Unique Challenges & Novel Approaches in Young Adult Cancer Care

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CENTER

Optimizing Outcomes for AYA Oncology Patients

Challenges in Diagnosis, treatment and survivorship

Kenneth R. Cooke, MD

Director, Pediatric BMT Program

Objectives

- Recognize unique Challenges facing AYA oncology patients
- Review details regarding the complexities ` surrounding the diagnosis, treatment and outcomes of oncologic disorders and HSCT in AYA patients
- Identify strategies to improve outcomes of AYA cancer patients
- Describe what we are planning as we move forward

Advances are bypassing this age group

The Facts

More than 70,000 young adults are diagnosed with cancer every year.

ESTIMATED NUMBER OF PERSONS DIAGNOSED WITH INVASIVE CANCER YEAR 2000, US; SEER 1975-2000

The Facts

Cancer is the Leading Disease Killer Among 20-39 Year Olds**

Cancer kills more adolescents than AIDS, heart disease, cerebrovascular disease, pneumonia, influenza, cystic fibrosis, diabetes, and asthma *combined.*

DEATHS DUE TO CANCER IN
YEAR 2002, US: 10,029

The Facts

- One in every 210 persons in the U.S. develops cancer between ages of 15 and 30
- The incidence of cancer among adolescents and young adults is on the rise
- The causes of these cancers and of the increased incidence are not known

Advances are bypassing this age group

The Facts

Young adults with cancer face a variety of unique short- and long-term medical and psychosocial issues

AYA = Adolescents and Young Adults

Ages 15 to 40!

AYA Oncology Issues

- Delayed diagnosis
- Rare tumor
- Biology not understood
- No clinical trial
- Poor prognosis
- No local specialists
- Insurance issues

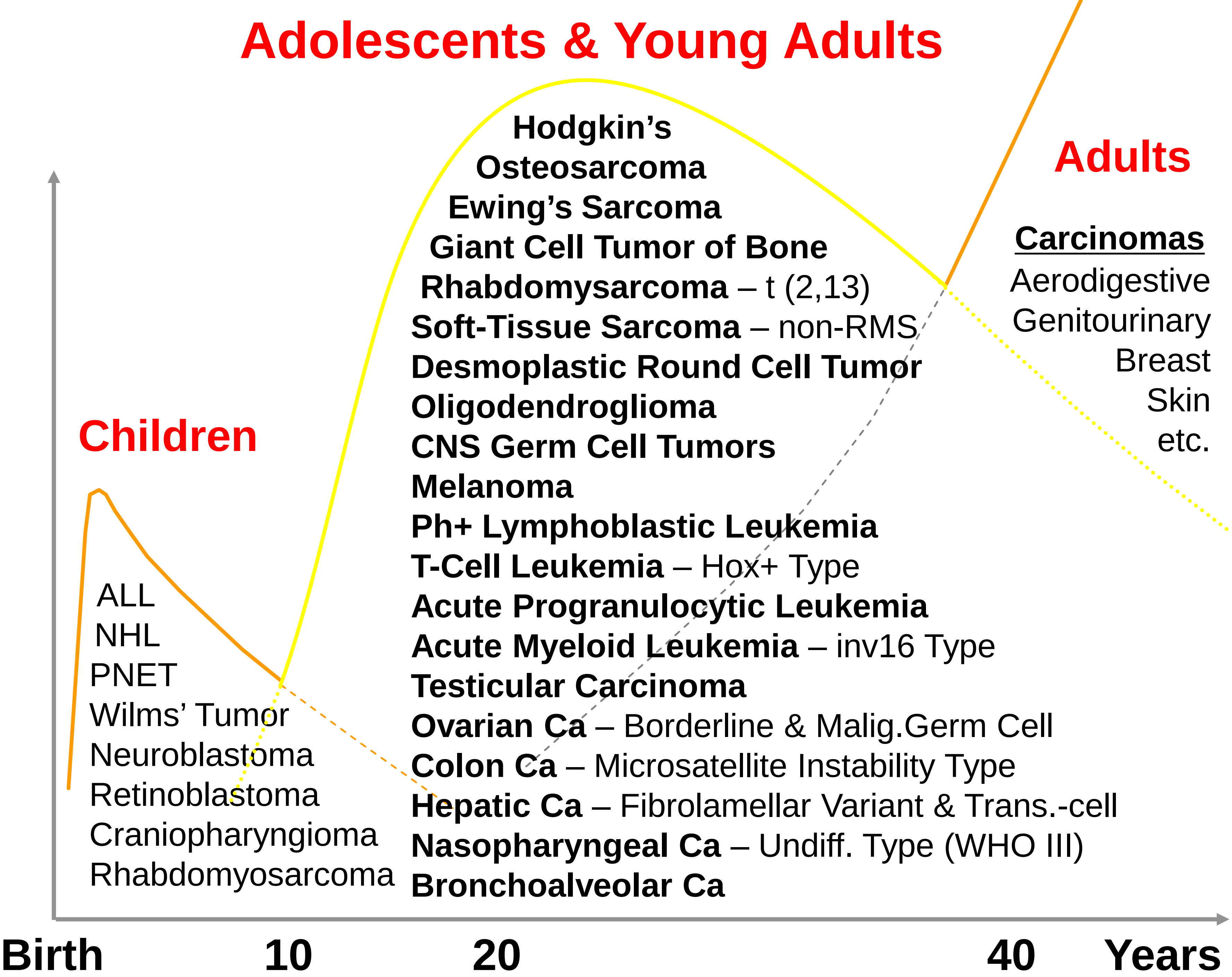
- Sense of invincibility
- Egocentrism
- Identity development
- Sexuality, body image
- Development of ideals, morals
- Vocational / career path
- Evolving relationships
- Move toward independence

AYA Oncology Issues

Development of Cancer / Need for HSCT

- Threatens sense of safety, security
- Feelings of loss of control
- Body image concerns may impact self-esteem, relationships
- Sense of self may change
- Occupational path is interrupted
- Peer relationships may change, dissolve
- Family relationships may change
- Sense of independence is threatened

Adolescents & Young Adults



Children

ALL
NHL
PNET
Wilms' Tumor
Neuroblastoma
Retinoblastoma
Craniopharyngioma
Rhabdomyosarcoma

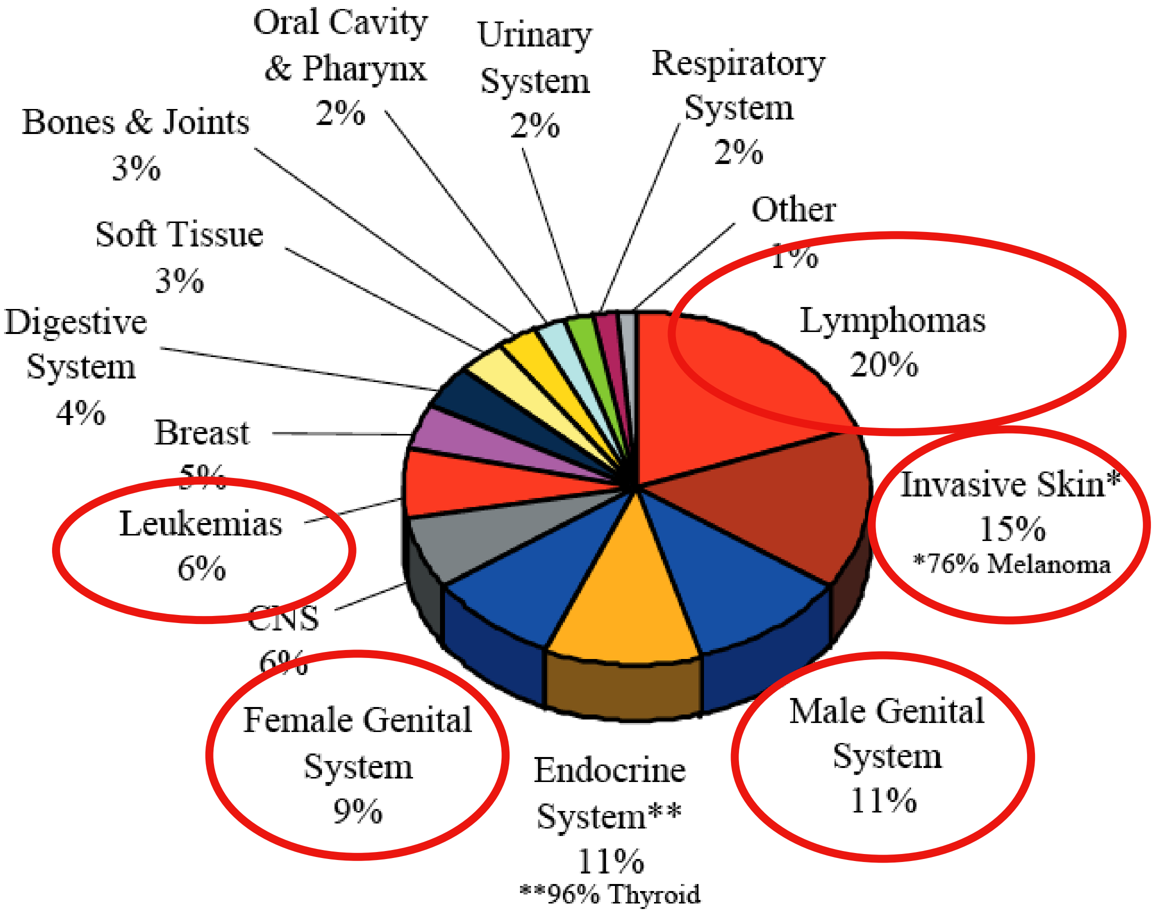
Hodgkin's
Osteosarcoma
Ewing's Sarcoma
Giant Cell Tumor of Bone
Rhabdomysarcoma – t (2,13)
Soft-Tissue Sarcoma – non-RMS
Desmoplastic Round Cell Tumor
Oligodendroglioma
CNS Germ Cell Tumors
Melanoma
Ph+ Lymphoblastic Leukemia
T-Cell Leukemia – Hox+ Type
Acute Progranulocytic Leukemia
Acute Myeloid Leukemia – inv16 Type
Testicular Carcinoma
Ovarian Ca – Borderline & Malig.Germ Cell
Colon Ca – Microsatellite Instability Type
Hepatic Ca – Fibrolamellar Variant & Trans.-cell
Nasopharyngeal Ca – Undiff. Type (WHO III)
Bronchoalveolar Ca

Adults

Carcinomas
Aerodigestive
Genitourinary
Breast
Skin
etc.

AYA Oncology

Cancer in 15- to 29-Year-Olds by Primary Site (SEER Site Recode) U.S., SEER 1975-2000

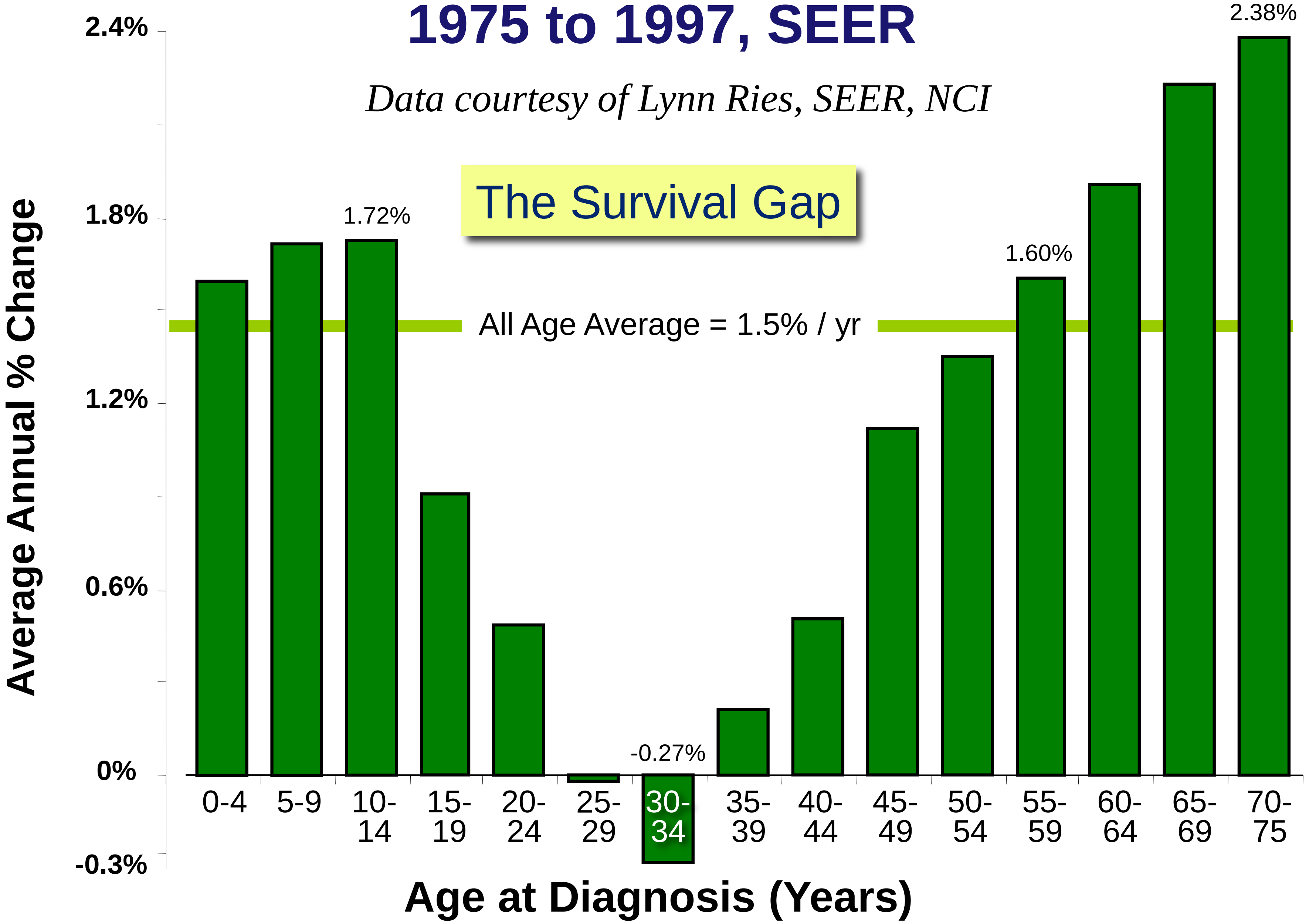


The Problem

The AYA population has not experienced improvements in mortality rate reduction and overall survival seen in both younger and older populations

Relative Change in 5-Year Survival
1975 to 1997, SEER

Data courtesy of Lynn Ries, SEER, NCI



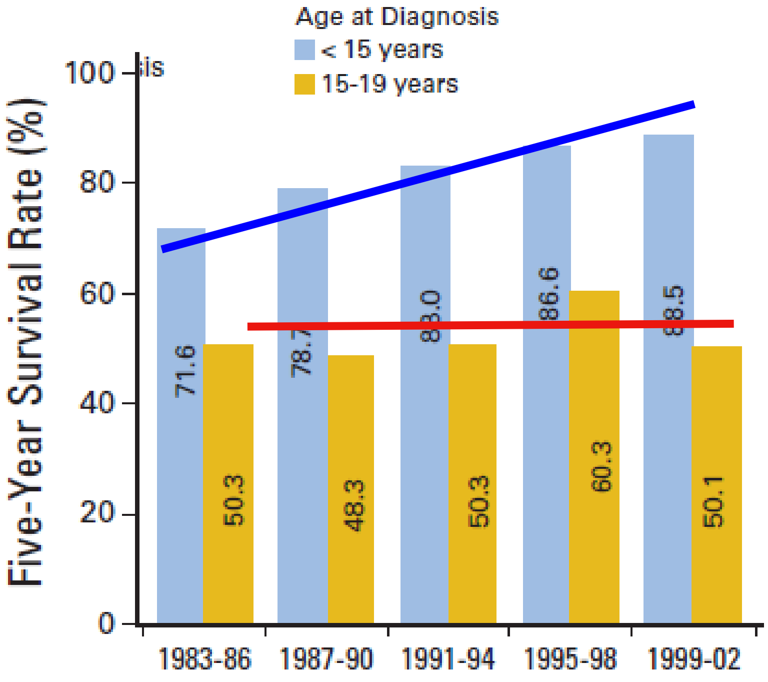
VOLUME 28 · NUMBER 15 · MAY 20 2010

JOURNAL OF CLINICAL ONCOLOGY

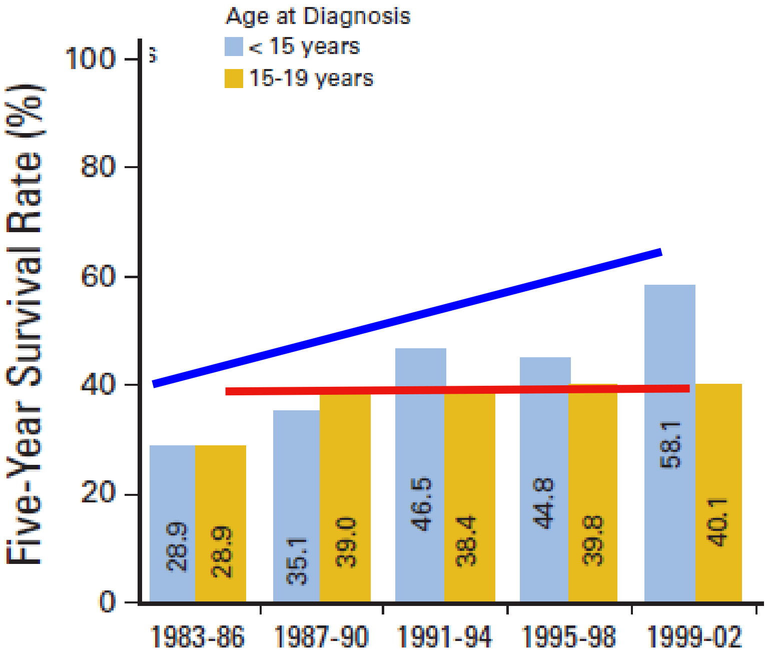
SPECIAL ARTICLE

Outcomes for Children and Adolescents With Cancer: Challenges for the Twenty-First Century

Malcolm A. Smith, Nita L. Seibel, Sean F. Altekruse, Lynn A.G. Ries, Danielle L. Melbert, Maura O'Leary, Franklin O. Smith, and Gregory H. Reaman



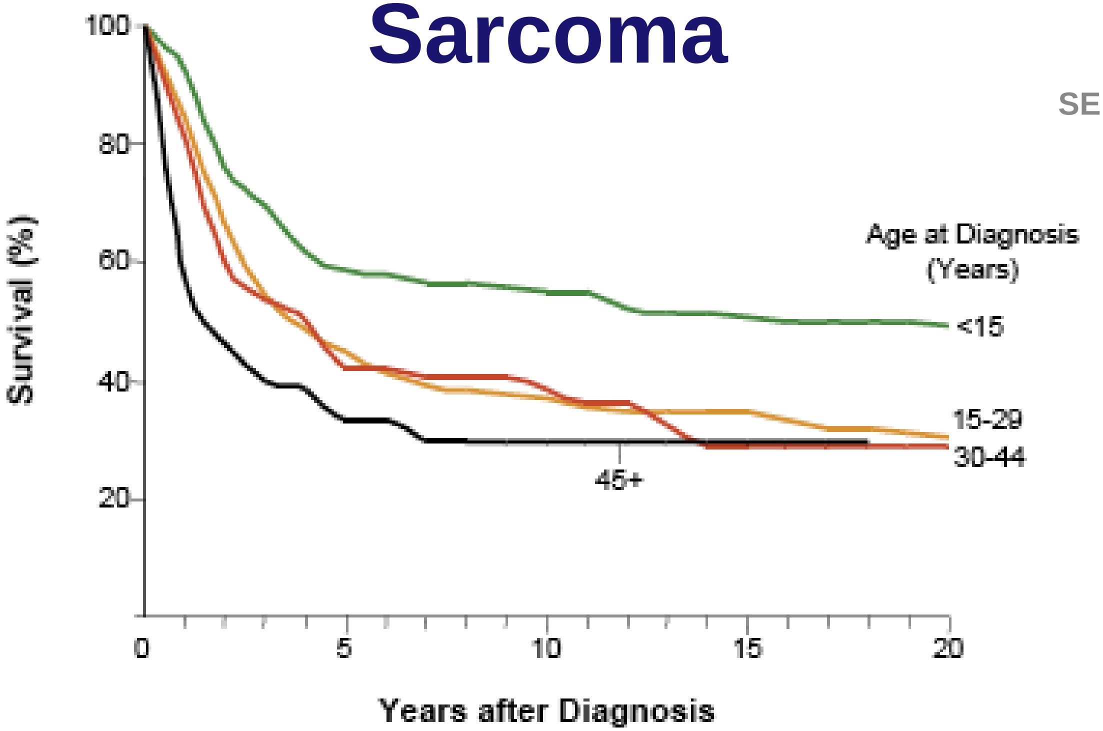
ALL



AML

Actual Survival Gap

Sarcoma



SEER Monograph 2006

Figure 8.18: Relative Survival by Age, Ewing Sarcoma & Peripheral Primitive Neuroectodermal Tumors, SEER 1975-2000

Actual Survival
Gap

Lymphoma (NHL)

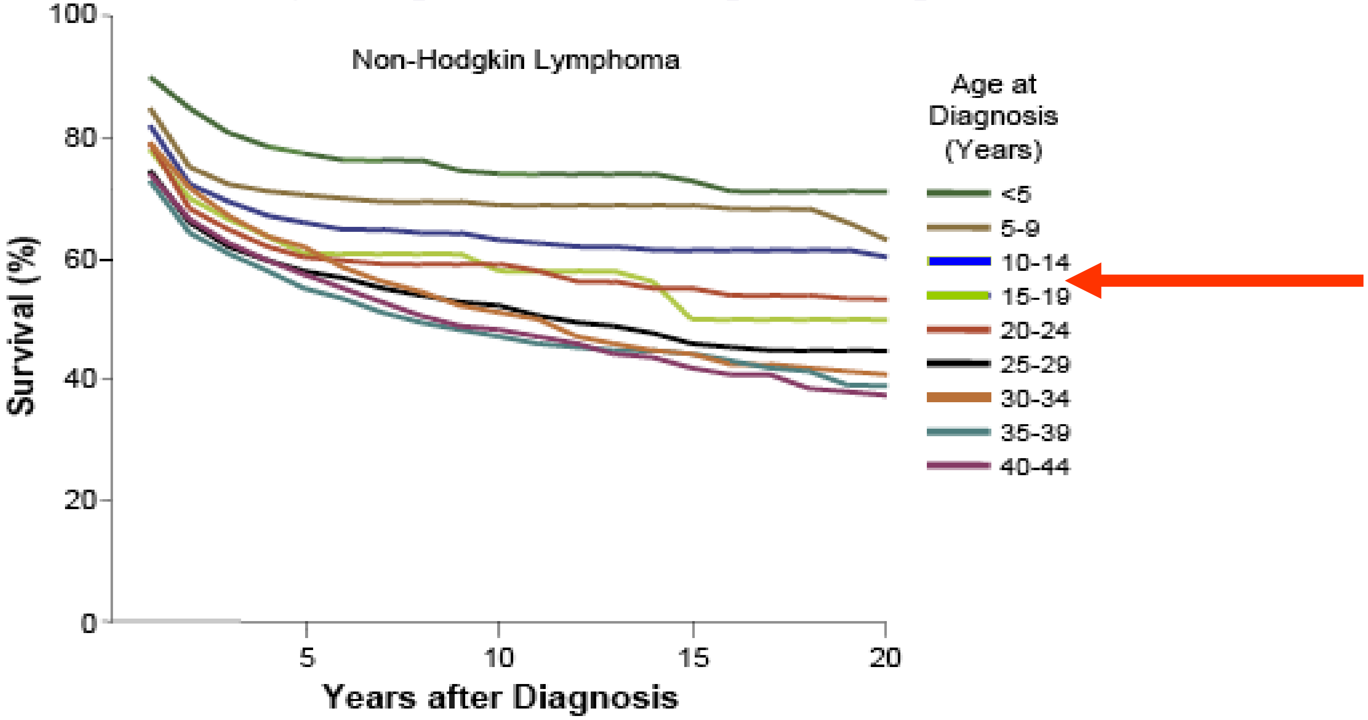


Figure 3.31: Survival Rates for Non-Hodgkin Lymphoma, SEER 1975-1998

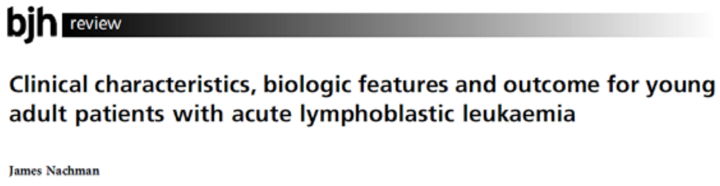
The Cause?

