Overview of Cancer Survivorship in AYAs

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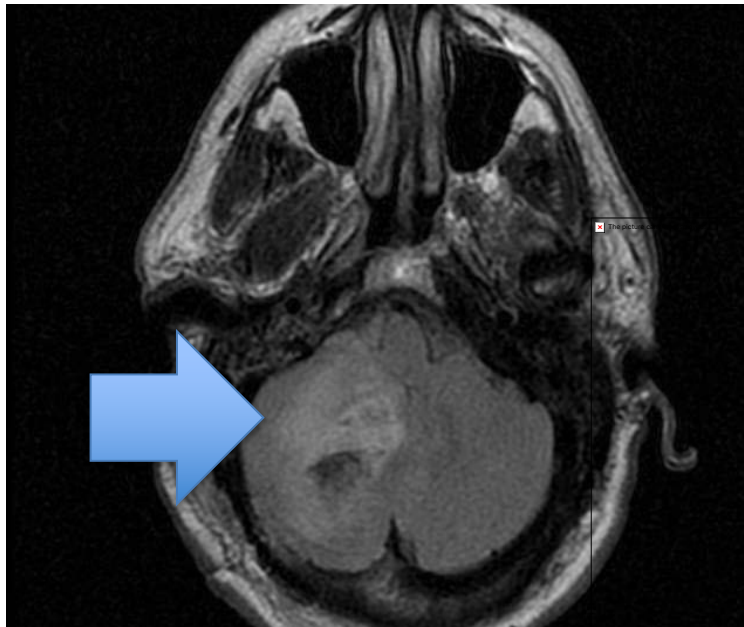jcancersurvivorship@gmail.com

Overview

- Patient and researcher perspective

- Cancer Survivor: Case definitions

- AYA Cancer Survivor: Case definition

- "Global" burden of AYA Cancer Survivors

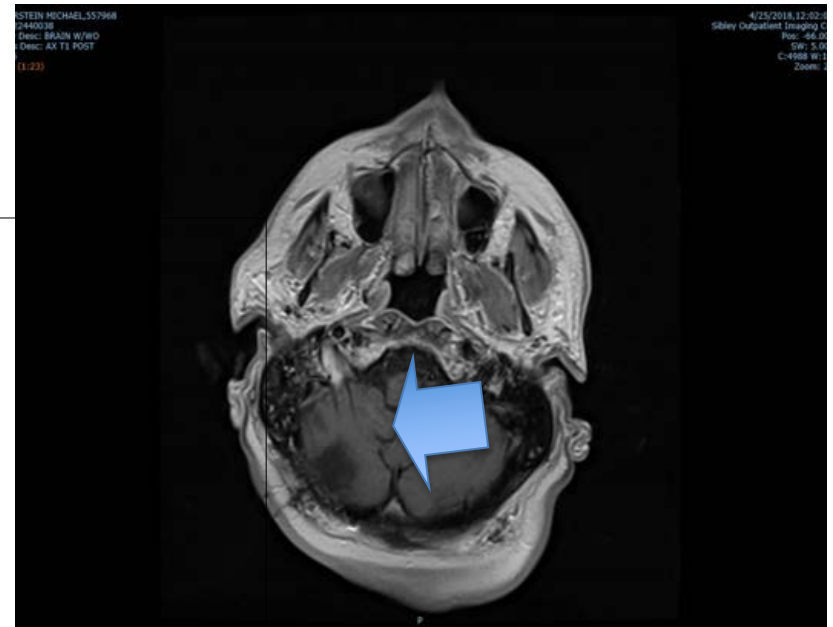- Concerns of AYA Cancer Survivors *"in their own words"*

Personal and Research Perspectives
Anaplastic Astrocytoma: Grade III

At Diagnosis- 6/03

At year 15- 4/18

Who is an "adult" cancer survivor?

