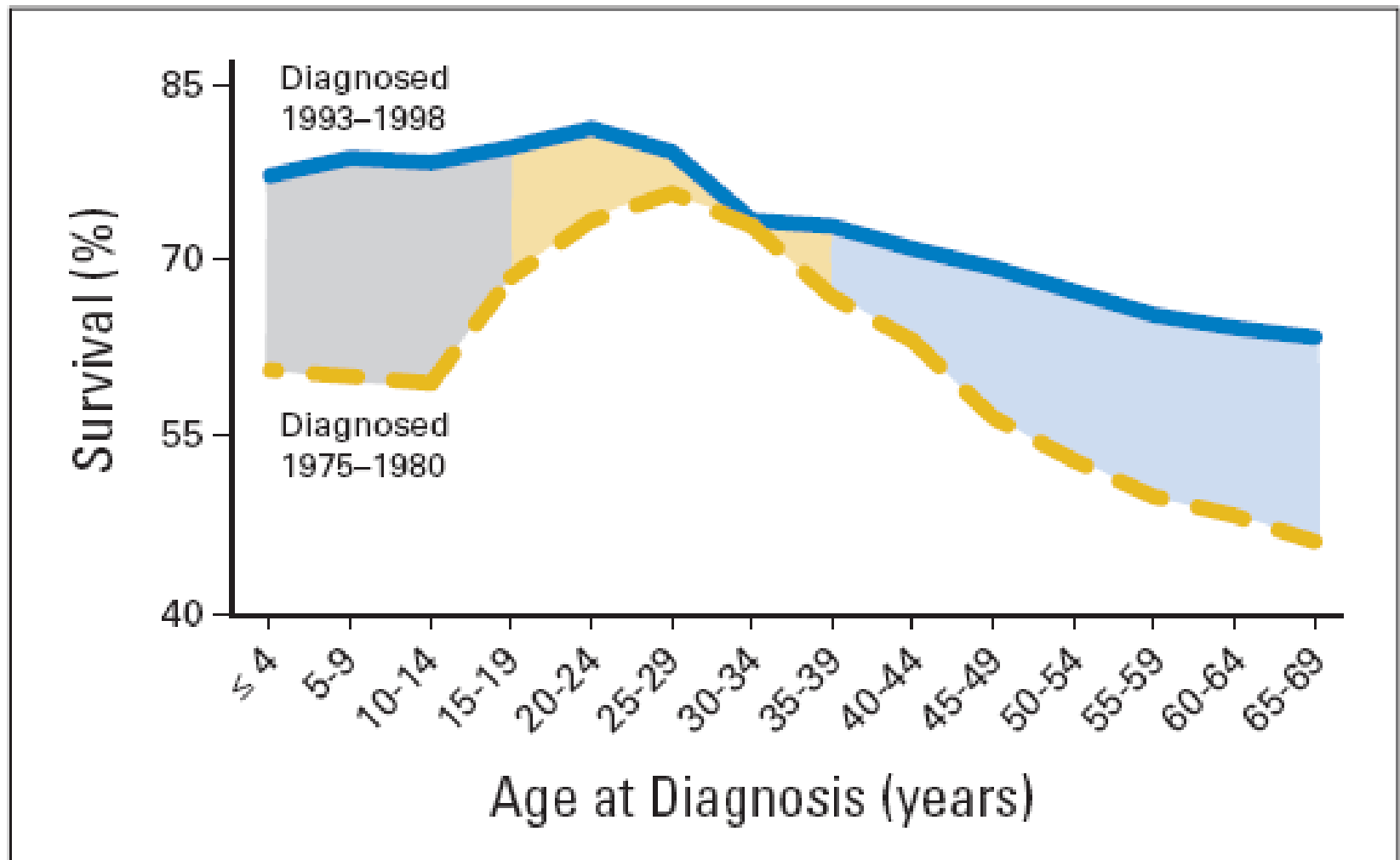


Gaps in the Evidence Base and Research Priorities for AYA Oncology Care



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Disparity in survival progress