Multifactorial

- Biology of underlying cancer
- Participation in clinical trials
  - key to success in pediatric age range
- Insurance issues?
- Approach to therapy
  - time to medical attention
- Pediatric vs. adult regimens
  - dose intensity
- Compliance with medical plan

Cancer Biology

Biology of AYA cancers:



bjh review

Clinical characteristics, biologic features and outcome for young adult patients with acute lymphoblastic leukaemia

James Nachman

Acute lymphocytic leukemia (ALL)

A. No change in signs and symptoms of disease at presentation

B. increase in T cell ALL (more aggressive)

C. change in genetics of ALL in AYA patients
  - ↓ in low risk cytogenetics
  - ↑ in hi risk cytogenetics
    Ph+ ALL

D. change in response to Rx
  - ↑ rates of MRD after therapy.

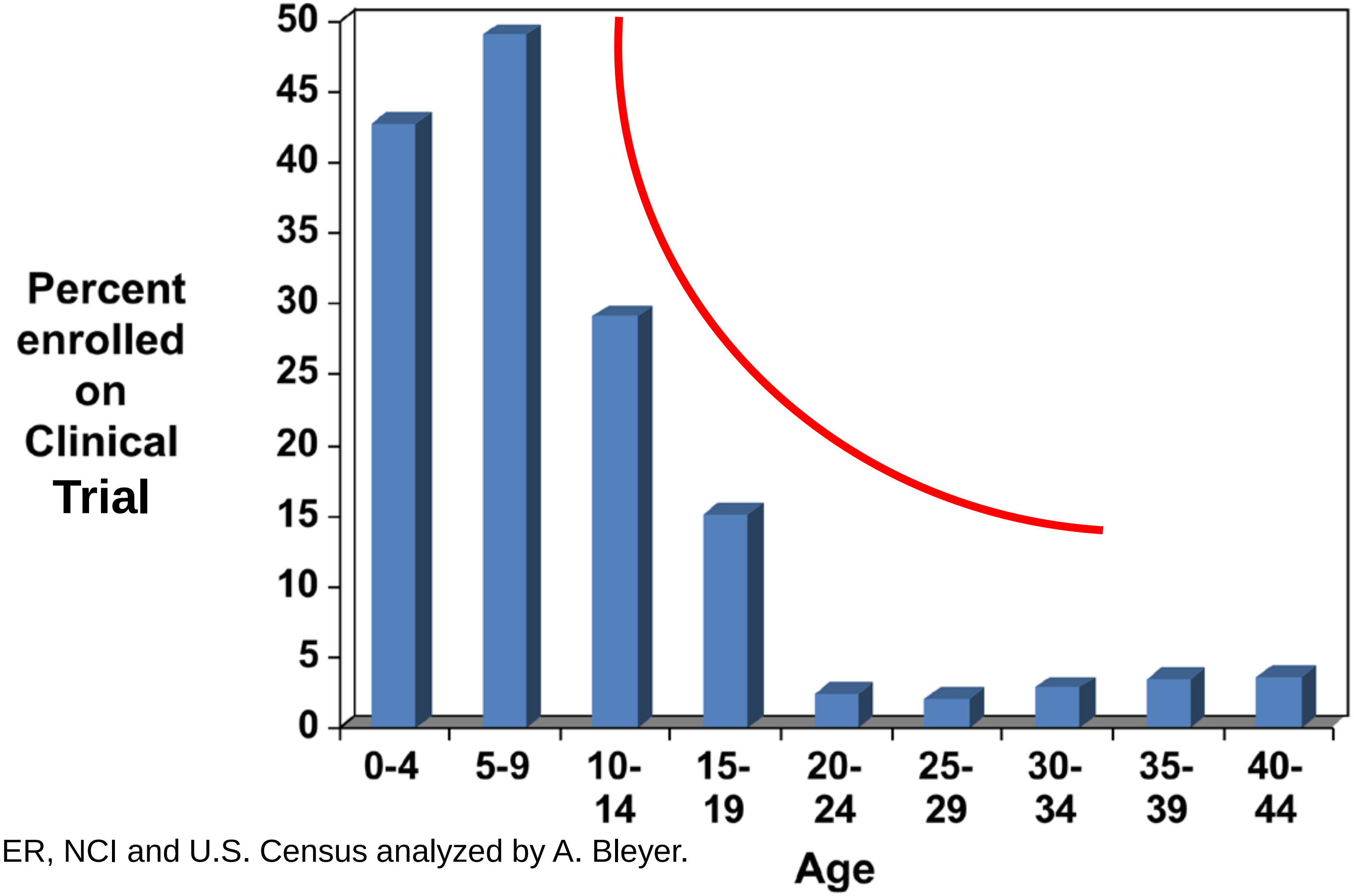
Clinical Trials

Older adolescents & young adults are disproportionately under-represented on clinical trials

Mortality rate reduction is correlated with clinical trial participation

Clinical Trials

Participation

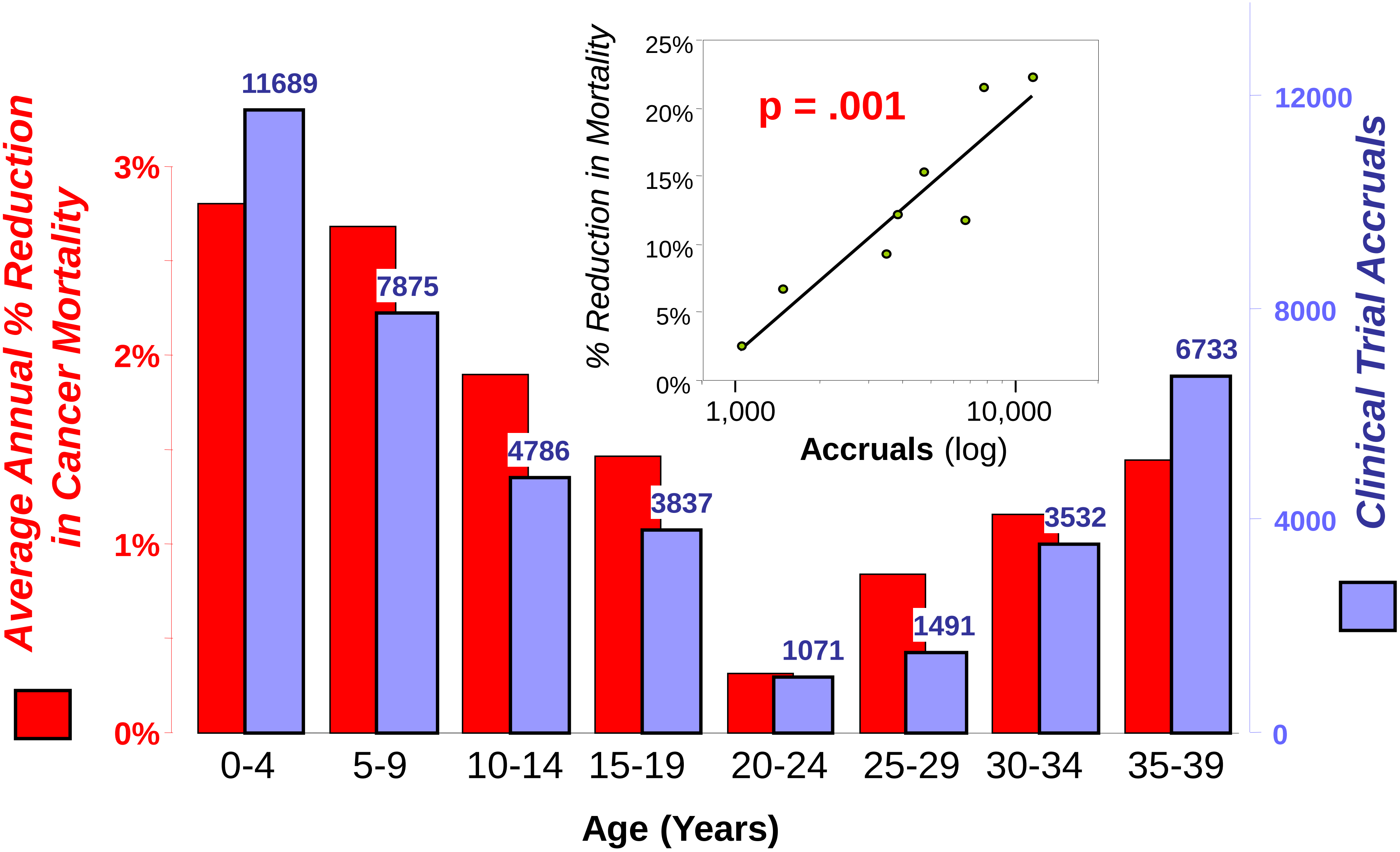


Data from SEER, NCI and U.S. Census analyzed by A. Bleyer.

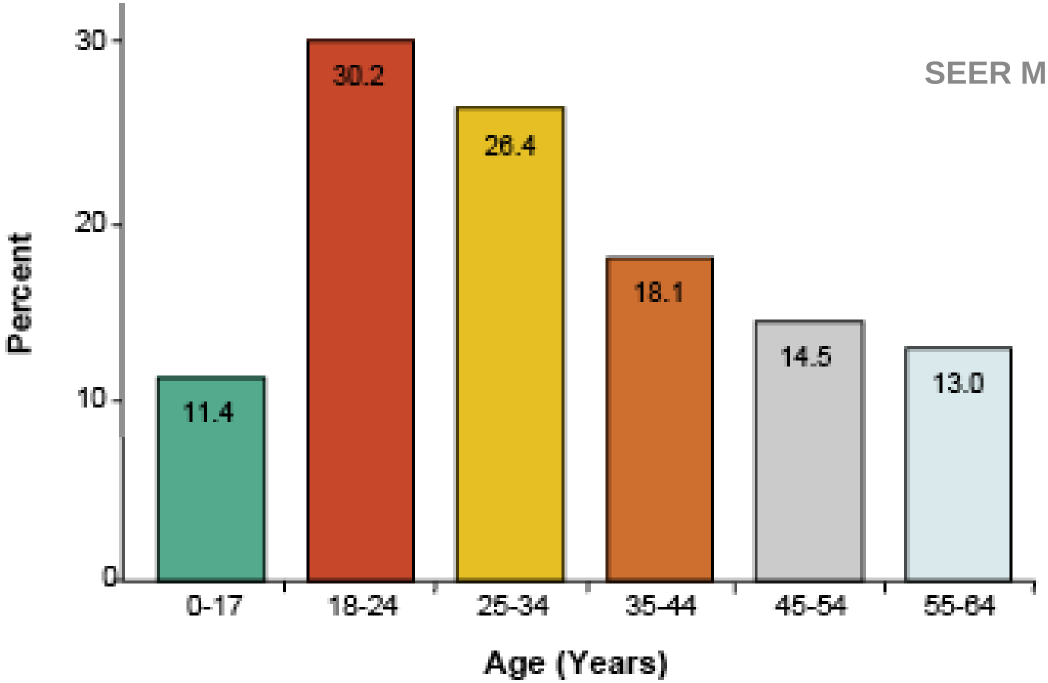
ASCO 2002

National Cancer Mortality Reduction, 1990-1998

National Treatment Trial Accruals, 1990-1998



Lack of Insurance

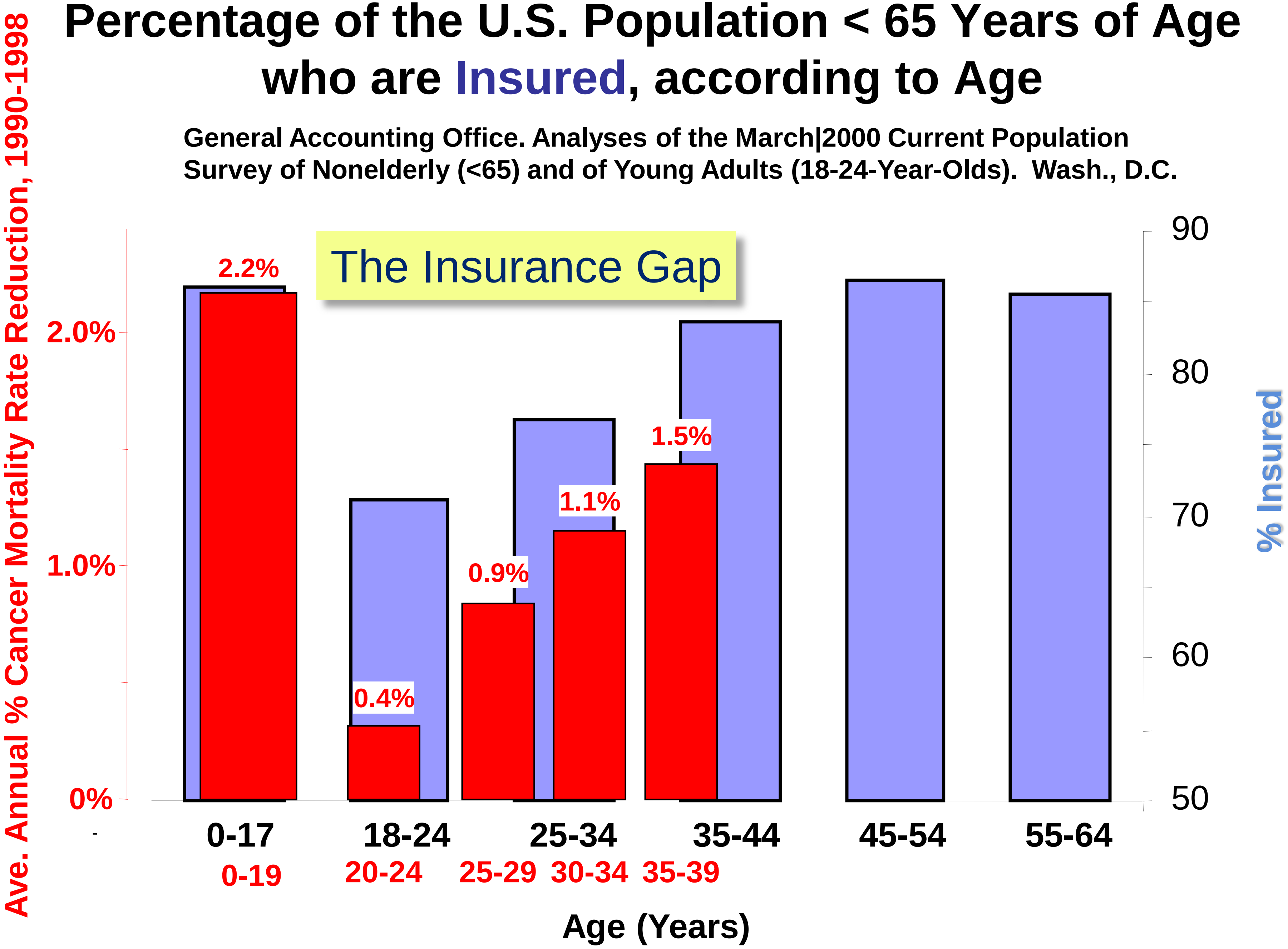


SEER Monograph 2006

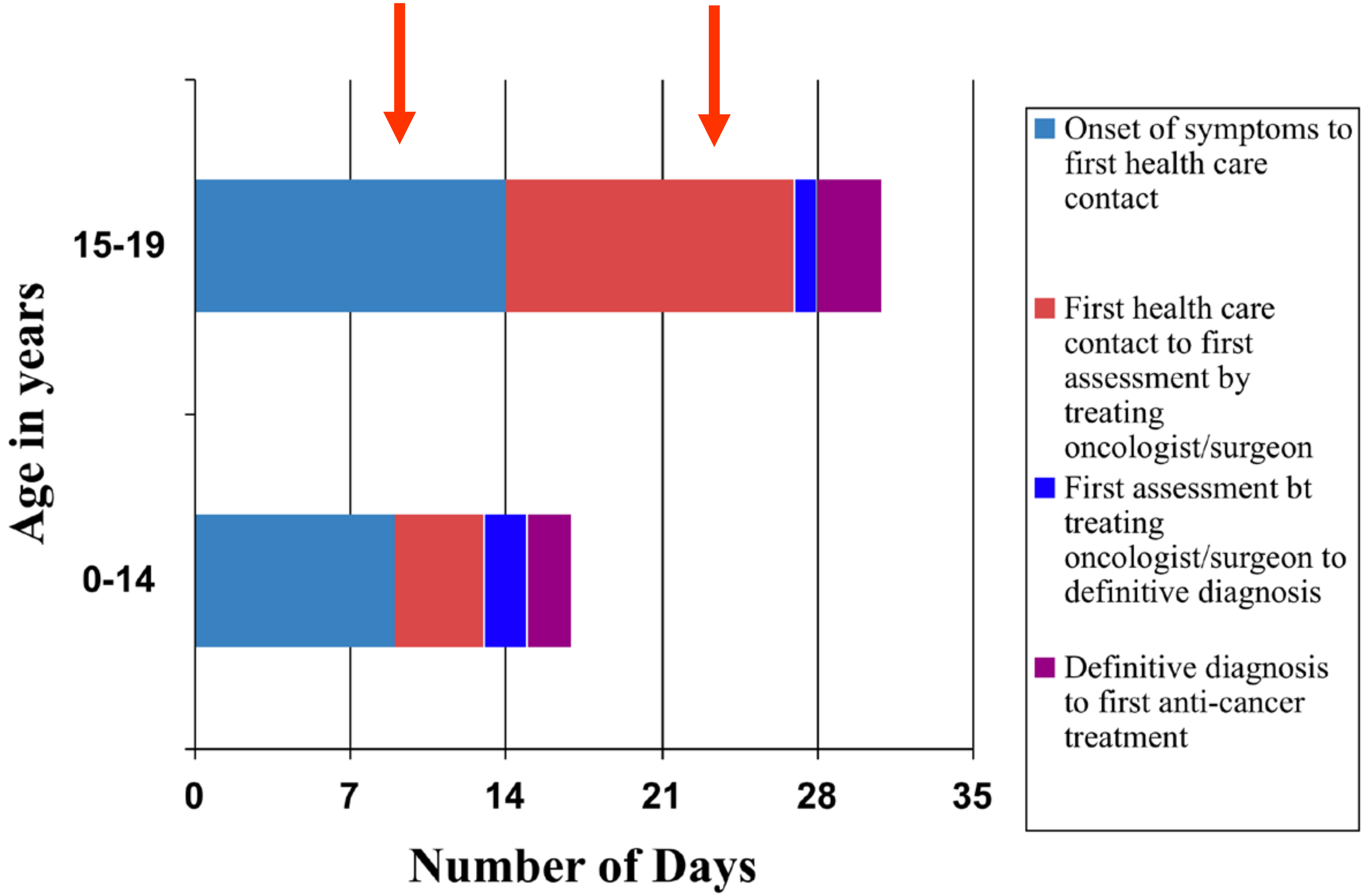
Figure 15.2: Percent without Health Insurance, Under 65 Years of Age, U.S., 2003

Percentage of the U.S. Population < 65 Years of Age who are Insured, according to Age

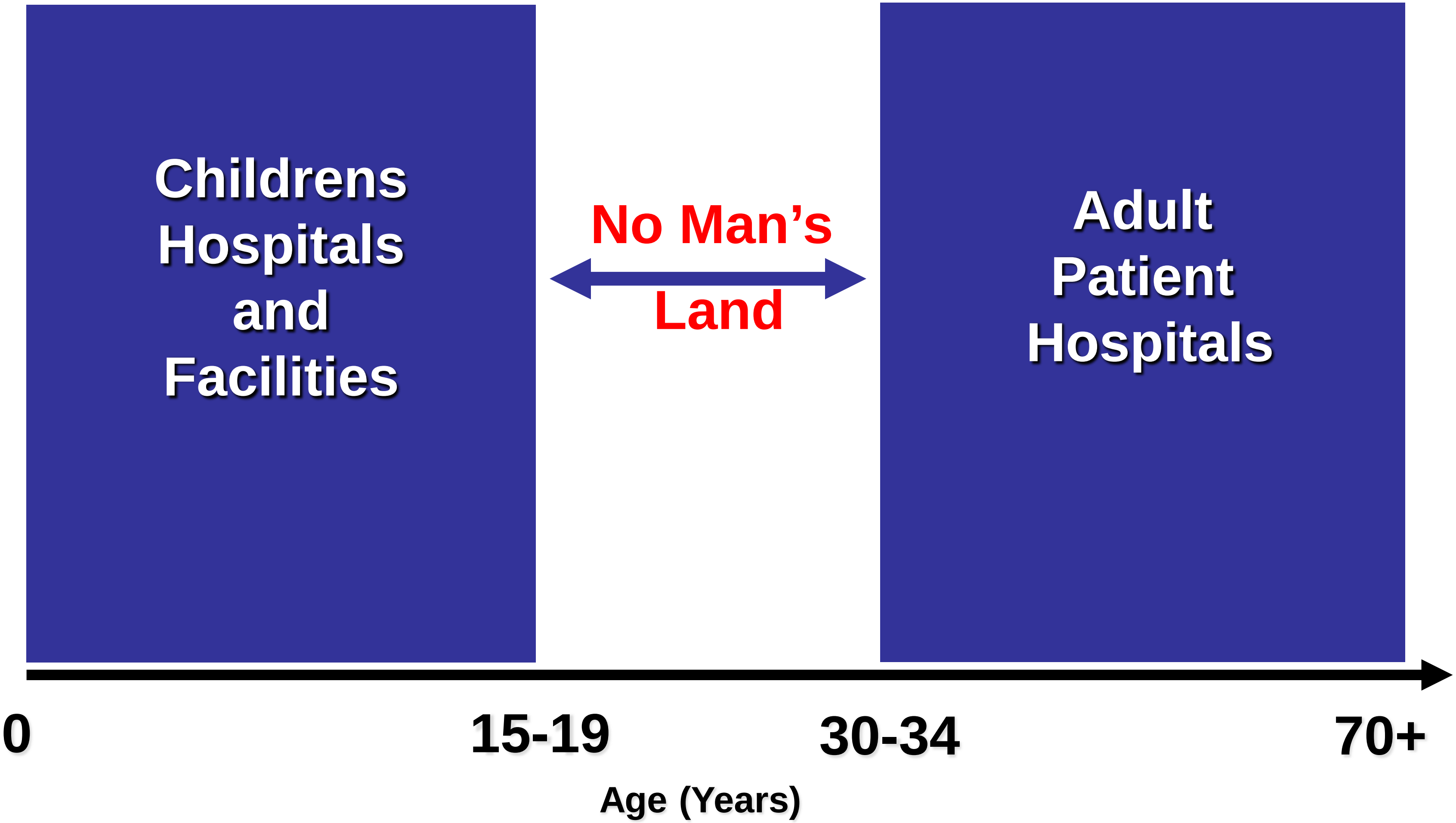
General Accounting Office. Analyses of the March|2000 Current Population Survey of Nonelderly (<65) and of Young Adults (18-24-Year-Olds). Wash., D.C.