- **Classic/Traditional**
  - Period after diagnosis and during primary treatments
  - Patients focused on dealing with the physical and psychological consequences after completion of treatment
  - Period when patients are living with cancer as a chronic disease or when individuals are in remission
  - Mullan, NEJM, 1985

- **NCI-General**
  - One who remains alive and continues to function during and after overcoming cancer
    - From the time of diagnosis to the end of life.
    - https://www.cancer.gov/publications/dictionaries/cancer-terms/def/survivor 2019
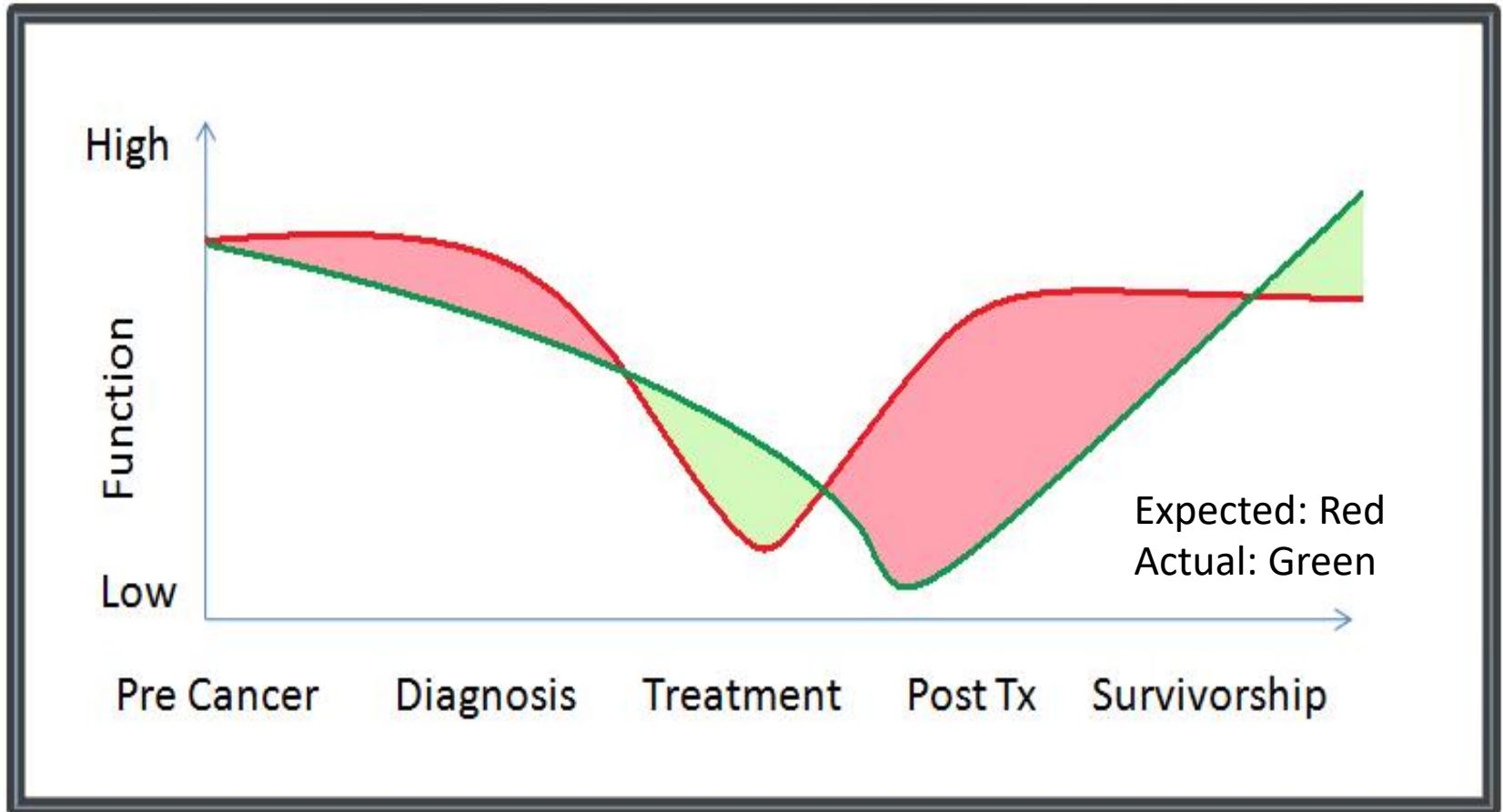
- **NCI- Office of Cancer Survivorship**
  - Survivorship
    - Health and life of a person with cancer post treatment until the end of life.