AYA: A unique population

- ▶ Psychosocial and medical needs associated with cancer diagnosis that are challenging to developmental phase:
 - Loss of independence
 - Isolation from peers
 - Concerns for future fertility
 - Impact on academic/vocational goals
 - Threat to future health care and insurance access

AYA: A unique population

Delivery of medical care must:

- ▶ Respect communication preferences
 - Information sharing with caregivers
 - Involvement by caregivers in decision-making
 - Evolving modalities of communication
- ▶ Acknowledge need for independence and autonomy
- ▶ Address age-appropriate experimentation with health risking behaviors
- ▶ Recognize impact on body image, sexuality and intimacy

Cancer histology prevalence by age

- ▶ Distinctive distribution of cancer histological subtypes
- ▶ Variable source of care

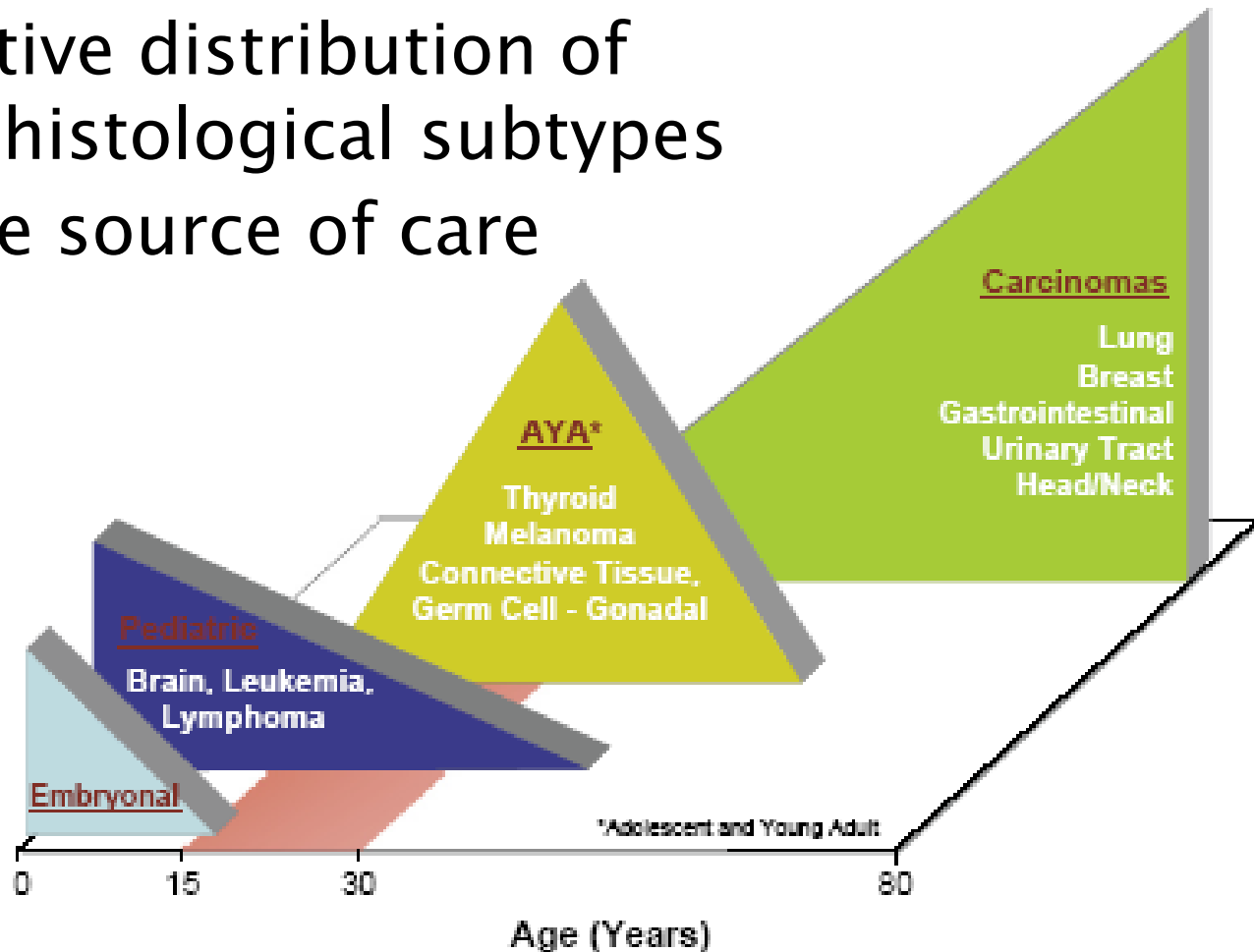


Figure 15.4: The Interface Between Pediatric and Adult Oncology

AYA delays in diagnosis

- ▶ Diagnosis lagtime: interval between onset of symptoms/signs and date of pathology confirmation of cancer
- ▶ Study cohort: 270 cancer patients (15–29 years) evaluated between June 2001 and June 2003
- ▶ Lagtimes evaluated in 235 (88%) and associated with type of cancer and health insurance status
 - NHL, Hodgkin lymphoma, leukemia predictive of shorter lagtimes
 - Mean lagtime by insurance status: Public (124 d) v Private (76 d) v Self-pay (32 d)
- ▶ In cancers evaluable for stage at diagnosis, advanced stage associated with longer lagtimes

AYA participation in clinical trials

- ▶ Study population: 1,358 AYA patients with cancer (age 15 to 39 years) from SEER
- ▶ 14% enrolled on clinical trial
- ▶ Enrollment on trial varied by diagnosis:
 - Diagnosis: ALL (37%), sarcoma (32%) v GCT (<1%)
 - Age: 15–19 (34%) v 35–39 (3%)
 - Race/ethnicity: white (9%) v black (11%) non-Hisp
 - Provider: ped onc (70%) v heme onc (11%)
 - Insurance: Public (14%) and Private (14%) v HMO (7%) and None (3%)