Time From Symptoms to Rx



Facilities and Service GAP



Childrens Hospitals and Facilities

No Man’s Land

Adult Patient Hospitals

0

15-19

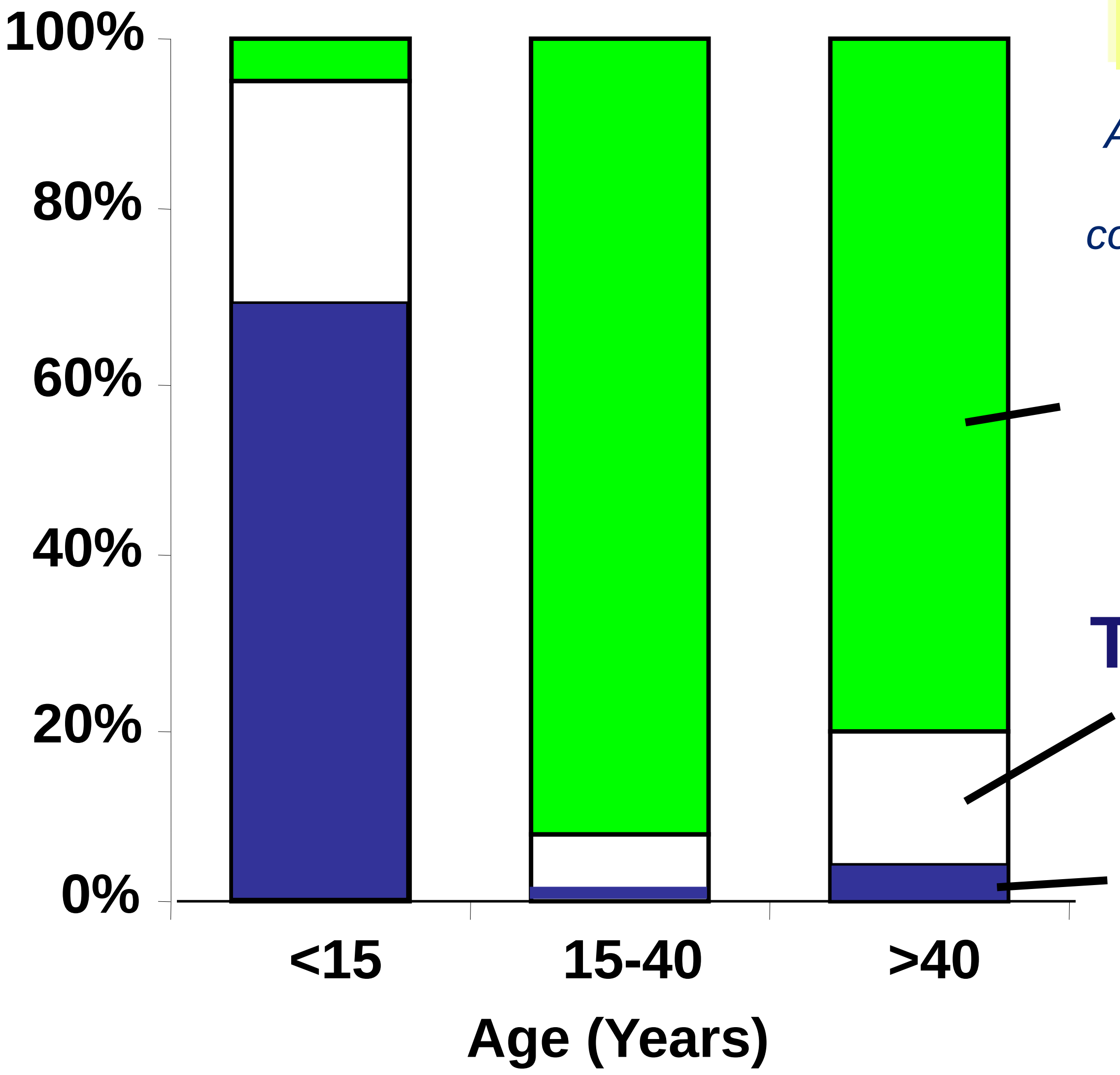
30-34

70+

Age (Years)

Management Sites of Cancer Patients, U.S.

in part from Lui L, et al, Cancer 97, 1339, 2003



The Referral Gap

AYA cancer patients are least likely to be referred to comprehensive cancer centers.

Community Oncology

Tertiary Cancer Centers

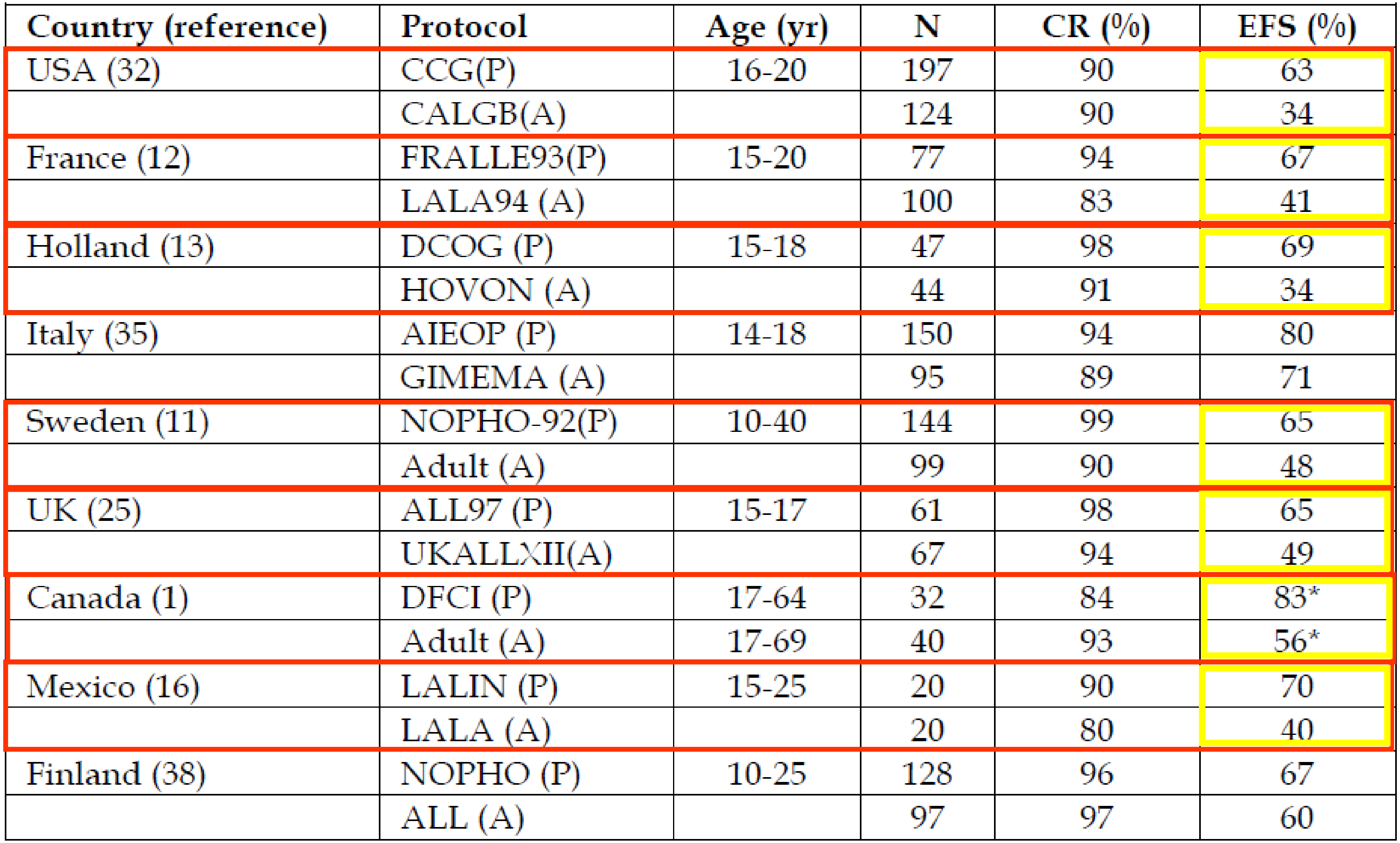
Participate in Clinical Trials

Regimen Intensity

Pediatric vs. Adult based protocols

ALL Regimens

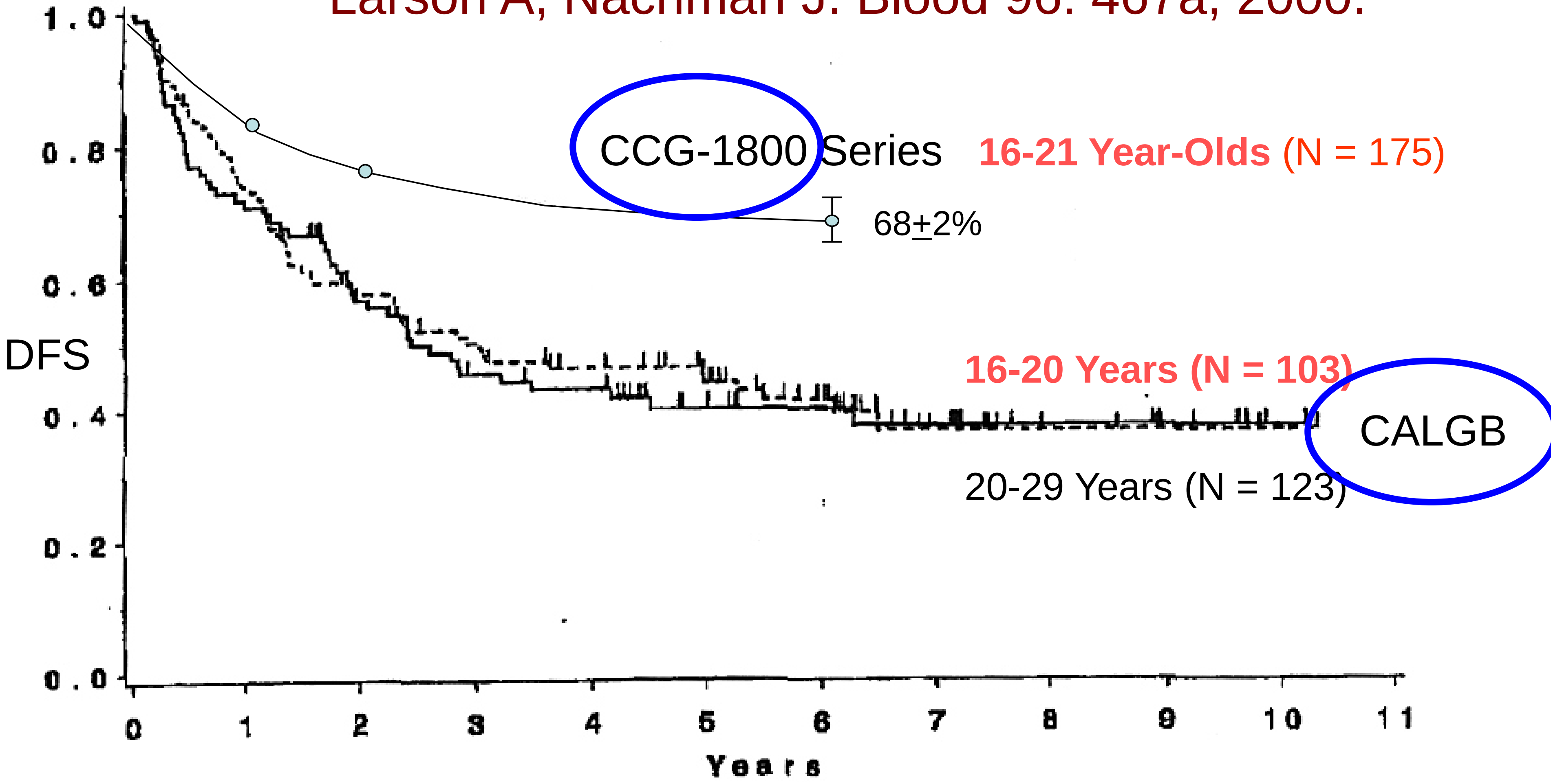
Ped vs. Adult



Country (reference)	Protocol	Age (yr)	N	CR (%)	EFS (%)
USA (32)	CCG(P)	16-20	197	90	63
	CALGB(A)		124	90	34
France (12)	FRALLE93(P)	15-20	77	94	67
	LALA94 (A)		100	83	41
Holland (13)	DCOG (P)	15-18	47	98	69
	HOVON (A)		44	91	34
● Italy (35)	AIEOP (P)	14-18	150	94	80
	GIMEMA (A)		95	89	71
Sweden (11)	NOPHO-92(P)	10-40	144	99	65
	Adult (A)		99	90	48
UK (25)	ALL97 (P)	15-17	61	98	65
	UKALLXII(A)		67	94	49
Canada (1)	DFCI (P)	17-64	32	84	83*
	Adult (A)	17-69	40	93	56*
Mexico (16)	LALIN (P)	15-25	20	90	70
	LALA (A)		20	80	40
● Finland (38)	NOPHO (P)	10-25	128	96	67
	ALL (A)		97	97	60

ALL Regimens
Ped vs. Adult

Stock W, Sather H, Dodge RK, Bloomfield CD, Larson A, Nachman J. Blood 96: 467a, 2000.

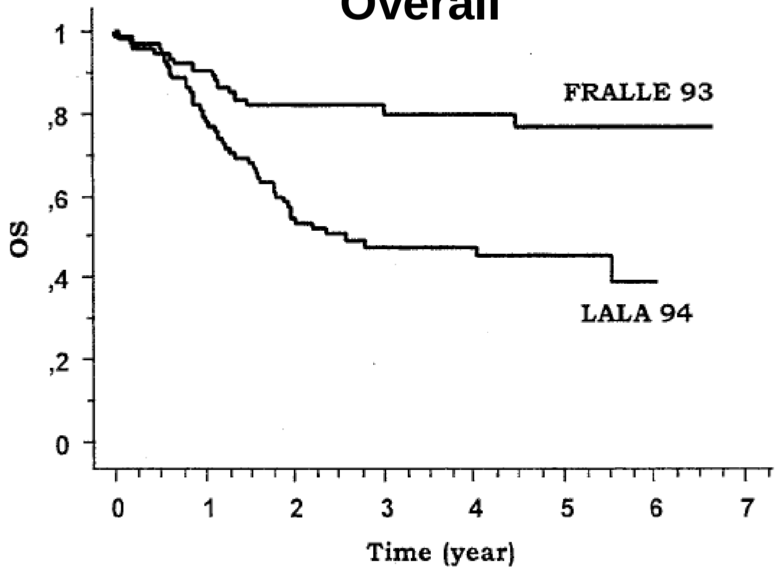


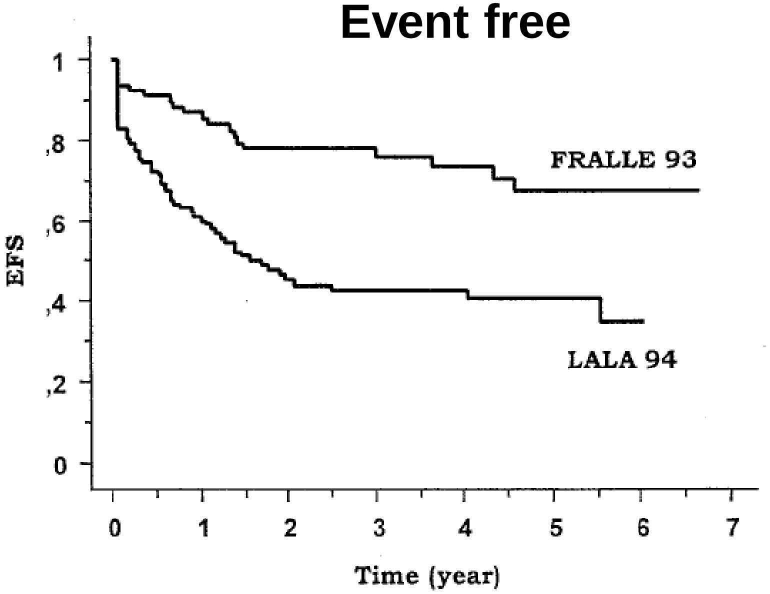
ALL Regimens
Ped vs. Adult

Same Results in France

Comparison of the French FRALLE-93 and LALA-94 trials

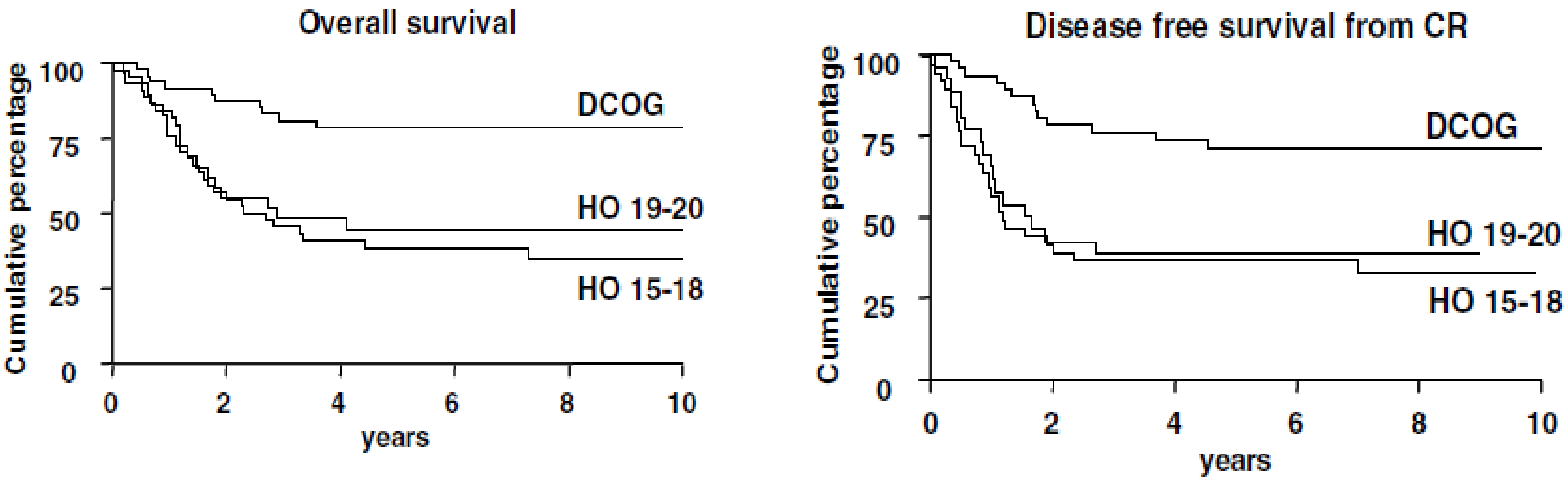
75% vs. 40% 5-Year Survival

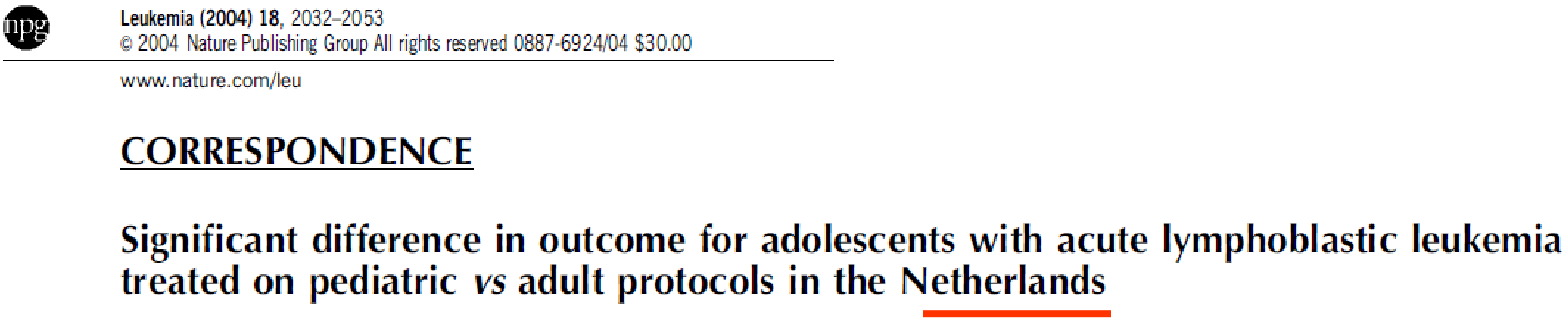

Overall


Event free

J Clin Oncol, 2003:2(5):774-780

ALL Regimens
Ped vs. Adult





Leukemia (2004) 18, 2032–2053
© 2004 Nature Publishing Group All rights reserved 0887-6924/04 $30.00