- **WHO**
  - Survivorship care-after active treatment for cancer
    - Surveillance plan- monitor cancer recurrence or spread
    - Follow up and management-health problems related to cancer diagnosis and treatment
    - Evaluate development of new cancers
    - https://www.who.int/cancer/treatment/en/ 2019

Cancer Survivorship

Feuerstein, 2004

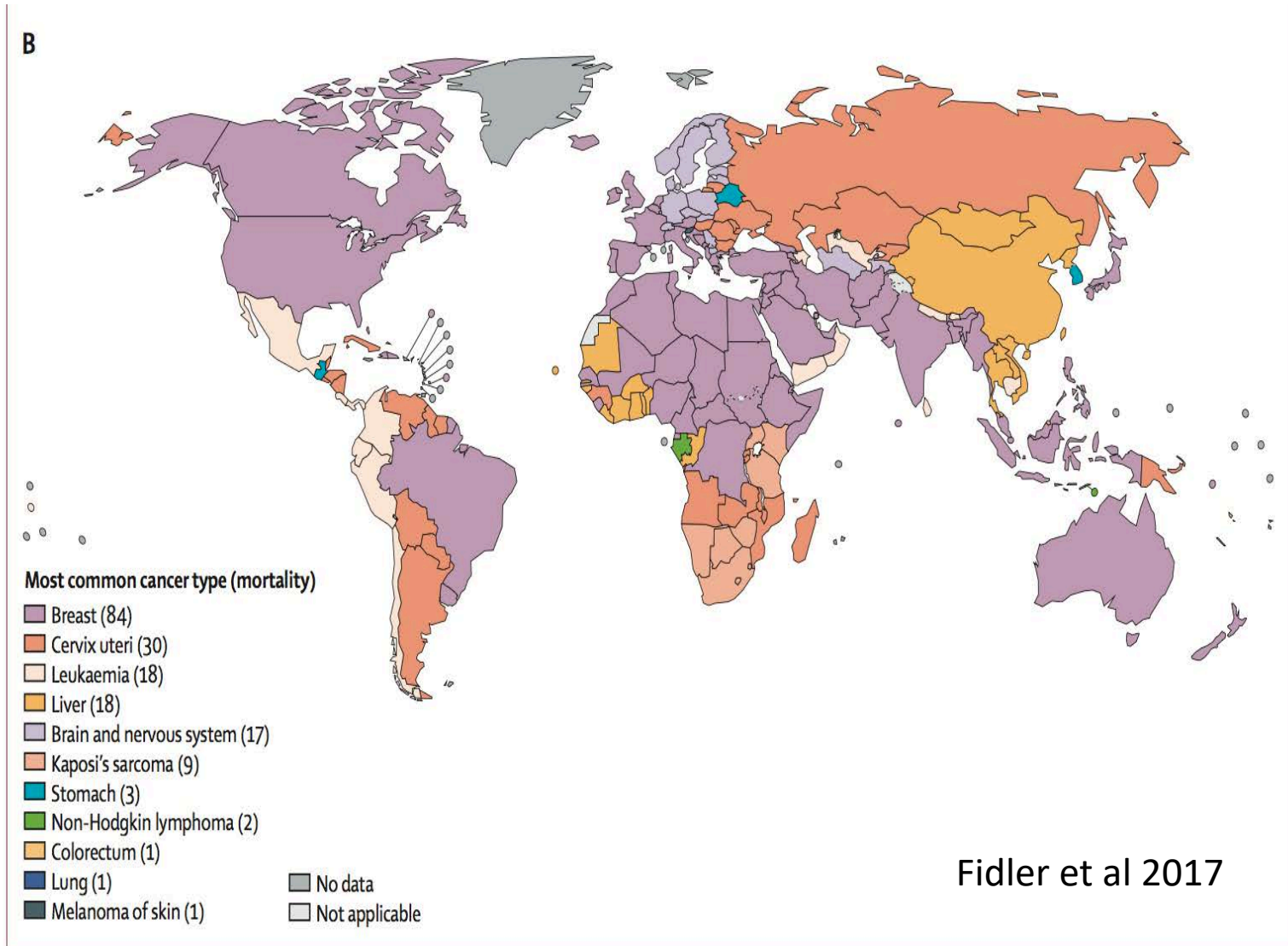# Who is an "AYA" Cancer Survivor?