Parsons et al. JCO 2011

AYA time to initiation of treatment

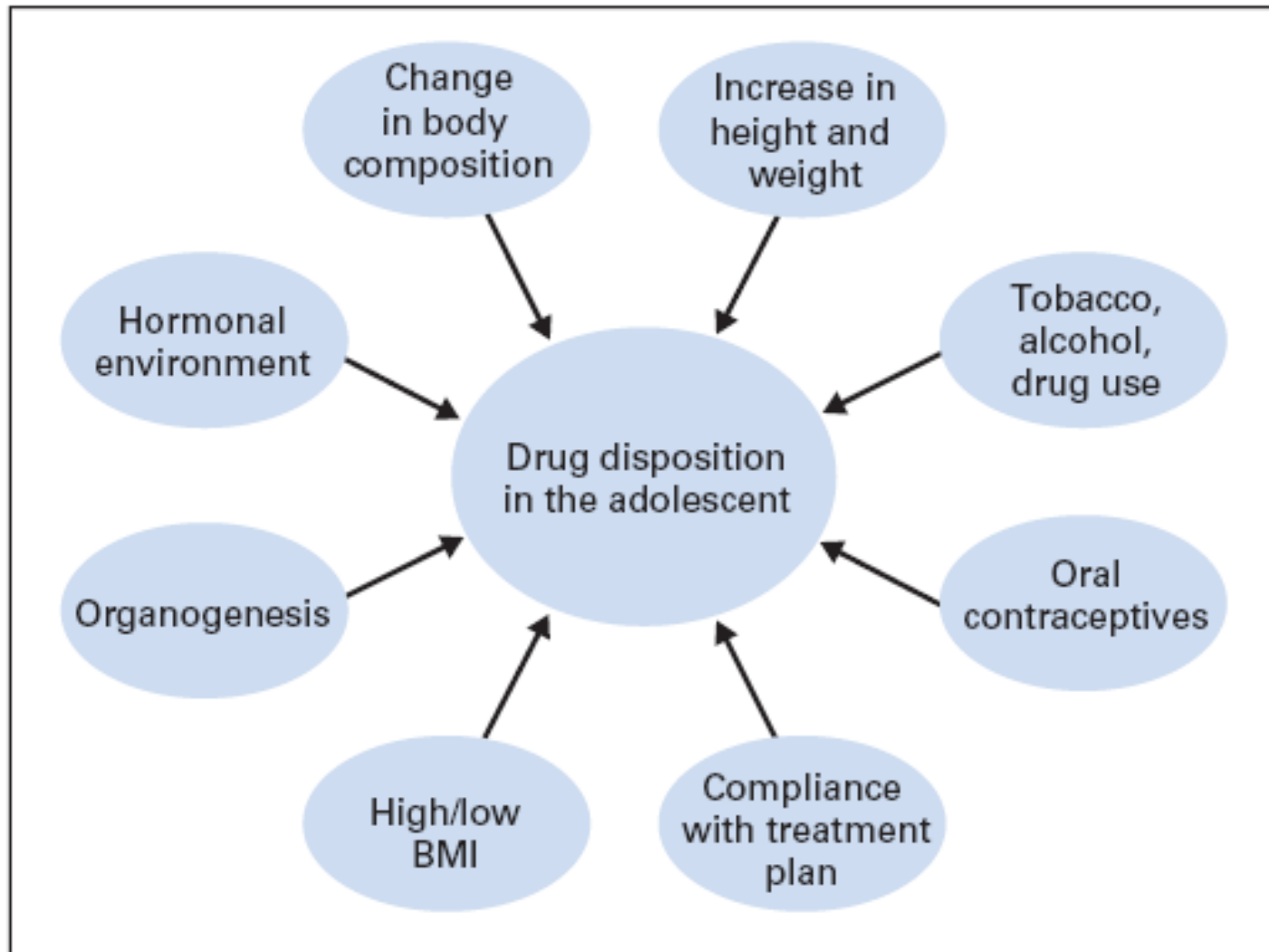
- ▶ Median time to treatment: 3 days
- ▶ Time to treatment varied by:
 - Diagnosis: HL (21d), NHL (19d) v ALL (1d), GCT (0 d)
 - AJCC stage: stage III v I (4-fold excess risk of longer time to Rx)
 - Facility: outpatient v. inpatient (3-fold excess risk of longer time to Rx)

Disparities in AYA outcomes

Trial	Pediatric	Adult
FRALLE-93/LALA-94 ²⁸	5-y EFS: 67%	5-y EFS: 41%
CALGB/CCG ³⁴	7-y EFS: 63%	7-y EFS: 34%
MRC ALL 97-99/UKALLXII-E2993 ²⁹	5-y EFS: 65%	5-y EFS: 49%
GIMEMA/AIEOP ³⁰	2-y OS: 80%	2-y OS: 71%
HOVON/DCOG ³¹	5-y EFS: 71%	5-y EFS: 38%
Adult ALL Grp/NOPHO-92 ³²	5-y OS: 74%	5-y OS: 39%
Finnish Leukemia/NOPHO ³³	5-y OS: 67%	5-y OS: 60%

