

SESSION 2: UNIQUE RISKS & VULNERABILITIES OF AYA PATIENTS ACROSS THE LIFESPAN

LIVESTRONG Foundation: AYA Survey Results

Ruth Rechis, PhD
Director, Research & Evaluation
July 2013

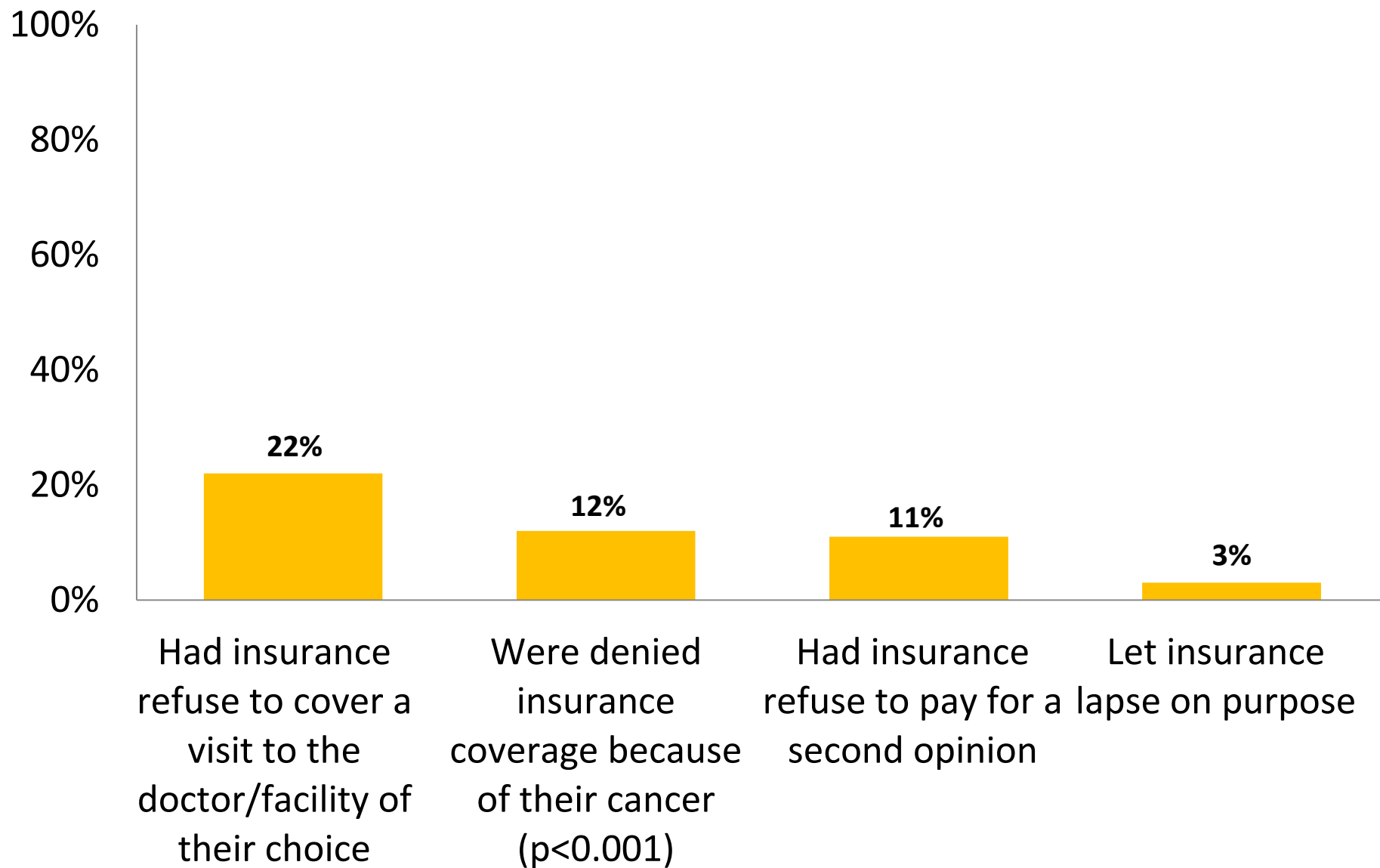
- Questions harmonized with the MEPS Cancer Survivors Supplement
- Survey was administered entirely online
- Available from June 2012 through December 2012
- Promoted the survey through email, Facebook, Twitter and through national and community partners
- LIMITATION: Online, convenience sample