www.nature.com/leu

CORRESPONDENCE

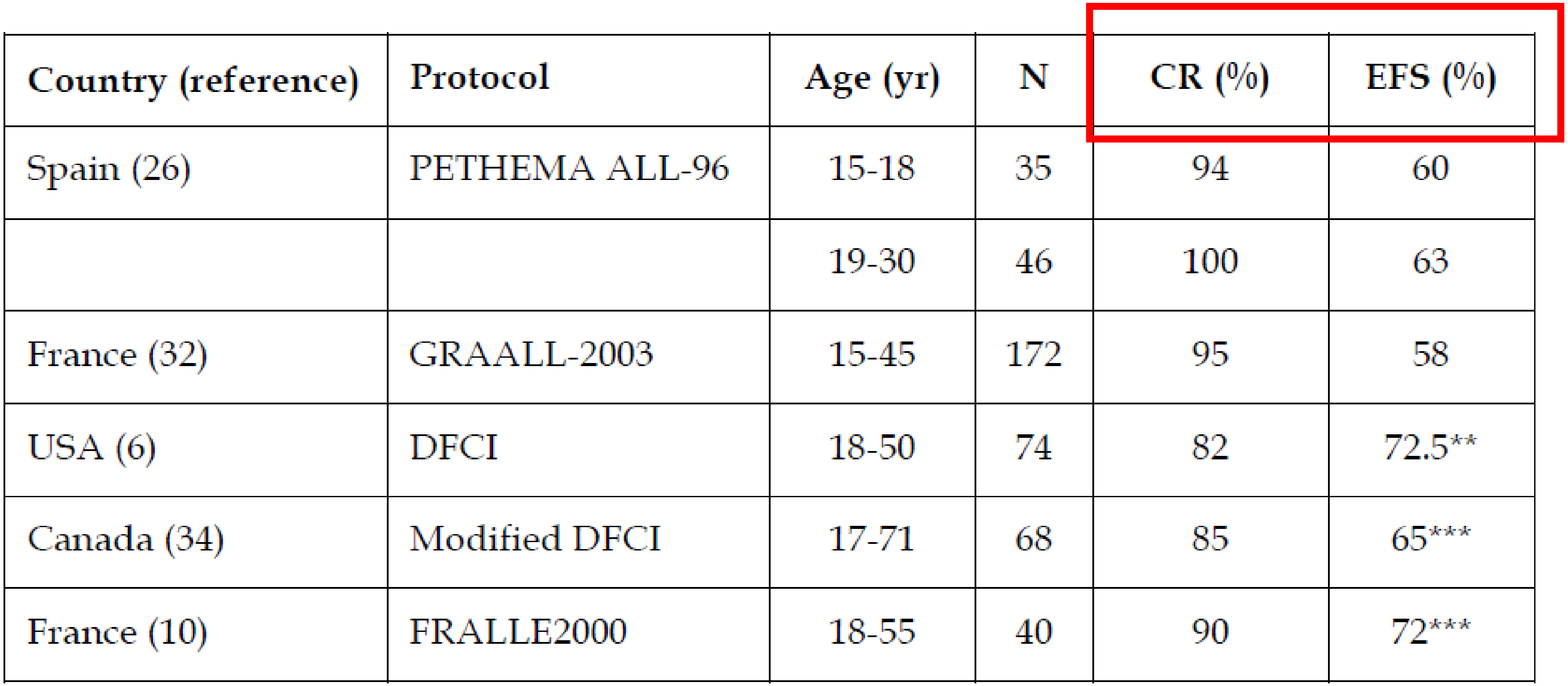
Significant difference in outcome for adolescents with acute lymphoblastic leukemia treated on pediatric *vs* adult protocols in the Netherlands

Pediatric Protocols Superior?

1. Drugs used
    - tolerability of side effects
2. Treatment duration
3. Schedule of drug delivery
    - dose intensification
    - CNS prophylaxis
4. Are pediatricians better doctors?
    - adherence to treatment regimen
    - clinical trial enrollment
5. Site of care delivery
    - university hospital vs. community
    - resource availability

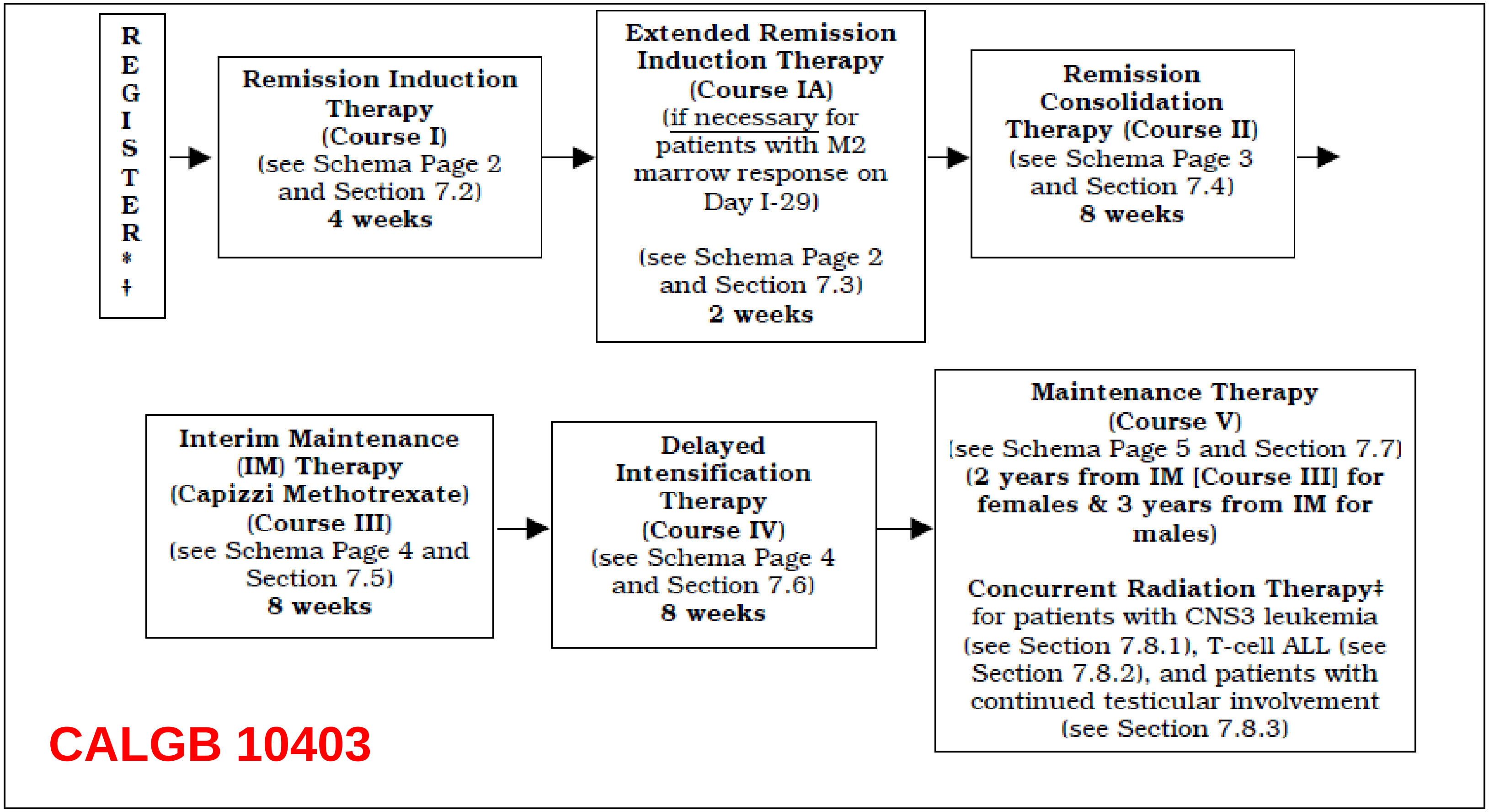
New Approach

Acute Lymphocytic Leukemia



Country (reference)	Protocol	Age (yr)	N	CR (%)	EFS (%)
Spain (26)	PETHEMA ALL-96	15-18	35	94	60
		19-30	46	100	63
France (32)	GRAALL-2003	15-45	172	95	58
USA (6)	DFCI	18-50	74	82	72.5**
Canada (34)	Modified DFCI	17-71	68	85	65***
France (10)	FRALLE2000	18-55	40	90	72***

New Approach



REGISTER*‡

Remission Induction Therapy (Course I) (see Schema Page 2 and Section 7.2) **4 weeks**

Extended Remission Induction Therapy (Course IA) (if necessary for patients with M2 marrow response on Day I-29)

(see Schema Page 2 and Section 7.3) **2 weeks**

Remission Consolidation Therapy (Course II) (see Schema Page 3 and Section 7.4) **8 weeks**

Interim Maintenance (IM) Therapy (Capizzi Methotrexate) (Course III) (see Schema Page 4 and Section 7.5) **8 weeks**

Delayed Intensification Therapy (Course IV) (see Schema Page 4 and Section 7.6) **8 weeks**

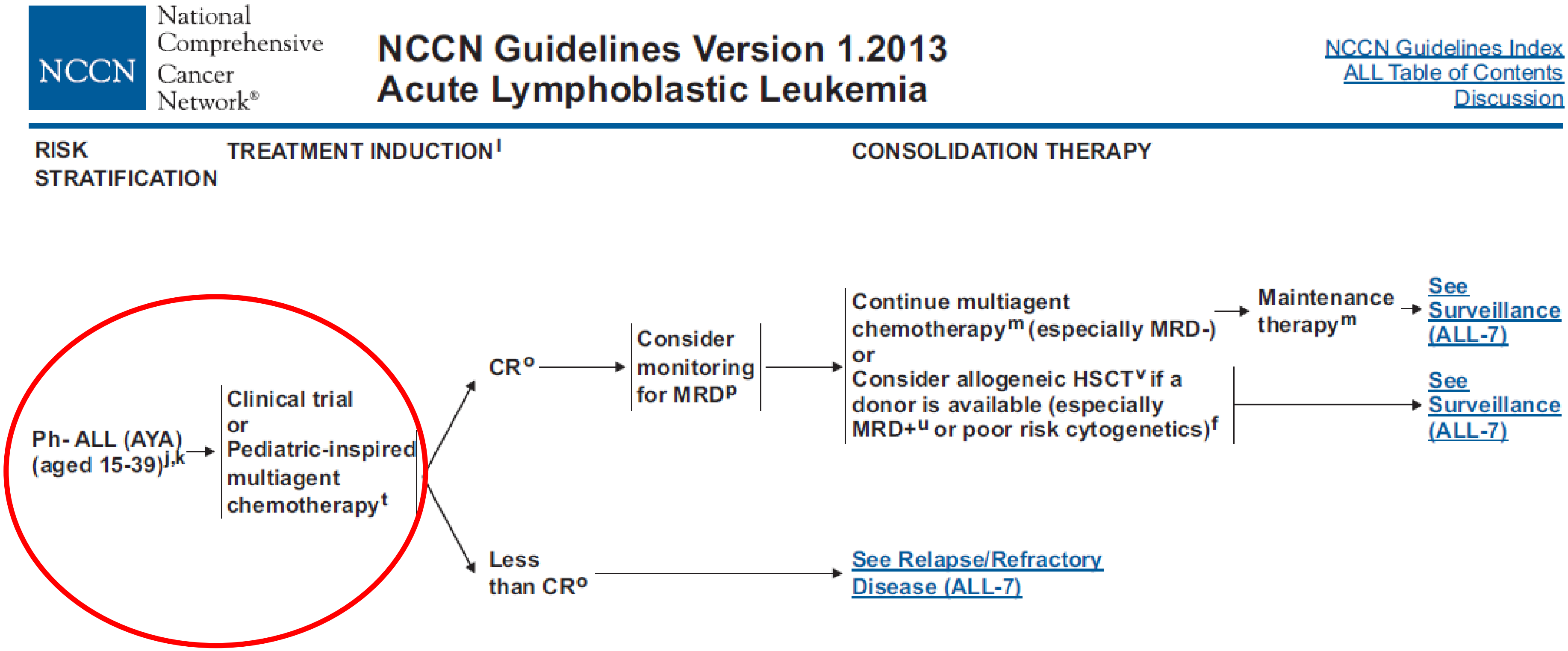
Maintenance Therapy (Course V) (see Schema Page 5 and Section 7.7) **(2 years from IM [Course III] for females & 3 years from IM for males)**

Concurrent Radiation Therapy‡ for patients with CNS3 leukemia (see Section 7.8.1), T-cell ALL (see Section 7.8.2), and patients with continued testicular involvement (see Section 7.8.3)

CALGB 10403

Inter-group; phase II; 16 to 39 yrs; accrual complete

The Future



NCCN National Comprehensive Cancer Network®

NCCN Guidelines Version 1.2013
Acute Lymphoblastic Leukemia

NCCN Guidelines Index
ALL Table of Contents
Discussion

RISK STRATIFICATION

TREATMENT INDUCTION[l]

CONSOLIDATION THERAPY

Ph- ALL (AYA) (aged 15-39)[j,k] → Clinical trial or Pediatric-inspired multiagent chemotherapy[t]

→ CR[o] → Consider monitoring for MRD[p] → Continue multiagent chemotherapy[m] (especially MRD-) → Maintenance therapy[m] → See Surveillance (ALL-7)

or

Consider allogeneic HSCT[v] if a donor is available (especially MRD+[u] or poor risk cytogenetics)[f] → See Surveillance (ALL-7)

→ Less than CR[o] → See Relapse/Refractory Disease (ALL-7)

Compliance

Adherence to treatment regimens has been studied extensively

- Extent to which person’s behaviors corresponds with agreed recommendations from a health care provider Or mentor….or boss…
- Medication, diet, lifestyle change

Compliance

Adherence to treatment regimen

- Measured over a continuum
- Evaluated based on the impact of the behavior on therapeutic benefit of the treatment regimen
- Dynamic process
  - Interaction between patient and medical team
  - Cognitive-motivational components
  - Direct and Indirect measures

Butow, et al., Journal of Clinical Oncology, v28(32); Kondryn et al., Lancet Oncology v12

Compliance

Practical strategies to improve Adherence:

- Communicate… ask, ask, and ask again!
- Non-judgmental exploration of adherence behaviors
- Identify risk factors, including high risk behaviors
- Discuss barriers, collaborate with AYA to generate a solution
- Encourage questions, make sure AYA patients understand treatment regimen… all aspects!

Takes time and resources!

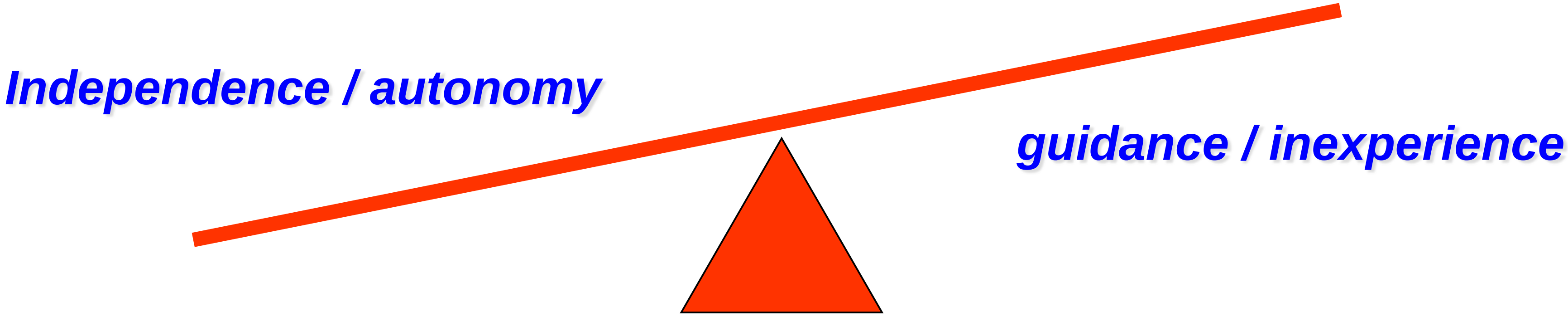
AYA Oncology

AYA Oncology: Specific Challenges

- **Under-representation on clinical trials**

  < 15 yrs on NCI trials; > 15 yrs → no so much

- **Lack of Insurance; access to health care**
- **Issues pertaining to body image, school, career**
- **concerns about fertility**



Independence / autonomy

guidance / inexperience

The Future

Multi-disciplinary Team Approach

- Oncologists
  - Pediatric and Internal medicine
  - Hospital base + community
- Nursing / advanced practitioners
- Coordinators / social workers
- Surgeons
- Fertility experts
- Endocrinologists

The Future

- Dedicated clinicians and practitioners, RNs
    - Pediatric and Adult protocols
    - Clinical-laboratory bio-repositoriess
- Triage
    - Age
    - Diagnosis
    - Psycho social assessment
    - Protocol availability
- Determine treatment institution / strategy
    - Internal medicine
    - Pediatrics

The Future

- Create a ***seamless continuum of care*** by pediatric & medical oncologists at the time of Dx and treatment

- Build awareness with primary care physicians and oncologists regarding the need for and availability of ***long term follow-up*** to address late effects.

Conclusions

Many unique challenges must be considered:

- Choice of oncology specialist and center
- Therapeutic regimen: Peds vs. Adult based
- Clinical trial participation
- Identify and address unique AYA issues
- Multi-disciplinary approach
- Integration of psychosocial care
- Heightened awareness of Late effects

Together we can make a difference!

AYA Oncology
Case Presentation

- **23 y/o WM, college grad, unemployed, lives @ home; 155 kg**
- **8 week h/o groin abscesses → ER → ABX + steroids**
- **5 to 7 day h/o fatigue, malaise, SOB, Fever → ER**
- **Diagnostic work-up:**
  - Exam: Febrile, pale, anxious, tachycardic, tachypneic
  - CBC: Pancytopenia, CXR: NED; Coags wnl, Chem 20; wnl
  - BM: 80% blasts, myeloid morphology, flow and cytogenetics sent
- **AYA issues:**
  - L/O independence, invasion of privacy → anger / frustration
  - Disruption of daily routine, Insurance issues
  - Recreational drug use, fertility → sperm banking
- **Treatment considerations:**
  - Adult vs. Pediatrics?; Clinical Trial vs. SOC?

Communicating about Advance Care Planning With Adolescents and Young Adults

Lori Wiener, PhD

National Cancer Institute

Objectives

Going through cancer treatment can be really tough. Sometimes it’s unclear how things are going to turn out. There may be difficult conversations that young people want to have with family, friends and their healthcare team that they might not have the words for.

- To review the development of an adolescent and young adult (AYA) planning document

- To describe communication about end-of-life care and barriers and opportunities to integrating advance care planning

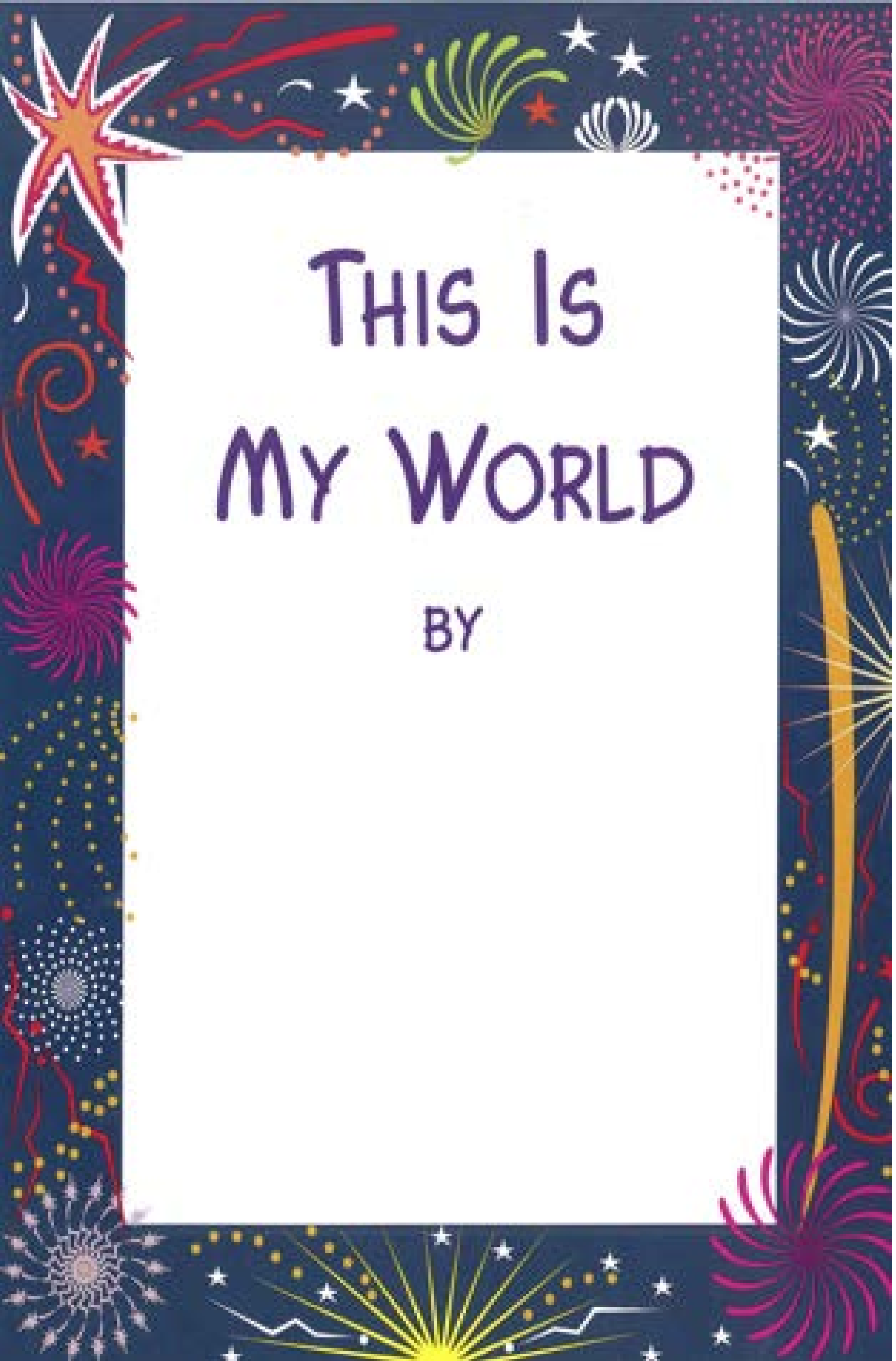
End of Life (EoL) in the AYA Population

- Each year >11,000 adolescents and young adults, ages 15-34, die from cancer and other life-limiting conditions.
- The **AAP**, **IOM** and **WHO** recommend involving youth in decisions regarding their care as they are emotionally and developmentally ready.
- A minority of children living with a chronic illness have an Advance Directive (AD). (Liberman et al., *Pediatrics*, 2014)
- 82% of families want their child to participate in the decisions. (Lotz, et al. *Pediatrics* 2013)
- Few formal resources/tools for **pediatric** or **AYA** advance care planning are available
    - informed by adult experiences

Talking About Death with Children

- Survey in 2001 of 429 Swedish parents who had lost child to cancer between 1992-1997
- None of 147 parents who talked with their child about death regretted it
- 69 of 258 parents (27%) who did not talk with their child about death regretted not having done so

Kreicbergs U et al, *NEJM* 2004



THIS IS MY WORLD

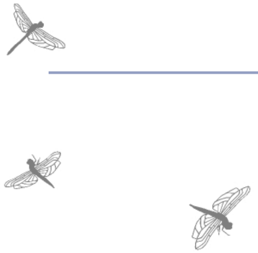
BY

TODAY'S DATE ____________ HOW I FEEL TODAY

A MOCK WILL

FROM TIME TO TIME, MOST PEOPLE THINK ABOUT WHAT WOULD HAPPEN TO THEM AND/OR ALL OF THEIR STUFF IF THEY DIED. HERE YOU HAVE AN OPPORTUNITY TO WRITE DOWN WHAT YOU WOULD WANT TO HAPPEN TO YOU, YOUR BELONGINGS, OR ANY OTHER WISHES.