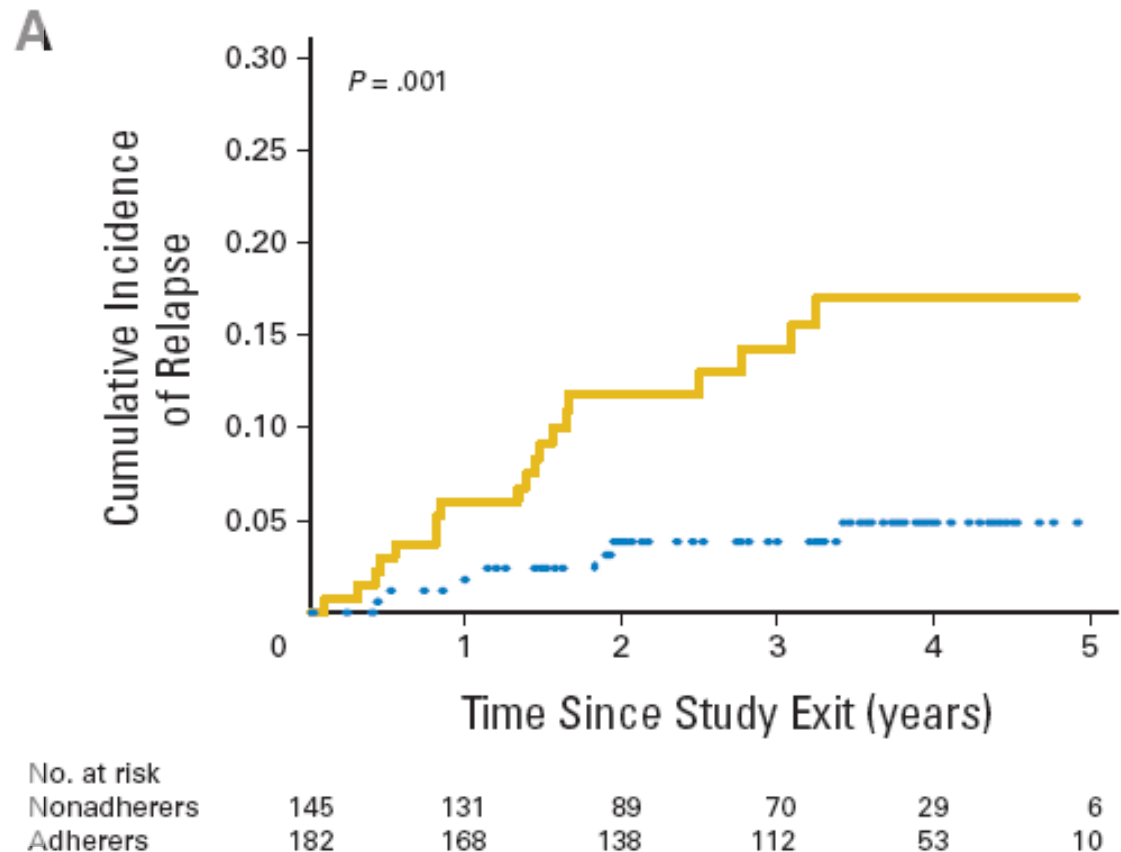
Are disparities due to differences in cancer biology, treatment approach or environment of care?

AYA: Unique biologic differences



Non-adherence and risk of relapse

- N=327 ALL patients
169 Hispanic
158 non-Hispanic
- Factors associated with risk of non-adherence
 - Longer time on Rx
 - Older age (> 12y)
 - Household (single mother)
 - Ethnicity (Hispanic)
- Progressive increase in risk of relapse associated with decreasing levels of adherence