AYA -adolescent and young adult
*cancer care **or** research focused
on those diagnosed with cancer
between the ages of **15 to 39
years old***

US National Cancer Institute , 2019

Two common views on AYA Cancer Survivors

- ***Developmental*** Aubin 2011
  - Early young adulthood 15-18
    - individuation
  - Young adulthood 19-24
    - flux social/sexual experimentation, dating, academic goals
    - Full maturation frontal lobes (early-mid 20s
  - Late young adulthood 25-39
    - Settling down, consolidation of existential goals, starting a family, caring for young children, maintaining couple relationship, further career to achieve financial autonomy

- ***Bio-psychosocial/ Contextual*** Barr 2011
  - Age range , 15-39 NIH and SEER
  - Important to consider context (variability)
    - developmental age, psychosocial circumstances but also **underlying biology of the malignant disease being treated**
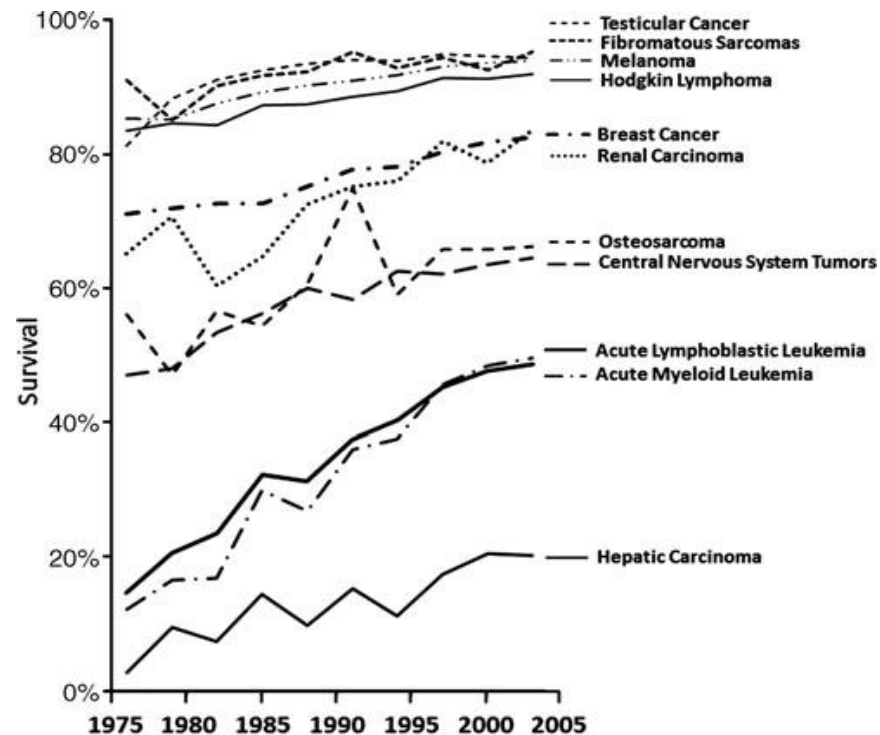
Cancer Incidence: Country (20-39 yo)