1. ____________________
2. ____________________
3. ____________________
4. ____________________
5. ____________________
6. ____________________
7. ____________________
8. ____________________
9. ____________________
10. ____________________
11. ____________________
12. ____________________
13. ____________________
14. ____________________
15. ____________________



Would an advance care planning tool be helpful?

Phase I: Development of an Advance Care Planning Tool

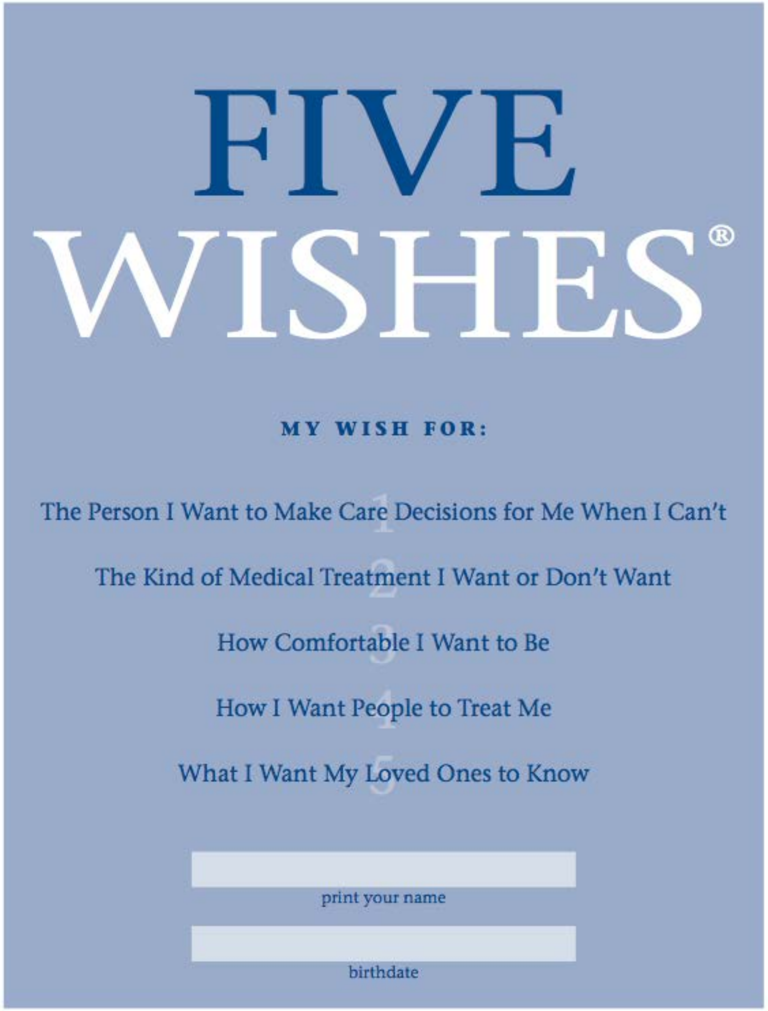
Study Aims:

To explore whether adolescents/young adults living with a life-limiting illness are ***interested*** in a developmentally appropriate EoL planning document.

Methods

- AYA participants (N = 20, ages 16-28) were asked to critically evaluate whether the concepts included in *Five Wishes®* and *Focus Groups* were:
  1. **Helpful** to themselves and others their age living with a serious illness?
  2. **Appropriate** to ask individuals their same age?
  3. **Stressful** to contemplate?

- Participants were also asked to:
  - Which questions/statements should be added or removed and why



FIVE WISHES®

MY WISH FOR:

1 The Person I Want to Make Care Decisions for Me When I Can't

2 The Kind of Medical Treatment I Want or Don't Want

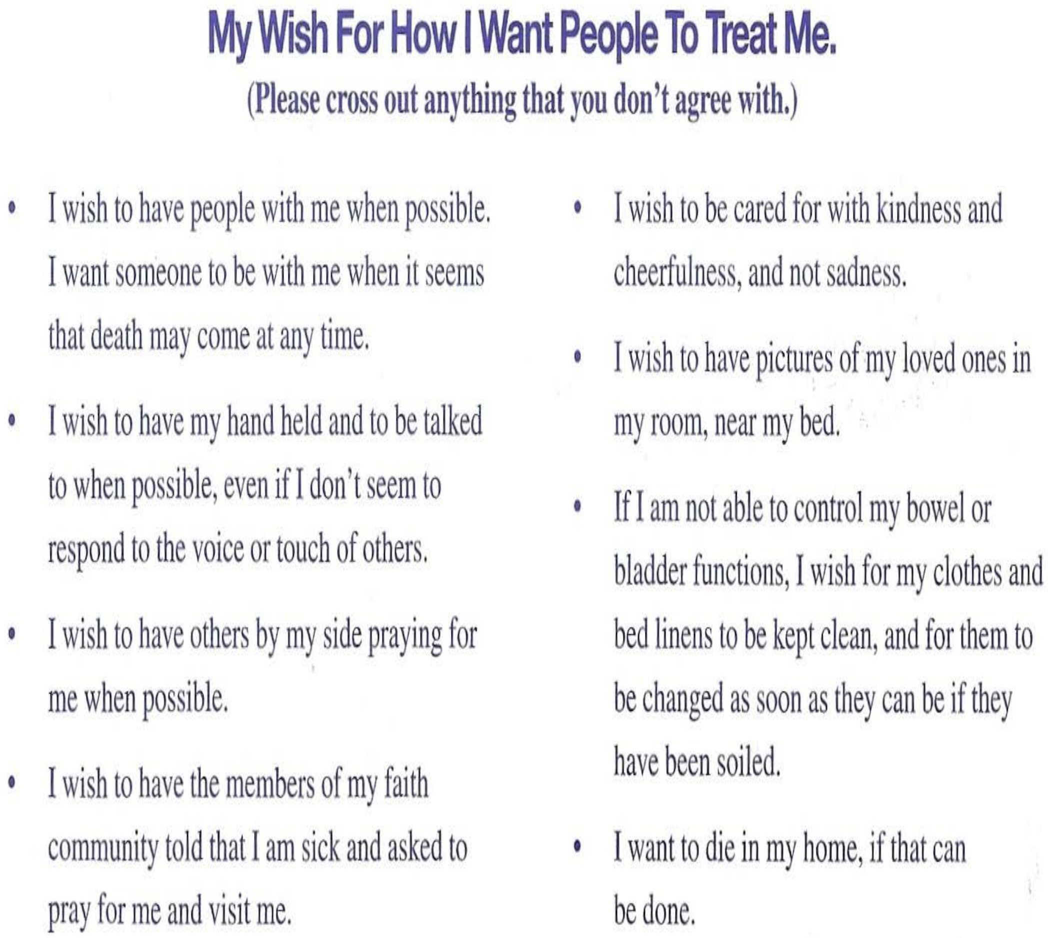
3 How Comfortable I Want to Be

4 How I Want People to Treat Me

5 What I Want My Loved Ones to Know

print your name

birthdate



My Wish For How I Want People To Treat Me.

(Please cross out anything that you don't agree with.)

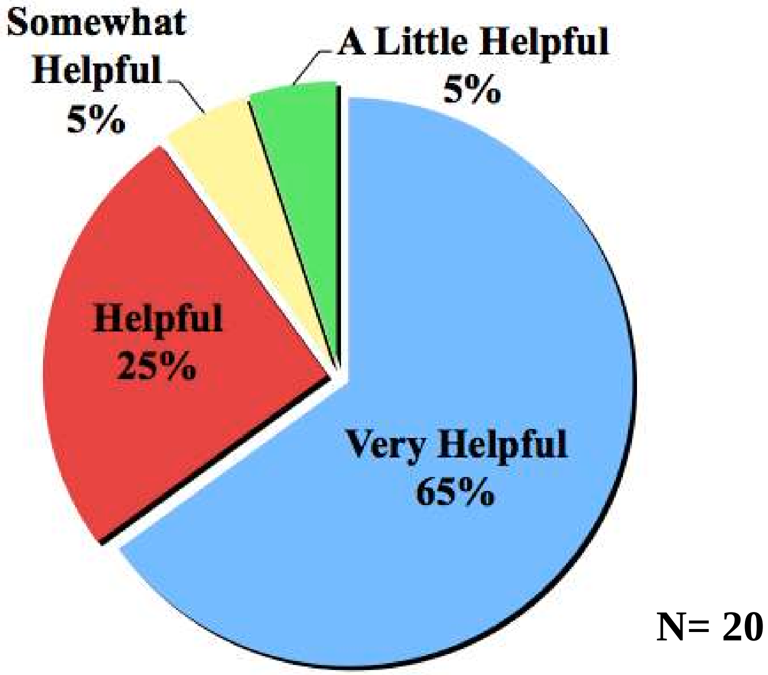
- I wish to have people with me when possible. I want someone to be with me when it seems that death may come at any time.
- I wish to have my hand held and to be talked to when possible, even if I don't seem to respond to the voice or touch of others.
- I wish to have others by my side praying for me when possible.
- I wish to have the members of my faith community told that I am sick and asked to pray for me and visit me.
- I wish to be cared for with kindness and cheerfulness, and not sadness.
- I wish to have pictures of my loved ones in my room, near my bed.
- If I am not able to control my bowel or bladder functions, I wish for my clothes and bed linens to be kept clean, and for them to be changed as soon as they can be if they have been soiled.
- I want to die in my home, if that can be done.

Results: First Cohort

- How *Appropriate* would an EoL planning document be for Adolescents and Young Adults with a serious illness?

- How *Helpful* Could An EoL Planning Document For *Others* Your Age?

100% of participants reported that an ACP document would be *appropriate* for adolescents and young adults living with a serious illness



Wiener L et al., *Journal of Palliative Medicine*, 2008

What Needed To Be Added:

"**Where** I want to be when the end of my life is near" and "the **people** I would like to be with me".

"The clothes I want to wear at my funeral"; "The **friends and family** who I would like to attend the service"; and "The specific music and readings I would like".

"A place to describe **spiritual** preferences".

"The **people** who I would like to receive my belongings" (clothes, music, photographs, jewelry, books, artwork, etc.).

"How I would like to be **remembered** by my **family** and by my friends on my birthday and on specific holidays".

"A place for letter writing".

What was missing were the developmental considerations…

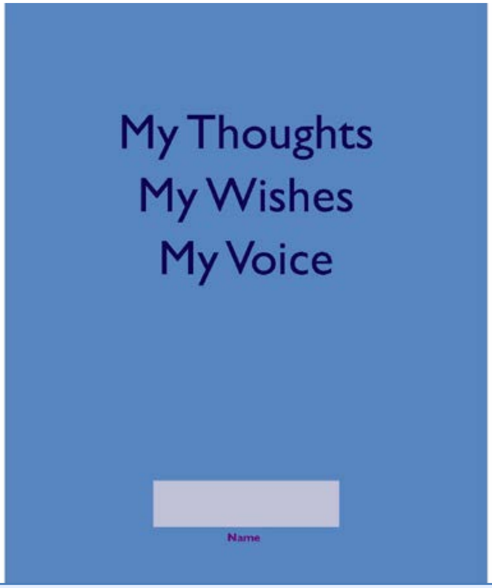
Three I’s of Adolescent Development

- **Identity**
- **Independence**
- **Intimacy**

Death
is the
ultimate
challenge to
each of these
processes

The **loss** of identity,
the **demise** of
independence, the
end of intimacy

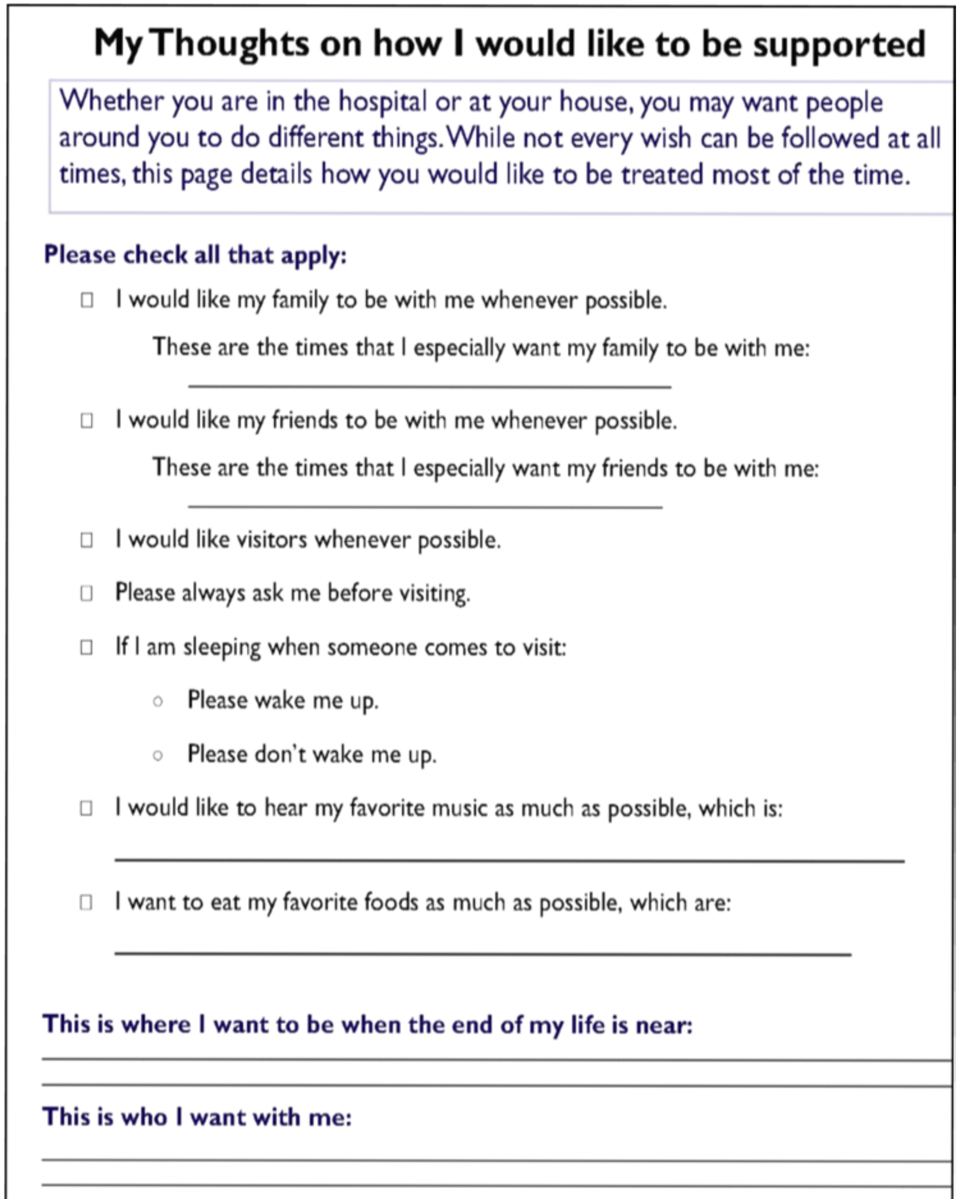
An Interim Document Was Created



My Thoughts
My Wishes
My Voice

Name

- Took into account the **importance of both familial** and **peer relationships** and the need for intimacy
- Recognized the **capacity** for independent decision-making
- Addressed identity through **personalization** of the end of life experience (music, readings, etc)



My Thoughts on how I would like to be supported

Whether you are in the hospital or at your house, you may want people around you to do different things. While not every wish can be followed at all times, this page details how you would like to be treated most of the time.

Please check all that apply:

☐ I would like my family to be with me whenever possible.

These are the times that I especially want my family to be with me: __________

☐ I would like my friends to be with me whenever possible.

These are the times that I especially want my friends to be with me: __________

☐ I would like visitors whenever possible.

☐ Please always ask me before visiting.

☐ If I am sleeping when someone comes to visit:

- ○ Please wake me up.
- ○ Please don't wake me up.

☐ I would like to hear my favorite music as much as possible, which is: __________

☐ I want to eat my favorite foods as much as possible, which are: __________

This is where I want to be when the end of my life is near:

____

This is who I want with me:

____

Study Phase 2 – Methods

FIVE WISHES

My Thoughts
My Wishes
My Voice

- Pediatric Branch NCI & Georgetown University
- 52 participants, ages 16-28 (M= 20.3)
- Participants critically reviewed the new document in conjunction with *Five Wishes*®

Qualitative information was gathered regarding document preferences, design, and specific content.