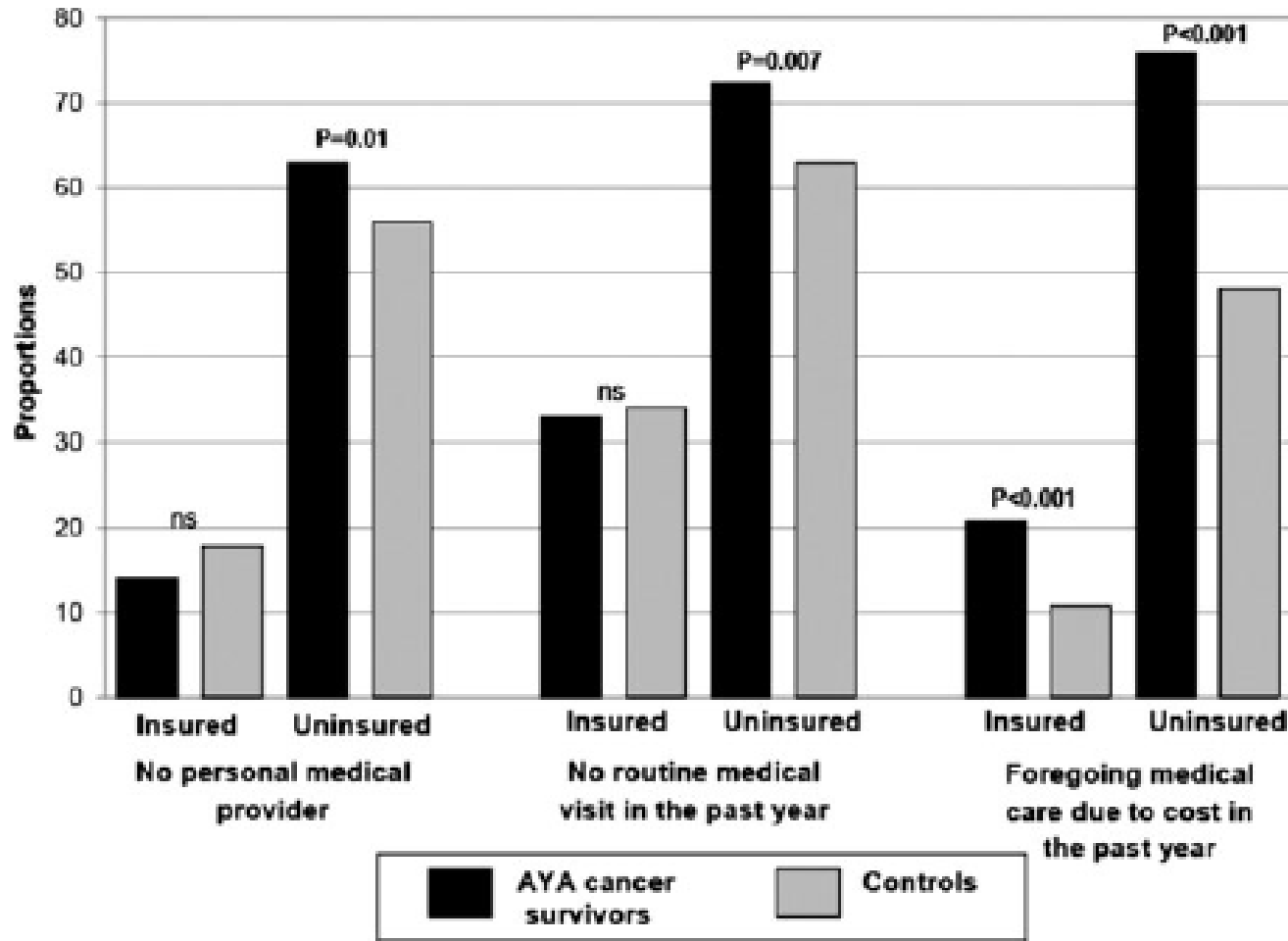


Health status of AYA survivors

Outcome	AYA	Non-AYA
Current smoking	26%	18%
No leisure time physical activity	31%	24%
Obesity	31%	27%
Cardiovascular disease	14%	7%
Hypertension	35%	29%
Asthma	15%	8%
Disability	36%	18%
Poor mental health	20%	10%
Physical health	24%	10%
Not receiving medical care due to cost	24%	15%