B

Most common cancer type (mortality)
- Breast (84)
- Cervix uteri (30)
- Leukaemia (18)
- Liver (18)
- Brain and nervous system (17)
- Kaposi's sarcoma (9)
- Stomach (3)
- Non-Hodgkin lymphoma (2)
- Colorectum (1)
- Lung (1)
- Melanoma of skin (1)
- No data
- Not applicable

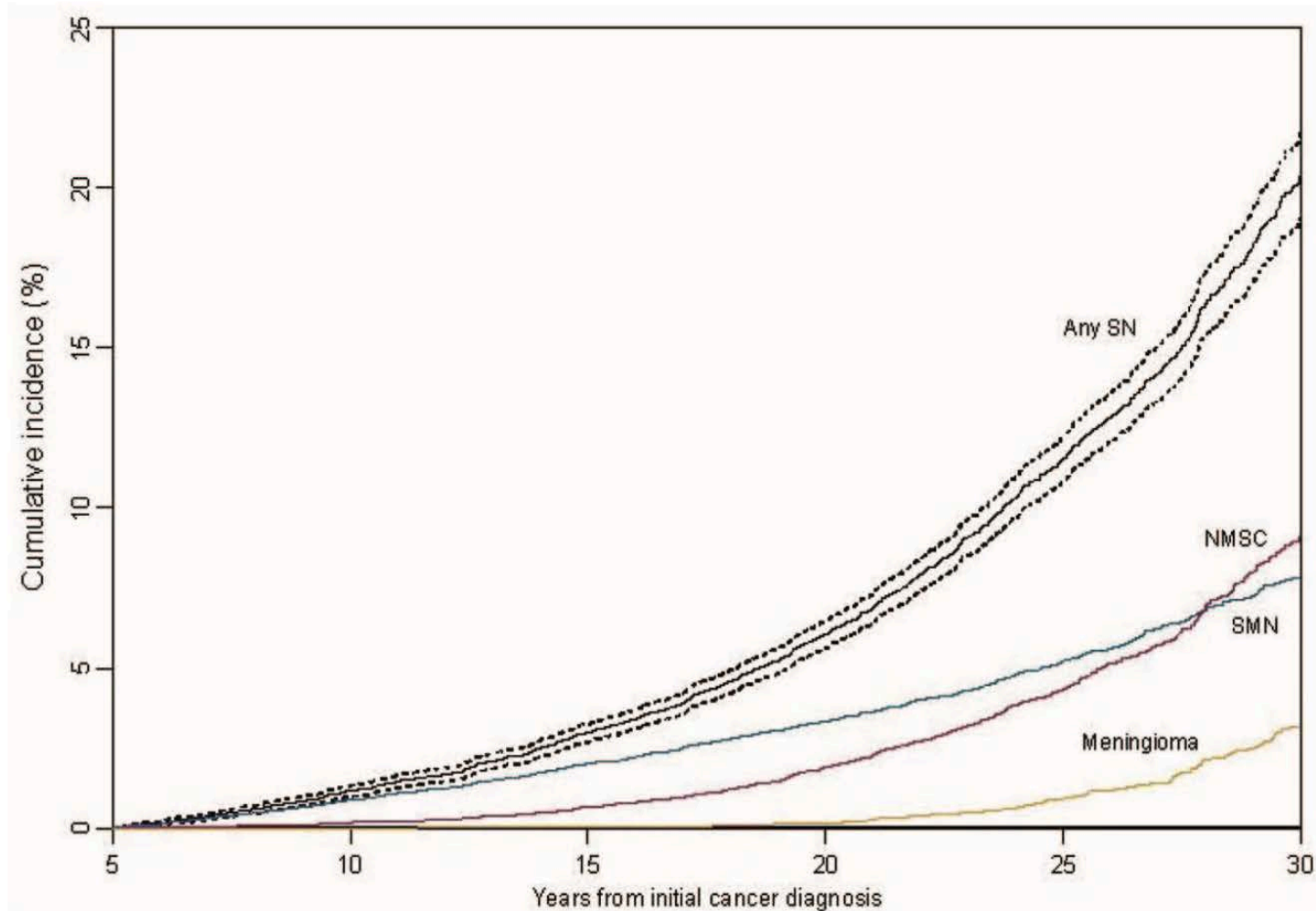Fidler et al 2017

Survival rates of Common Cancers in AYA in US Bleyer, 2011

Based on data from the Surveillance Research Program, NCI SEER*Stat software (www.seer.cancer.gov/seerstat) version 6.4.4, SEER9, SEER13 and SEER17, accessed January 29, 2011

Cumulative Incidence of Second Cancers in the Childhood Cancer Survivor Study
Friedman et al 2017

SN=subsequent neoplasm, **NMBC**=non-melanoma skin cancer, **SMN**=subsequent malignant neoplasm

Neurocognitive outcomes in long-term (29 yrs post diag) survivors of Wilms tumor

Table 4. Cognitive outcome associated to HRQOL and social attainment

Separate models for each cognitive variable and each outcome variable. Generalized linear models for HRQOL outcomes, logistic regression models for social attainment; reference category least favorable outcome (<college graduate, household income <$40000/year). **Bold type** indicates p<0.05

	Education College graduate or higher		Household income		SF-36 Social functioning		SF-36 Mental health	
	OR	**P-val**	**OR**	**P-val**	**Est.**	**P**	**Est.**	**P**
Verbal reasoning	**2.23**	**<0.001**	**1.59**	**0.029**	0.11	0.17	0.12	0.15
Word reading	**3.47**	**0.0025**	**2.82**	**0.024**	0.11	0.47	0.25	0.12
Mathematics	**2.55**	**<0.001**	**1.74**	**0.050**	0.098	0.33	0.17	0.11
Sustained attention, CPT variability	**1.59**	**0.0067**	1.12	0.51	0.11	0.12	0.10	0.14