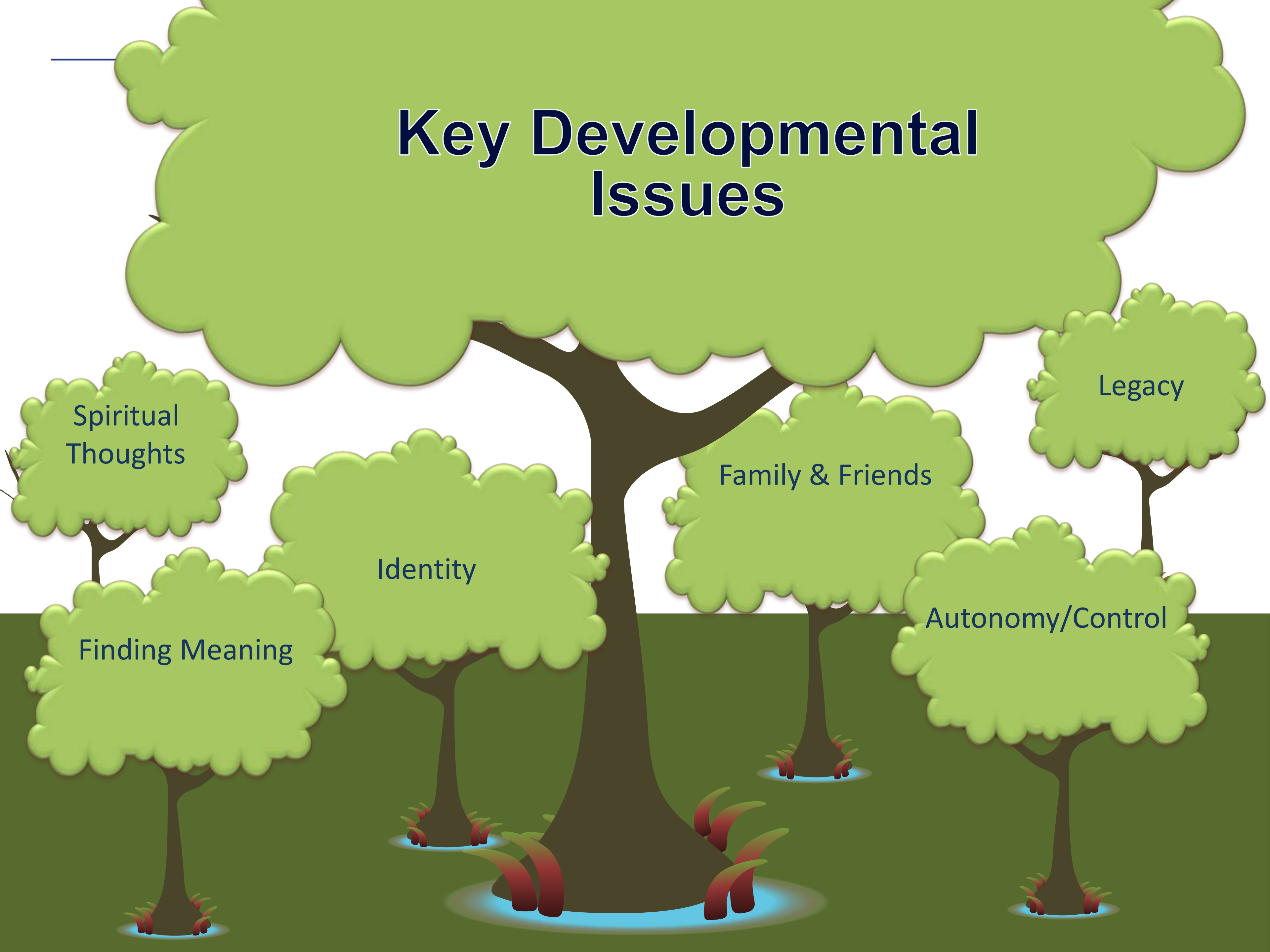
Wiener ….Pao, *Pediatrics*, 2012

the ULMAN CANCER fund for YOUNG ADULTS

NATIONAL CANCER INSTITUTE

JOHNS HOPKINS MEDICINE
THE SIDNEY KIMMEL COMPREHENSIVE CANCER CENTER

Key Developmental Issues



Spiritual Thoughts

Identity

Family & Friends

Legacy

Finding Meaning

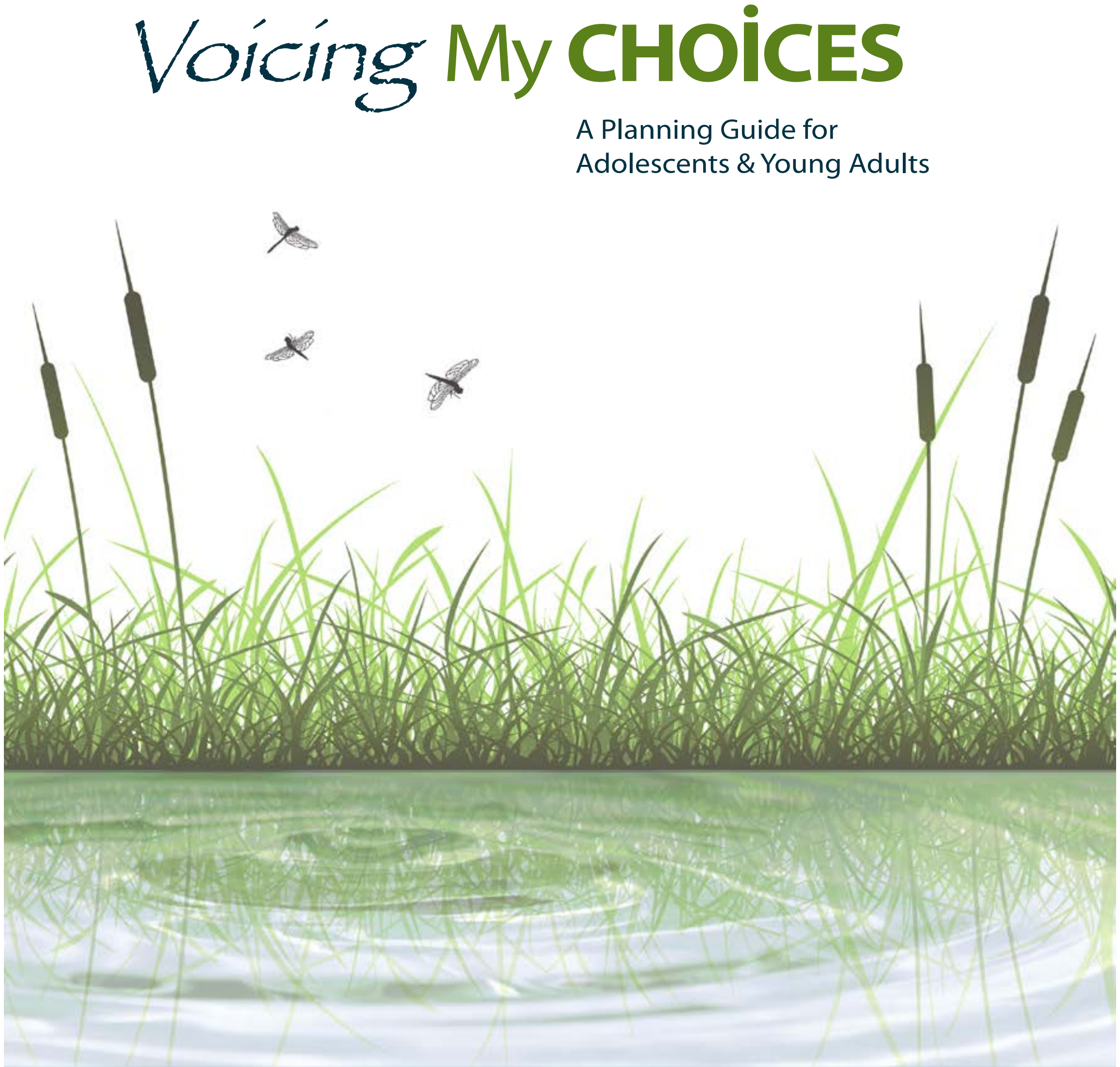
Autonomy/Control

The Current Document:

Wiener, Zadeh, Battles, Baird, Ballard, Osherow, Pao, *Pediatrics,* 2012, *130*:897.

Zadeh, Pao, Wiener, *Palliative and Supportive Care*, 2015

Aging with Dignity
www.agingwithdignity.org



Voicing My **CHOICES**

A Planning Guide for
Adolescents & Young Adults

Voicing My **CHOICES**

I, ________________________________, ask
that my family, my doctors, my friends, and my health care providers follow my wishes as communicated in this booklet. This booklet is only to be used in the case I can no longer communicate my wishes myself.

My **SIGNATURE:** ____________________________________
My Date of Birth: ______________________________________
Address: ____
Phone: ________________________ Today's Date: __________

Witness Statement:

I, the witness, declare that the person who signed or acknowledged this booklet is known to me, that he/she signed this booklet based on his/her own thoughts, wishes and desires, and that he/she is of sound mind and no duress, or undue influence.

Signature of Witness # 1	Signature of Witness # 2
Printed Name	Printed Name
Address	Address

Notarization *(If required by the state you live in)*

i s

When living with a serious illness there are often things in life that are out of your control. *Voicing My CHOICES* gives you a way to express something very important – your thoughts about how you want to be comforted, supported, treated, and remembered.

This booklet was developed based on feedback from young people living with a serious illness. There are no right or wrong ways to answer the items in *Voicing My CHOICES.* You can complete as much or as little of this booklet as you would like. There are boxes to check if you agree with certain items, and there is also space to express your thoughts in your own words.

At the end of the booklet, there are some blank pages. On these pages, feel free to share any additional thoughts and wishes not covered in this booklet. You can also use these pages to write a letter(s) to friends or family members.

Please keep in mind that the topics covered in this book can sometimes be difficult or confusing to think about. Your healthcare providers are available to help explain terms and/or procedures that you may not understand or may have questions about.

Additionally, there is a glossary of terms that may provide clarification for you on page 15. Any term **underlined in blue** throughout this booklet is defined in the glossary.

What Makes Yo

ite What Decisio

eace

Contents

Sometimes people can feel very uncomfortable when they are ill. For example, they might have pain, become sleepy or not feel like themselves. It is important for others to know how you want to be treated and what will make you feel more comfortable, especially if you become very ill and cannot express your wishes on your own.

How I Want To Be Comforted

My Voice

My favorite music/food is:

The kinds of books, stories, or readings I like, are:

Other thoughts I have about treating my pain, or helping to make me comfortable, are:

I would also like:

My Choice

These are a Few of the Comforts Important to Me

If I look like I am uncomfortable in the following ways: *(Please check all that apply)*

I want treatment to help me, if I:

- ☐ Look sad
- ☐ Am irritable/frustrated
- ☐ Look nauseated
- ☐ Look confused
- ☐ Look like I am having a hard time breathing
- ☐ Am cold or hot

If I am in pain, I would like:

- ☐ My doctor to give me enough medicine to relieve my pain, even if that means I will not be awake enough to interact with my friends or family.

Or,

- ☐ To receive medications to reduce my pain but I do not want to be too sleepy or drowsy. I want to be awake enough to interact with my friends and family.

Other things that are important to me are:

- ☐ If I am not able to get to the bathroom in time, please change my clothes and sheets right away so that I am always clean.
- ☐ If friends are coming to visit, please dress me, comb my hair and do whatever else is needed to help make me look like myself.
- ☐ Massages whenever possible as long as they do not cause me discomfort.
- ☐ To be bathed.
- ☐ To have music playing in my room.
- ☐ To have my favorite foods available.
- ☐ To be read to.

Whether you are in the hospital or at home, when you are feeling badly or are very ill, there may be times when you want people around you, or you may prefer to not have visitors present.

How I Would Like To Be **Supported**

So I Don't Feel Alone

My Choice

(Please check all that apply)

☐ I do not want to be alone.
☐ I would like my family to be with me whenever possible.
☐ I would like my friends to be with me whenever possible.
☐ I would like visitors whenever possible.
☐ Please always ask me before visiting.
☐ If I am sleeping when someone comes to visit, I would like to be woken up.

My Voice

The people I want with me are:

I especially want these people with me when:

The things that I would find comforting to have in my room are:

If people are very upset or crying, I would like them to:

☐ Share their feelings with me ☐ Visit me at another time ☐ Other:

When the end of my life is near, I would like:

☐ To die at home ☐ To die at the hospital ☐ Other:

Who I Want to Make My
Medical Care Decisions
If I Cannot Make Them On My Own

There might be a time when you cannot make medical decisions for yourself. If this happens, it might be necessary for someone else to speak with the doctors and make decisions about your medical care. This person, called a healthcare agent, would make sure that your thoughts or wishes are respected.

Things To Consider When Choosing a Healthcare Agent:
It can be helpful to choose someone who knows you well, cares about you, lives nearby, and can make difficult decisions. If you are under the age of 18, your parents/ guardians will have legal rights to make decisions, so the person you recommend can be your parents/guardian or someone you would like your parents/guardians to work with.

Remember:
- Your healthcare agent must be at least 18 years old.
- Your healthcare agent cannot be your doctor or any of your other health care providers, nor can it be an employee of any your **health care providers**.
- To talk to the people you are choosing to make sure that they agree to follow your wishes.

The person(s) I want to make healthcare decisions for me is/are:

Name
Address
Phone

Name
Address
Phone

If this person(s) I chose above are somehow unavailable, others who can make healthcare decisions for me are:

Name
Address
Phone

Name
Address
Phone

I give my health care agent permission to make these choices for me about my medical care or services.
(Please check all that apply)

To allow or refuse:
- ☐ Tests
- ☐ Medicines
- ☐ Surgeries
- ☐ Other care that can help keep me alive
- ☐ Medication(s) or procedure(s) to help with pain
- ☐ Stop previously started treatment
- ☐ Donate usable organs and/or tissue of mine if it can help others

Act on my behalf to:
- ☐ Hire and/or fire any health care worker I may need to take care of me
- ☐ See and approve release of my medical records
- ☐ Apply for **Medicaid**, **Medicare**, or **insurance benefits** for me
- ☐ See my personal files, like bank records, to access necessary information
- ☐ Perform any necessary legal action(s)

Arrange for:
- ☐ Hospital or **hospice** admission
- ☐ Admission to a facility in another state to get the care I need or to carry out my wishes
- ☐ Hospital discharge to take me home

- ☐ My healthcare agent is also allowed to make decisions based on conversation(s) we have had about my wishes and what he/she believes my wishes to be

Other things I wish my health care agent to do are:

The types of Life Support Treatment I Want, or Do Not Want

If a time comes when you are very ill and not able to speak for yourself, it will be important for your health care agent to know whether you would choose to try life-support treatment.

Life-support treatment means any medical procedure, device or medication used to try to keep you alive. It can include: medical devices put in you to help you breathe (tracheotomy/mechanical ventilation); an artificial pacemaker to help maintain your heart-beat; food and water supplied by medical device (tube feeding); cardiopulmonary resuscitation (CPR); major surgery; blood transfusions; dialysis; antibiotics; blood pressure medications and anything else meant to keep you alive.

In place of life-support treatment, you may make the decision to allow a natural death, in which life-support treatments that prolong the dying process are not used, and everything possible is done to provide comfort and support.

If my doctor and another health care provider both decide that I am **close to death** and likely to die within a short period of time, and life support treatment would only delay the moment of my death:

- ☐ I want to have a natural death
- ☐ I want to try life support treatment if my doctor believes it could help my symptoms
- ☐ I want to try life support treatment no matter what

If my doctor and another health care provider decide that I have **permanent and severe brain damage** and I am not expected to get better, and life support treatment would only delay the moment of my death:

- ☐ I want to have a natural death
- ☐ I want to try life support treatment if my doctor believes it could help my symptoms
- ☐ I want to try life support treatment no matter what

Describe here if you want to have certain forms of life-support treatment, but not others, or if you wish to state other conditions in which you would want, or not want, life-support treatment:

Other decisions I would like respected:

What I Would Like **My Family and Friends to Know** About Me

My Choice

It is important to me that my family/friends:

- ☐ Get along
- ☐ Take care of themselves
- ☐ Take care of one another
- ☐ Respect my wishes, decisions and choices even if they don't agree with them
- ☐ Get counseling or find a support group for themselves and/or my siblings if they are having a hard time

My Voice

I want my family to know that I am thankful for their love and support. I am especially thankful for:

I want my friends to know that I am thankful for their love and support. I am especially thankful for:

If I have hurt or upset any of my friends, family or others, I wish to be forgiven for:

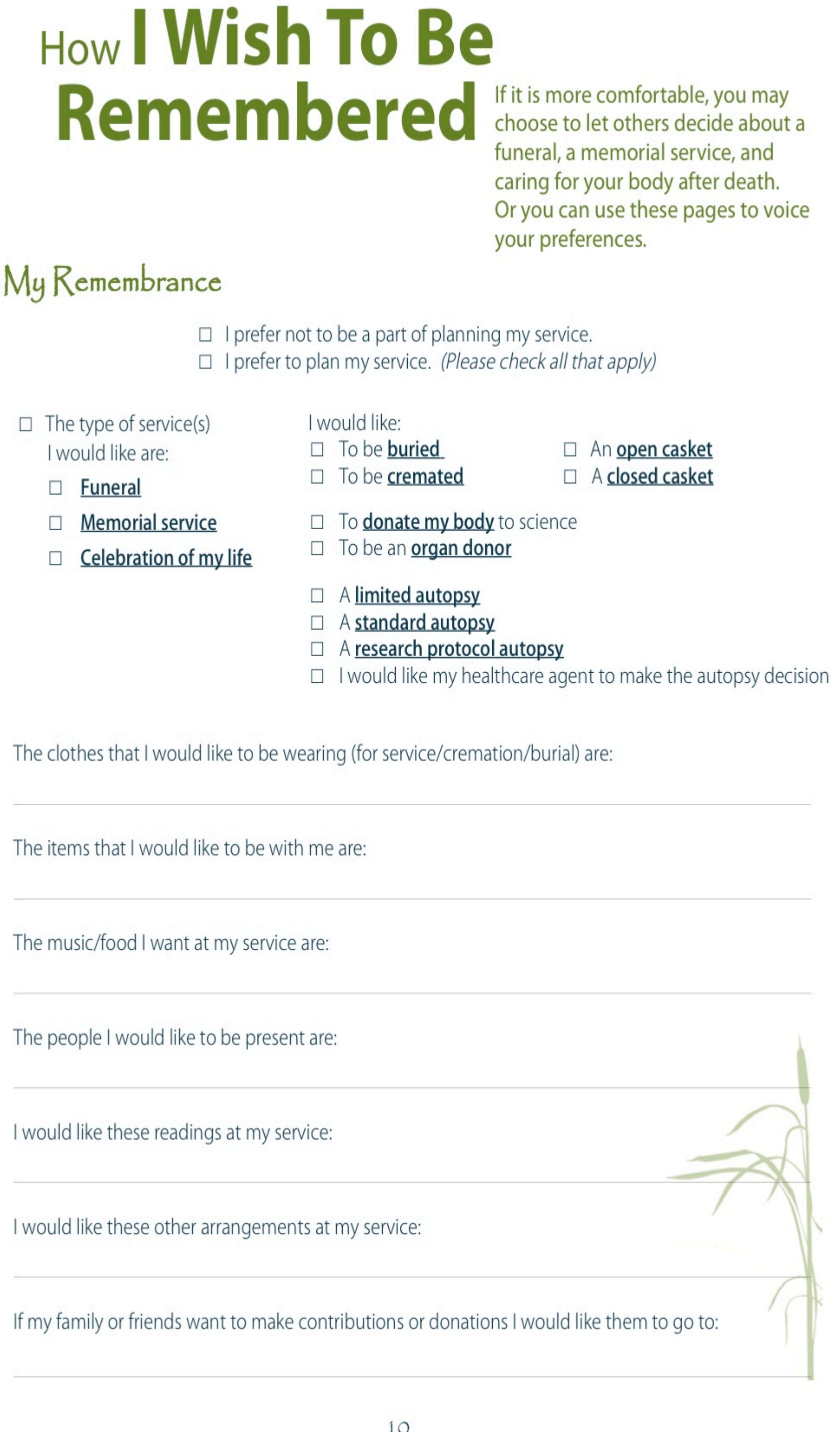
When I have been hurt or upset by my family, friends, or others, they should know I forgive them for:

These are the things that are important to know about me:

The things that give me strength are:

The things that give me joy are:

Emphasis on identity, present/ future. Preserve what is important to them today and how they wish to be remembered in the future.



How I Wish To Be Remembered

If it is more comfortable, you may choose to let others decide about a funeral, a memorial service, and caring for your body after death. Or you can use these pages to voice your preferences.

My Remembrance

☐ I prefer not to be a part of planning my service.
☐ I prefer to plan my service. *(Please check all that apply)*

☐ The type of service(s) I would like are:
- ☐ Funeral
- ☐ Memorial service
- ☐ Celebration of my life

I would like:
☐ To be buried
☐ To be cremated
☐ An open casket
☐ A closed casket

☐ To donate my body to science
☐ To be an organ donor

☐ A limited autopsy
☐ A standard autopsy
☐ A research protocol autopsy
☐ I would like my healthcare agent to make the autopsy decision

The clothes that I would like to be wearing (for service/cremation/burial) are:

The items that I would like to be with me are:

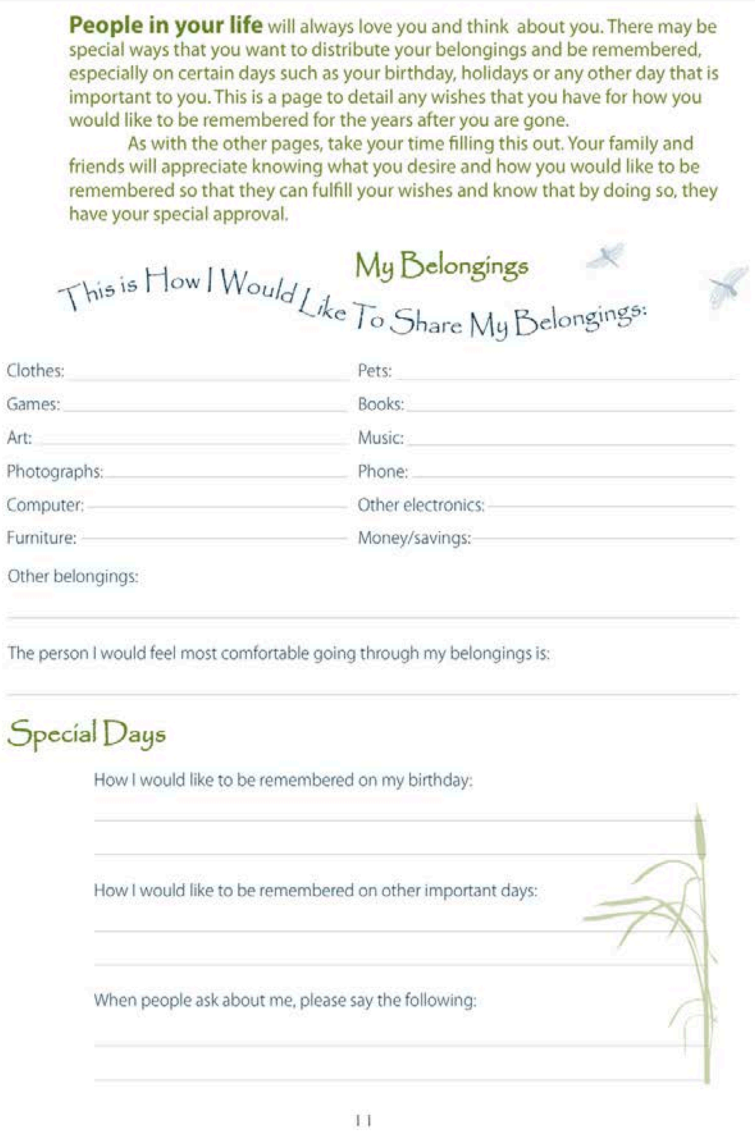
The music/food I want at my service are:

The people I would like to be present are:

I would like these readings at my service:

I would like these other arrangements at my service:

If my family or friends want to make contributions or donations I would like them to go to:



People in your life will always love you and think about you. There may be special ways that you want to distribute your belongings and be remembered, especially on certain days such as your birthday, holidays or any other day that is important to you. This is a page to detail any wishes that you have for how you would like to be remembered for the years after you are gone.

As with the other pages, take your time filling this out. Your family and friends will appreciate knowing what you desire and how you would like to be remembered so that they can fulfill your wishes and know that by doing so, they have your special approval.

My Belongings

This is How I Would Like To Share My Belongings:

Clothes:
Games:
Art:
Photographs:
Computer:
Furniture:

Pets:
Books:
Music:
Phone:
Other electronics:
Money/savings:

Other belongings:

The person I would feel most comfortable going through my belongings is:

Special Days

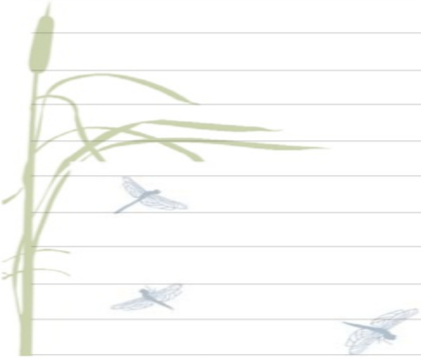
How I would like to be remembered on my birthday:

How I would like to be remembered on other important days:

When people ask about me, please say the following:

My Voice

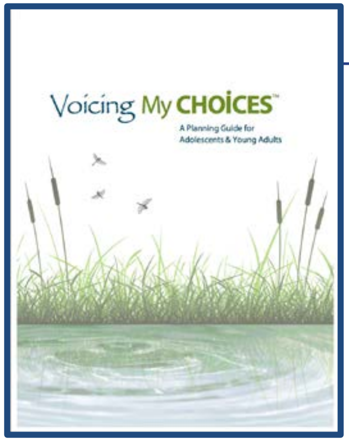
This is a space to write messages and/or letters to loved ones.