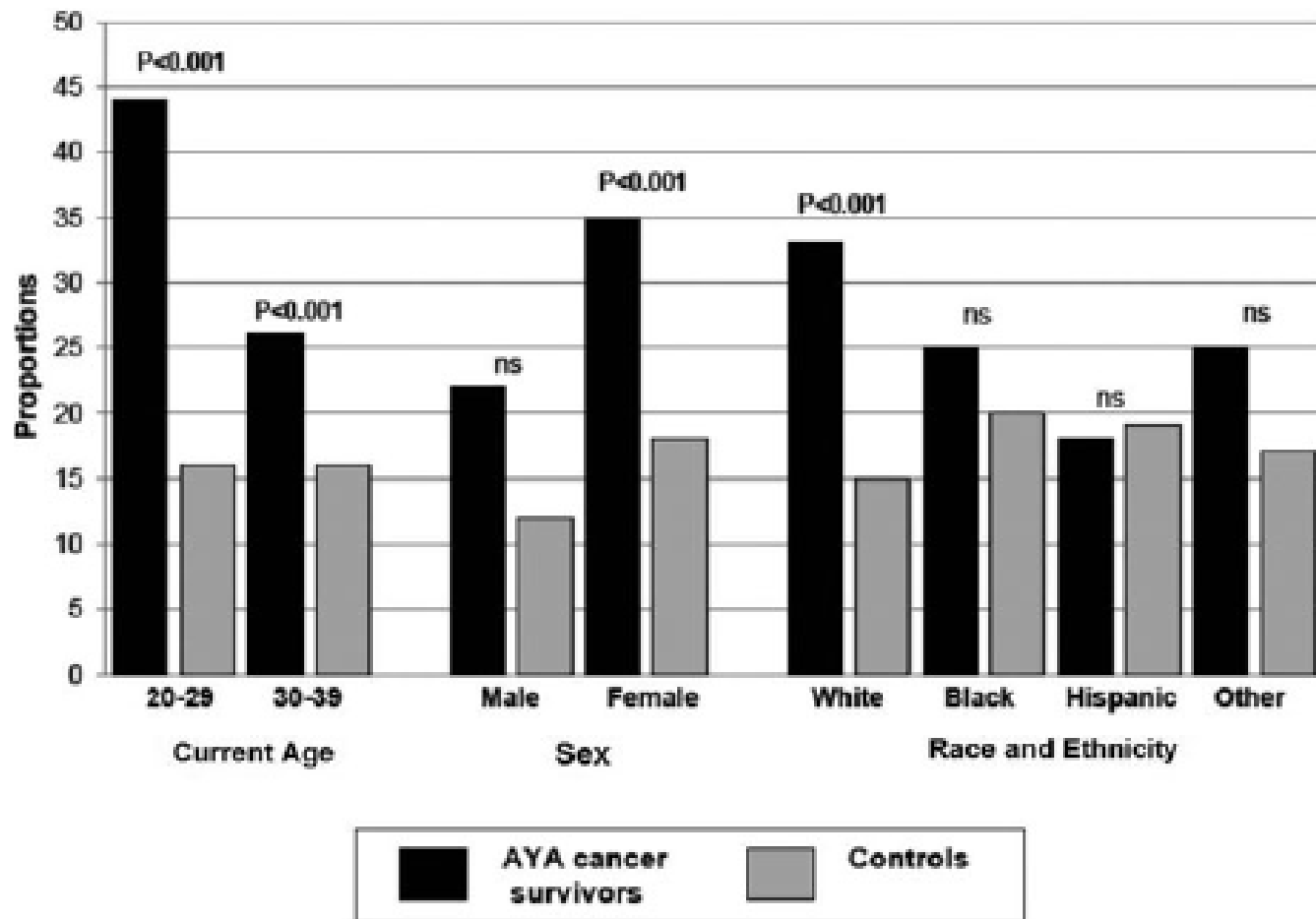
Based on 2009 BRFSS data from AYA survivors
(15–29 years) compared with non-cancer AYA.
Tai et al. Cancer 2012

AYA survivor health care access



Based on 2009 BRFSS data from AYA survivors (20–39 years) who self-reported cancer at age 15–34 compared with non-cancer AYA.
Kirchhoff et al. Cancer 2012

AYA survivors forgoing care



Based on 2009 BRFSS data from AYA survivors (20–39 years) who self-reported cancer at age 15–34 compared with non-cancer AYA.
Kirchhoff et al. Cancer 2012

AYA health care utilization

- ▶ Higher prevalence of chronic health conditions
- ▶ Unable to get/delayed necessary medical care
- ▶ Have higher medical expenditures
- ▶ Experience greater physical limitations
 - Health related unemployment
 - Limited ability to work
 - Lost household productivity
- ▶ Disparities in access to care for publicly insured and uninsured