Long-term verbal memory CVLT LD	**1.35**	**0.045**	1.24	0.23	**0.21**	**0.002**	**0.27**	**<0.001**
Initiation: verbal fluency FAS	1.289	0.14	1.04	0.86	0.081	0.32	0.13	0.14

Time since diagnosis=29 yrs, , SD=9.1 vs. Community controls

Olson et al, JCSU, in press (St Jude Lifetime Cohort)

Health Outcomes in Asian Survivors of Childhood Cancer

Poon et al *J Cancer Surv,* in press

Methods

- – 213 abstracts reviewed
- – 81 full text reviewed
- 59 quality studies, k=.82 n=13,442 survivors
- Japan, South Korea, Hong Kong, Taiwan, Singapore, Thailand, Malaysia, mainland China (7 studies, 12%)

Outcomes

- Neurologic, neurocognitive 20%
- Endocrine, metabolic, growth, fertility 19%
- Cardiac 15%
- Secondary malignancy 12%
- Other-dental, hepatic, renal, immunological, multiple organ systems

Psychosocial Concerns of AYAs

Team=pediatric oncologist, library scientist, OT, psychologist, AYA communication specialist

Wong et al. 2017

Methods

Extracted papers in peer reviewed GLOBAL literature (n=1324 AYAs)

Entered text verbatim into nVivo Software

Conducted line by line text coding (nVivo)

Identified "descriptive themes" n=3 "subthemes" n=13 with consensus

Computed prevalence of themes/subthemes

Generated an AYA -survivor specific reported measure- concerns in AYAs based on their own words

Outcomes

Themes (n=3)

Health and health care

Communication and relationships

Life role

Subthemes (n=13)

Emotional well being

Health care system

Health management

Reproductive health

Symptoms

Function

Social interactions

Cancer disclosure

Romantic relationships

Normalcy

Career development and employment

School

Fiscal concerns