The glossary was developed to help clarify terms in language an AYA could understand.

Glossary

Artificial Pacemaker	A small battery-operated mechanical device, which uses electrical impulses to keep the heart beating regularly. They can be internal (surgically implanted) or external (attached with wires to the skin). Pacemakers are usually only for temporary use.
Autopsy	A standard autopsy is a medical procedure that consists of a thorough examination of your body to determine the specific cause of death or to evaluate any disease or injury. There are 3 types of autopsies: 1) a limited autopsy (a specific part of the body or body system); 2) a full autopsy (studies most organs); and 3) a Research Protocol Autopsy (conducted for research purposes).
Blood Transfusion	The process of transferring blood or any of its components into the bloodstream of a person who has lost blood because of illness, an accident or surgery.
Body/Tissue Donation	You can choose to donate either your whole body, or some of your tissue for medical research and education after death.
Brain Damage	An injury to the brain caused by trauma to the head, infection, hemorrhage (bleeding), inadequate oxygen, or other complications, which results in significant loss in brain functioning or consciousness.
Burial	The act of placing a body into its final resting place. An urn or special container can be used to store remains from cremation.
Cardiopulmonary Resuscitation (CPR)	An emergency procedure performed on a person who has no pulse and has stopped breathing. CPR consists of external cardiac massage and artificial respiration (breathing) in an attempt to restore circulation of the blood and prevent death or brain damage.
Celebration of My Life	A gathering of your family/friends that is planned to honor and celebrate your life. Some choose to have a gathering yearly or just once after their death.
Closed Casket	When the casket is closed at a funeral so that those present do not view the body.
Coma	A state of unconsciousness, lasting more than 6 hours, in which a person cannot be awakened, fails to respond to external stimuli, including pain and light, lacks a normal sleep-wake cycle, and does not initiate voluntary actions.
Cremation	The process of reducing the body by intense heat. Cremated remains are typically placed in a container (urn) and can be placed or buried at memorial sites or kept by relatives/friends. If you choose to be cremated, it is still possible to have a viewing of your body (open casket) before the cremation process.
Dialysis	A medical treatment in which an artificial filtering system removes waste from the blood, performing the functions of the kidneys if they are not working.
Feeding Tubes	A medical device used to provide nutrition to patients who cannot obtain nutrition on their own.
Funeral	A ceremony used to mark a person's death. A person's body is typically at the funeral.
Healthcare Agent	The person chosen, legally named, or designated under state law to make healthcare decisions on behalf of a person who is no longer able to make his or her own decisions.
Healthcare Providers	A person or organization that provides healthcare in any way, including: doctors, nurses, administrators, and other staff who are affiliated with your care or your care facility.
Hospice	An organization or facility that provides care for the terminally ill focused on palliation (comfort) when curative treatment is no longer an option. Hospice care involves medical care, pain management, and emotional/spiritual support. It can be provided inpatient or outpatient and focuses on maintaining quality of life and symptom control.
Insurance	A program used to assist with costs of healthcare.
Insurance Benefits	Payments or compensation provided to assist with costs of healthcare.
Life-Support Treatment	Any treatments used to maintain the vital functions of the body in order to sustain the life of someone who is critically ill or injured.
Mechanical Ventilation	The medical procedure used to aid or replace breathing when someone is unable to breathe on his or her own. A machine called a ventilator forces air into the lungs via a tube that is inserted in the nose or mouth and down the windpipe.
Medicaid	A federal system of health insurance for those requiring financial assistance.
Medicare	A federal system of health insurance for people over age 65, or qualified young people with disabilities.
Natural Death	When life-support treatments are not used and everything possible is done to provide comfort and support.
Memorial Service	A service or ceremony performed to honor a deceased person. The body or cremated remains are typically not present. More than one memorial service can be held.
Open Casket	When the casket is left open during a funeral in order to allow for a viewing. A mortician at the funeral home will prepare and dress the body for viewing.
Organ Donation	The removal of the tissues (organs) of the body from a person who has recently died to a living recipient in need of a transplant.
Tracheostomy	A surgical operation that creates an opening into the trachea (windpipe) with a tube inserted to provide a passage for air in order to help someone breathe.



Voicing My CHOICES™

A Planning Guide for Adolescents & Young Adults

The New York Times

Sunday, March 29, 2015 | Today's Paper | Video | 45°F | Nasdaq +0.57%

Teenagers Face Early Death, on Their Terms

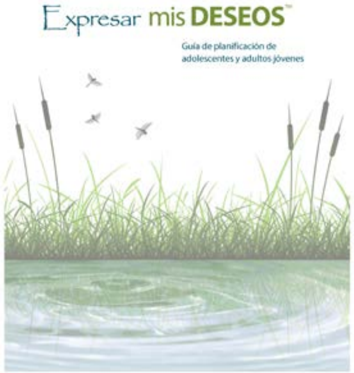
By JAN HOFFMAN

A national push and a new guide are giving critically ill young patients a voice in end-of-life discussions.

- Comments
- Video: Before I Die

Voce alle Mie SCELTE™

Una Guida alla Pianificazione per Adolescenti e Giovani adulti



Expresar mis DESEOS™

Guía de planificación de adolescentes y adultos jóvenes

Where Are We Now?

Youth with serious illness:

- Contemplate EoL issues
- Wish to participate in decisions
- Can effectively talk about death **if** given the proper format and a supportive environment
- Want a **developmentally appropriate** document to help them decide **how**, **where, with whom** and **how actively** they would like to be treated and **remembered** after they are gone

Future Empirical Research Is Needed

Does VMC improve patient outcomes?

Help with conversations around EoL decision-making?

Increase congruence between patients and families or their HCP?

Appropriate for older YA or those with children?

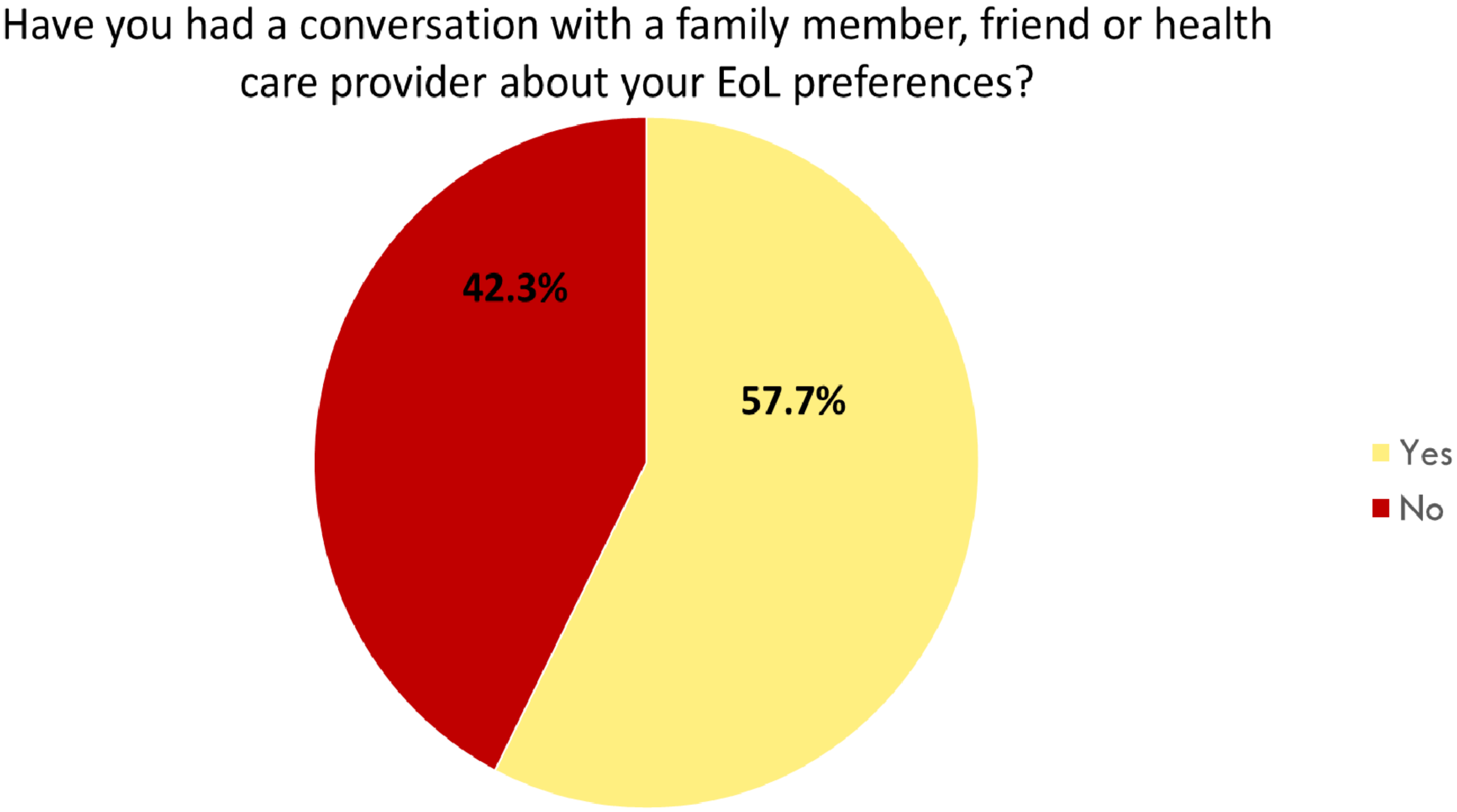
Voicing My CHOiCES™ as a Tool for Advance Care Planning

Primary Objectives

- To determine whether engaging in advance care planning using VMC is associated with **reduced anxiety**, **improved social support**, **increased acceptance of illness**, and/or **improved communication** with family, friends, and/or health care providers.

Study is currently open at NIH, Cook Children's Medical Center, Children's National Medical Center, CHOC, Dana Farber Cancer Institute, Moffit, UNC, University of Miami

Are AYA Having ACP Discussions?



N=72
18-39, mean=25.9

Why conversations don't happen?

…doctors always seem too busy. They come in and out so quickly. They never seem to want to talk about anything but what is needed for me to do that day.

I've tried, but my parents won't discuss it with me.

I haven't brought it up with friends. I never talk to them about these issues.

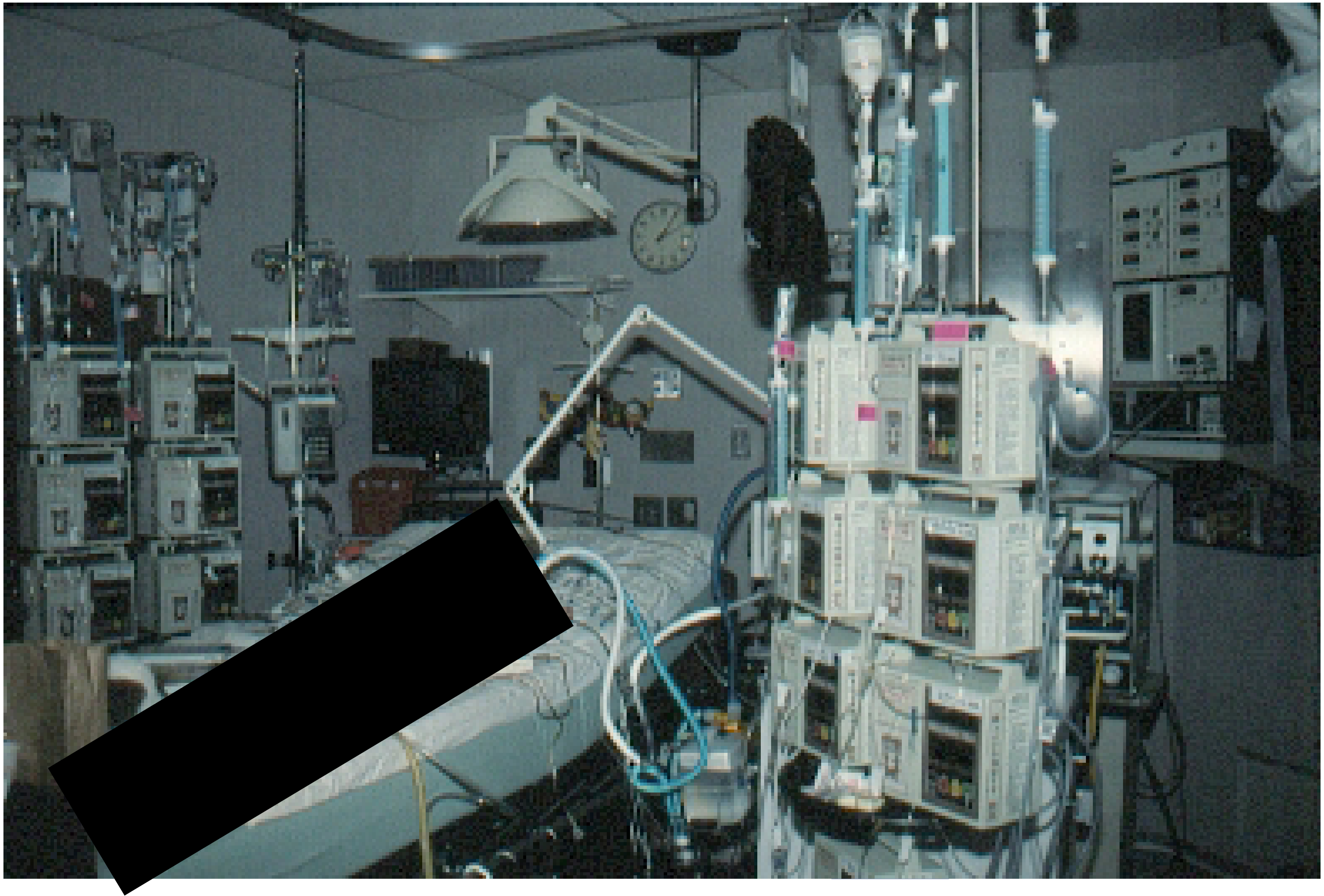
They aren't as concerned with the psychiatric or emotional side of my care.

I do not want to burden them.

I don't want people to think that I am miserable. It's not a situation that others can understand. I want them to think I am ok.

🟦 Family 🟩 Friend 🟧 Provider

What about when communication is AVOIDED?



[redacted]

HOW To Approach ACP

- **Develop a Systematic Approach and Use it Consistently**
  - A standardized message to implement consistently.

- **Team Approach**
  - Introduced by a member of the healthcare team who:
    - Has a trusting relationship with the AYA and their family to talk frankly about EoL without it being portrayed as loss of hope.
    - Maintains familiarity with specific physical, psychosocial, cultural and spiritual needs.

Weissman, 1998; Prendergast, 2001; Emanuel et al., 2004

WHEN To Approach ACP

- **Identify time points at which a patient's wishes and goals are discussed**
  - i.e., start of treatment, time of relapse, etc.
  - When the patient is relatively stable and not in a crisis.
  - Prognosis is not necessary to initiate the discussion.

- Remind families that communicating about EoL does not reflect a loss of hope
  - rather it informs the patient/family that the health care providers wish to **respect** individual wishes.

aspho
The American Society of
Pediatric Hematology/Oncology

Sponsoring Societies:
The American Society of Pediatric Hematology/Oncology
The International Society of Paediatric Oncology

SOCIÉTÉ INTERNATIONALE
D'ONCOLOGIE PÉDIATRIQUE
SIOP
INTERNATIONAL SOCIETY
OF PAEDIATRIC ONCOLOGY

Pediatric Blood & Cancer

Standards for Psychosocial Care for Children with Cancer and their Families

EDITOR-IN-CHIEF

PETER E. NEWBURGER, M.D.

SPECIAL ISSUE EDITORS

Standard: Palliative and End of Life Care

"Youth and their families should be introduced to palliative care concepts to reduce suffering throughout the disease process regardless of disease status."

Evidence from 36 Studies Support this Standard

Comprehensive Cancer Care for Children and Their Families

Summary of a Joint Workshop
by the Institute of Medicine
and the American
Cancer Society

Palliative care no longer means helping children die well;

It means helping children and their families live well and,
then,

When the time is certain,
helping them die gently.

Mattie Stepanek
July 17, 1990 – June 22, 2004

Leaving a legacy is a human need.

Help your patients plan
by asking what is most important to them.

It is the gift that keeps on giving.


THE GALLERY
B I N G O
JOE COOL

- https://www.agingwithdignity.org/latest/latest-news/2016/04/14/tara's-story

AYA ONCOLOGY PSYCHOSOCIAL ISSUES

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The Johns Hopkins Hospital
Ulman Cancer Fund for Young Adults
November 10, 2017

Objectives

- Understand unique psychosocial needs of AYA's with cancer
- Discuss how certain psychosocial issues may manifest in the health care and pediatric cancer camp environments.
- Identify clinical/programmatic interventions that may be able to better support this patient population.

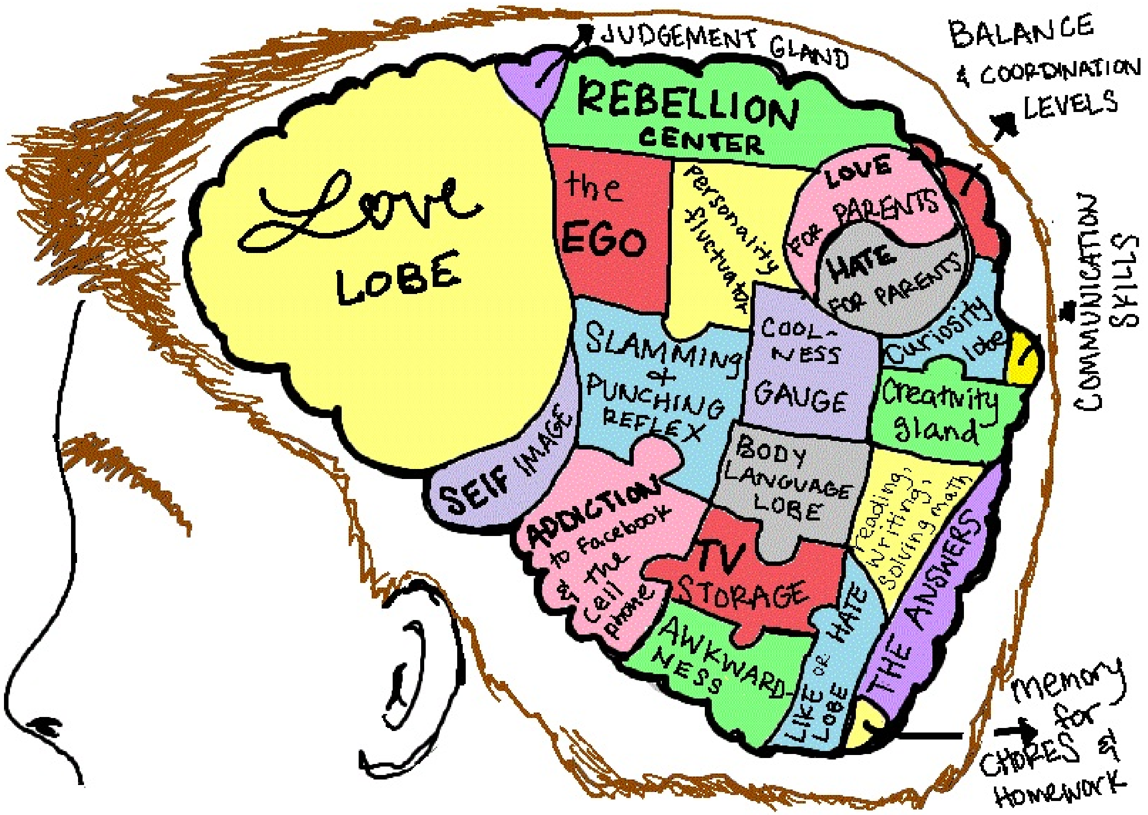
My Role

- Partnership between Ulman Cancer Fund for Young Adults and Johns Hopkins
- Support patients primarily of the ages of 15 to 25 who are in active treatment
- Strive to improve patient care through institutional initiatives (e.g. AYA Work Group, Fertility Preservation Protocol)
- Knowledge of AYA-related resources

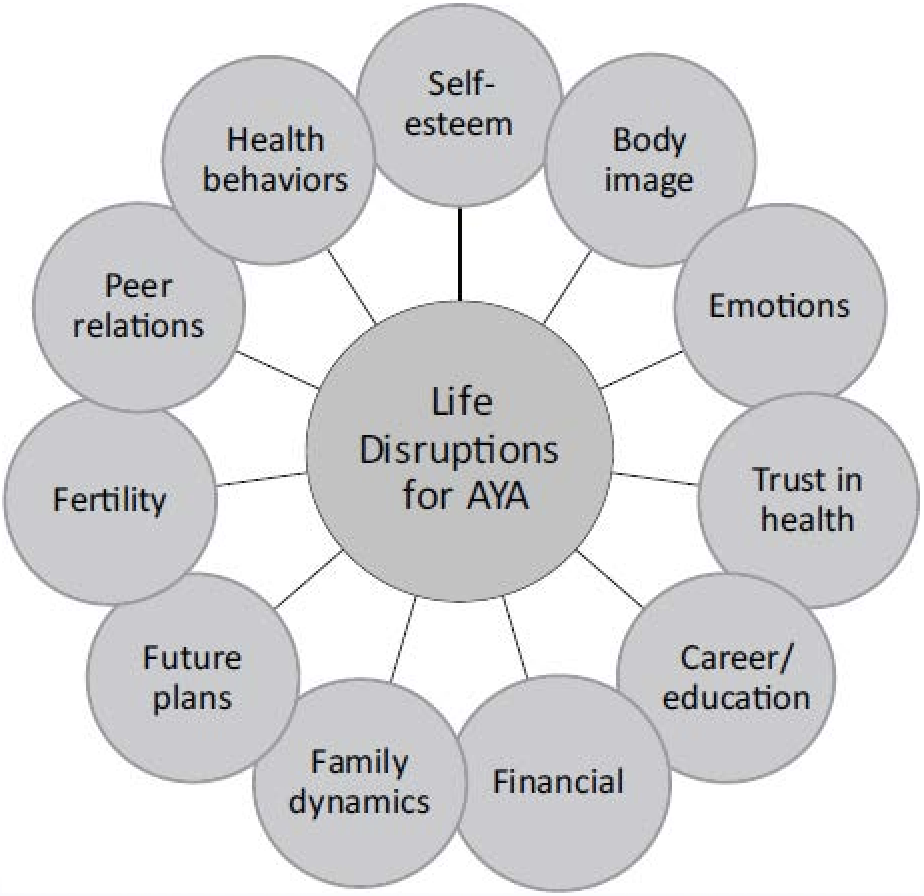
AYA Development

- Period of **Growth, Change and Instability**
- More independent
- Emphasis on establishing relationships (peer and romantic)
- Developing career goals
- Exploring sexuality
- Forming their own worldview
- Personal identity developing
- Engagement with parents decline
- Wide range of functioning within the population