Yabroff et al, MEPS: Experience with Cancer Survivorship

Factors contributing to disparities

- ▶ Delays in diagnosis of primary cancer
- ▶ Inadequate access to and low participation on clinical trials
- ▶ Differences in tumor biology
- ▶ Differences in body composition, hormonal status and maturity of organs
- ▶ Non-adherence to treatments
- ▶ Suboptimal access to medical and psychosocial services
- ▶ Lack of awareness of cancer treatment-related health risks

AYA Cancers: The bottom line

- ▶ Cancer is leading disease-related cause of death AYA in United States and affects eight times as many individuals between the ages of 15 and 40 as those younger than 15 years of age.
- ▶ Substantial prevalence of cancer and treatment-related morbidity among AYA cancer survivors
- ▶ Substantial prevalence of unmet needs among AYA cancer survivors

Metrics for quality AYA care

- ▶ Assistance with managing disease and treatment effects
- ▶ Cognizance among providers of the unique psychosocial context for AYA growth and development
- ▶ Assessment of and attention to cognitive, psychiatric, and psychosocial needs of AYA
- ▶ Referral to available age-appropriate resources during treatment
- ▶ Facilitation of transition to survivorship

Models of AYA oncology care

- ▶ Expertise in AYA oncology
- ▶ Expertise in AYA developmental issues
- ▶ Cancer center based
- ▶ Community based
- ▶ Hybrid

“A young person’s development is not postponed in the event of a cancer diagnosis, so it is also important to ensure that these aspects are revisited during the treatment journey.”

Morgan et al. JCO 2010

“...it is not only the fabric of an environment that matters, it is the ethos of care that does.”

Morgan et al, JCO 2010

Optimal venue of care

Available models of care

AYA transition issues

- ▶ Growth and development
- ▶ Promotion of healthy lifestyle
- ▶ Symptom management
- ▶ Cancer-related chronic health problems
- ▶ Fertility preservation
- ▶ Sexuality
- ▶ Contraception
- ▶ Sexually transmitted infections
- ▶ Impact of cancer on fertility
- ▶ Impact of cancer on reproductive outcomes
- ▶ Sexual dysfunction

Physical health

Sexual-reproductive health

AYA transition issues

- ▶ Psychological adjustment to cancer survivorship
- ▶ Cognitive functioning
- ▶ Psychopathology
- ▶ Emotional well-being
- ▶ Goal attainment
- ▶ Health-related hindrance
- ▶ Partnerships/marriage
- ▶ Interpersonal relations
- ▶ Reintegration into social systems
- ▶ Educational progress/resources
- ▶ Vocational planning
- ▶ Employment

Mental health

Social competence

AYA transition issues

- ▶ Alcohol consumption
- ▶ Tobacco use
- ▶ Illicit drug Use
- ▶ Physical activity
- ▶ Dietary habits
- ▶ Sun protection
- ▶ Risky sexual behavior
- ▶ Adherence to treatment
- ▶ Adherence to health screening/surveillance
- ▶ Diagnostic/treatment history
- ▶ Cancer-related health risks
- ▶ Self-management of medical issues
- ▶ Impact of health behaviors on cancer-related risks
- ▶ Health screening/surveillance recommendations
- ▶ Navigation of the adult health care environment
- ▶ Insurance and health care access

Health behaviors

Health education

Strategies to improve survival

- ▶ Education to enhance awareness, early detection and diagnosis of AYA cancers and cancer treatment–related health risks
- ▶ Establishment of care models to promote timely referral, initiation of treatment, attention to adherence, and transition of care
- ▶ Awareness by providers of biomedical and psychosocial issues specific to AYAs
- ▶ Development of AYA oncology research investigations

Research to close the AYA gaps

Survival outcomes

- ▶ Biologic variations
- ▶ Therapeutic approach
- ▶ Location of care

Models of AYA Care

- ▶ Metrics of quality care
- ▶ Care coordination
- ▶ Care transition
- ▶ Utilization and access
- ▶ Cost-benefit analyses

Health outcomes

- ▶ Biomedical
- ▶ Psychosocial
- ▶ Patient reported

Health promotion

- ▶ Adherence
- ▶ Self-management
- ▶ Health behaviors
- ▶ Health screening/surveillance