AYA Cognitive Development



Cancer-Related Challenges



Life Disruptions for AYA

- Self-esteem
- Body image
- Emotions
- Trust in health
- Career/ education
- Financial
- Family dynamics
- Future plans
- Fertility
- Peer relations
- Health behaviors

(Institute of Medicine, 2013)

Clinical techniques for Providers

- Promote self-awareness: Help adolescents / young adults identify emotions
- Focus on what a patient "can do" versus "can't do." Follow up about when limitations may be removed.
- General counseling strategies
  - Empathy, listening, reflection
- Behavioral strategies
  - Whatever you pay attention to will increase
  - Whatever you ignore will decrease
- Motivational strategies
  - Promote behavior change through skills that build insight into discrepant behaviors "help me understand how taking your chemotherapy whenever you feel like is helping you achieve your goal of survival"
- Mindfulness strategies
  - Focus on present moments with calm awareness of thoughts, feelings

Anna George, PsyD, The Johns Hopkins Hospital, 2016

Institutional Recommendations

- Identify internal champions of AYA Oncology Care
- Create a work group of multi-disciplinary providers to address gaps in health care system
- Provide education and training to health care providers about AYA-Oncology topics.
- Psychosocial providers to regularly assess and support AYA patients with potential barriers to treatment (e.g. mental health, financial, child care, housing).
- Importance of MULTI-DISCIPLINARY TEAM approach (e.g. chaplain, fertility specialist, palliative care, dietitian)

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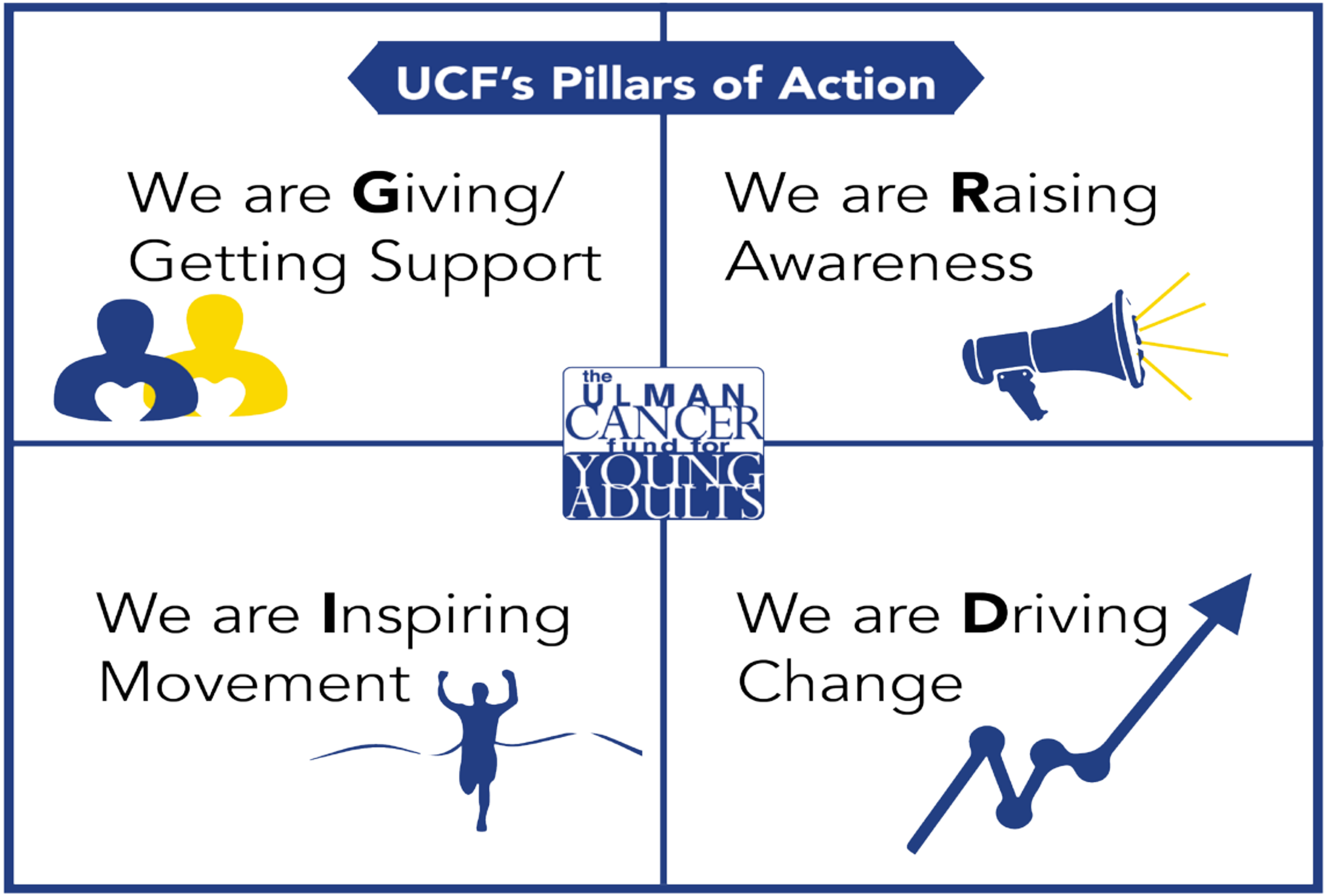
Building a “Home Away From Home” for Young Adults & Families Facing Cancer

Brock Yetso, MBA, President and CEO, Ulman Cancer Fund for Young Adults



UCF's Pillars of Action

We are **G**iving/ Getting Support

We are **R**aising Awareness

We are **I**nspiring Movement

We are **D**riving Change

The Unique Problem

- More and more young adults are coming to Maryland for life saving treatment
- Young adults are receiving more aggressive and lengthier treatment protocols that require overnight stays
- Shortage of affordable and age specific long-term for young adult patients and families

The Novel Approach

The UCF House:

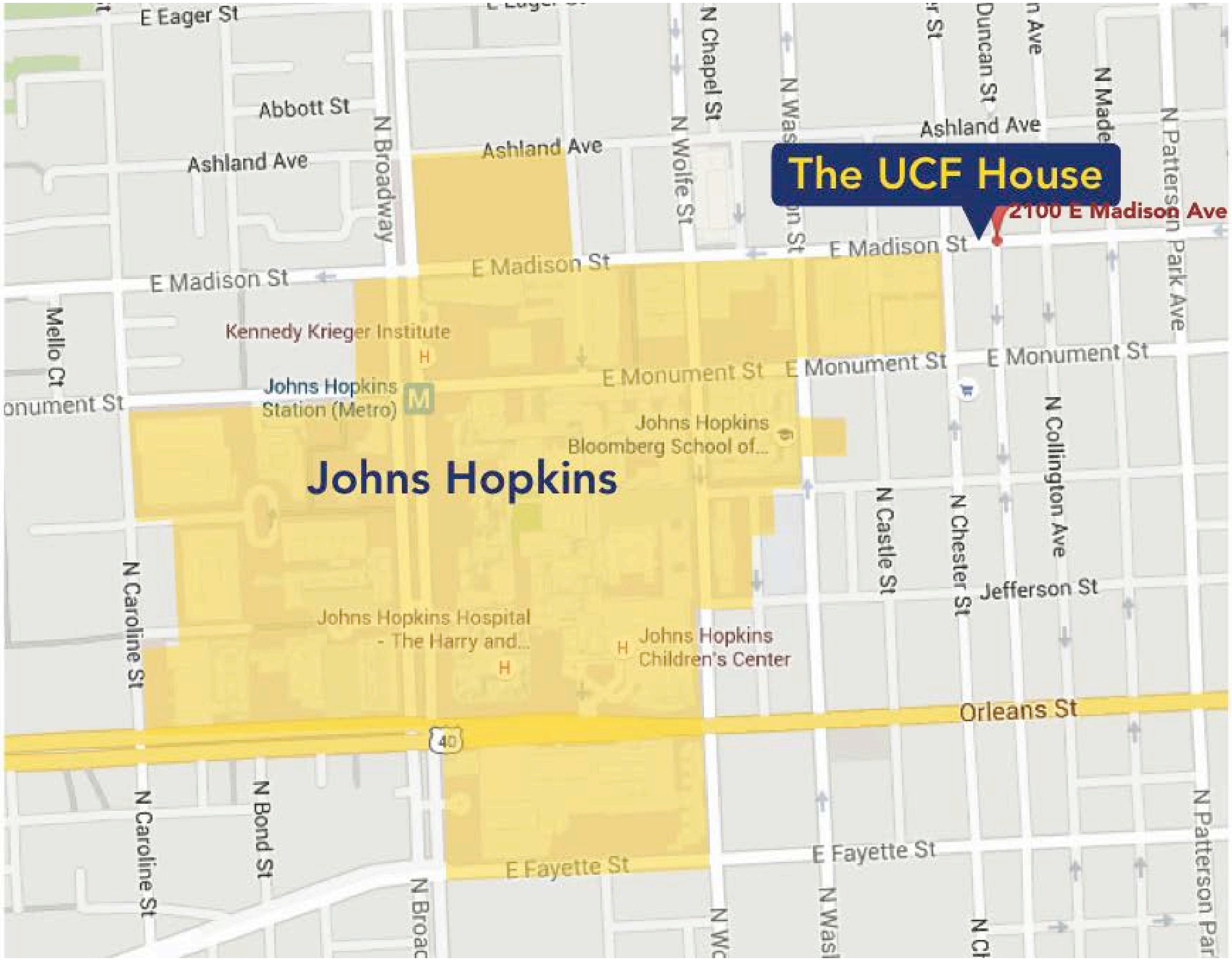
A Home Away from Home for Young Adult Cancer Patients and Families

8 Family suites for patients & caregivers

Communal living/dining, outdoor space, wellness/fitness space

Expected to serve 200 families in need each year

Open 24/7/365



The UCF House

2100 E Madison Ave

Johns Hopkins

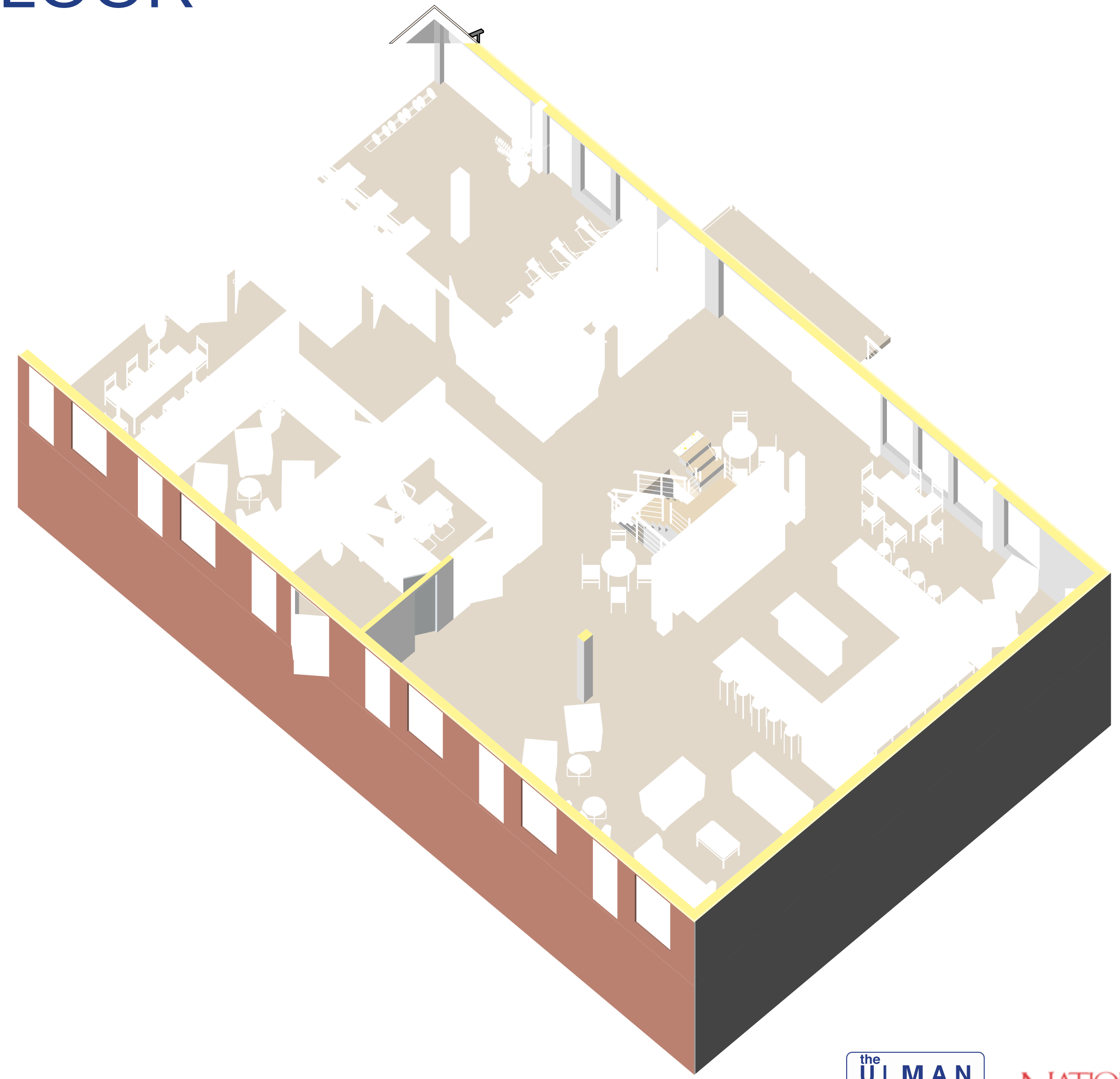
CURRENT FACADE

FUTURE FACADE CONCEPT

FUTURE FACADE CONCEPT

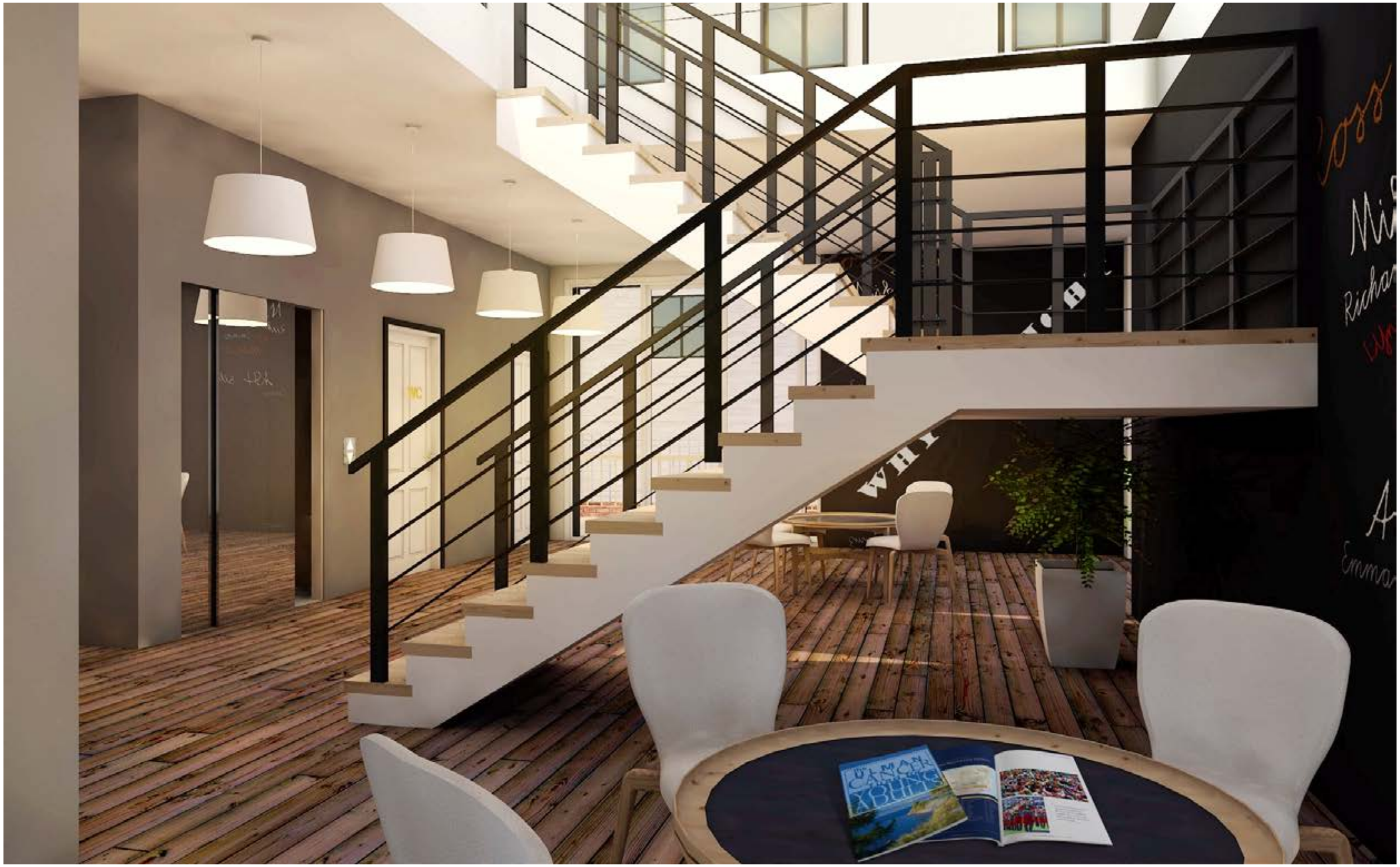
1ST FLOOR

CHICAD EDUCATION VERSION



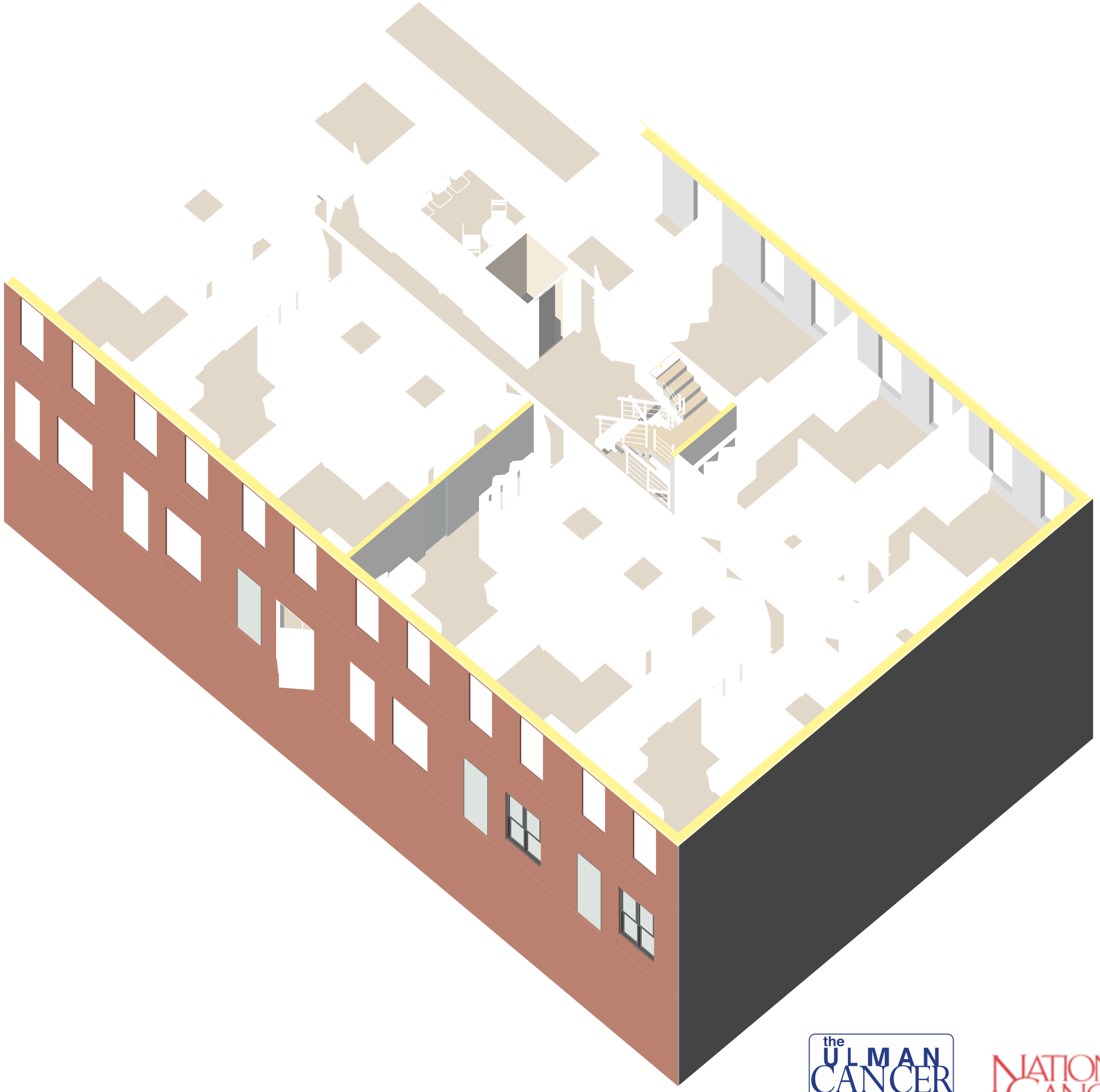
1ST FLOOR

1ST FLOOR



2ND FLOOR

RCHICAD EDUCATION VERSION



FUTURE BEDROOM SUITE CONCEPT

FUTURE WORKOUT ROOM CONCEPT

FUTURE PATIO CONCEPT

Anticipated Impact & Status

- 1,200 sq. ft. facility
- 300 unique patients/families every year
- Community Development & Economic Impact
- Construction and Q3 2018 completion and opening

Thank You & Questions

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