- 1,338 individuals diagnosed between the ages of 15-39 completed the survey (2002-2012)
- Majority were:
 - Female 59%
 - White 81%
 - Married/Domestic Partnership 61%
 - Have a college degree 65%
- 85% had worked (N=1,137) since a cancer diagnosis
- 91% had been covered by health insurance at any time since first diagnosed (N=1,217)

LIVESTRONG®

FOUNDATION

Insurance, Debt, Work & School Results



INSURANCE (N=1217)

LIVESTRONG

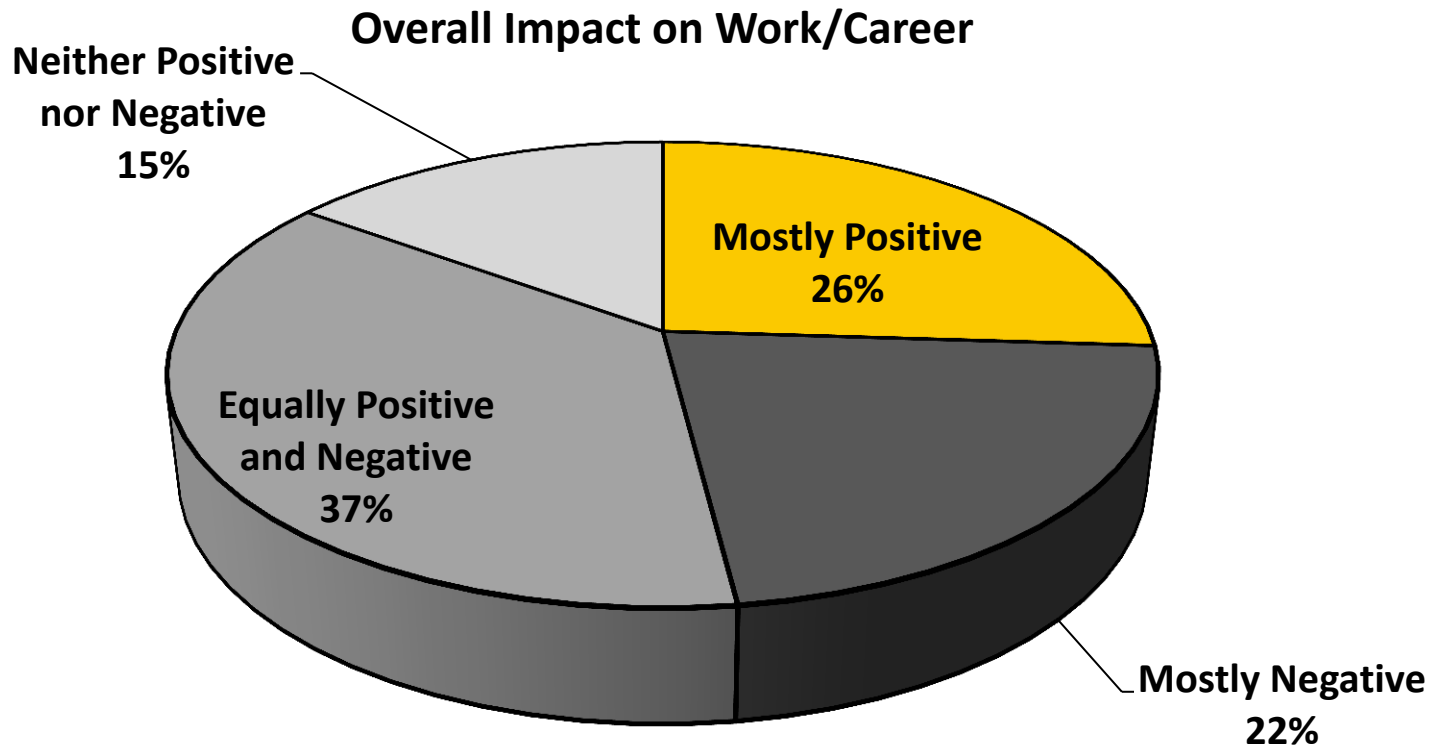
FOUNDATION

39% of AYAs had to or their family had to borrow money or go into debt because of their cancer*

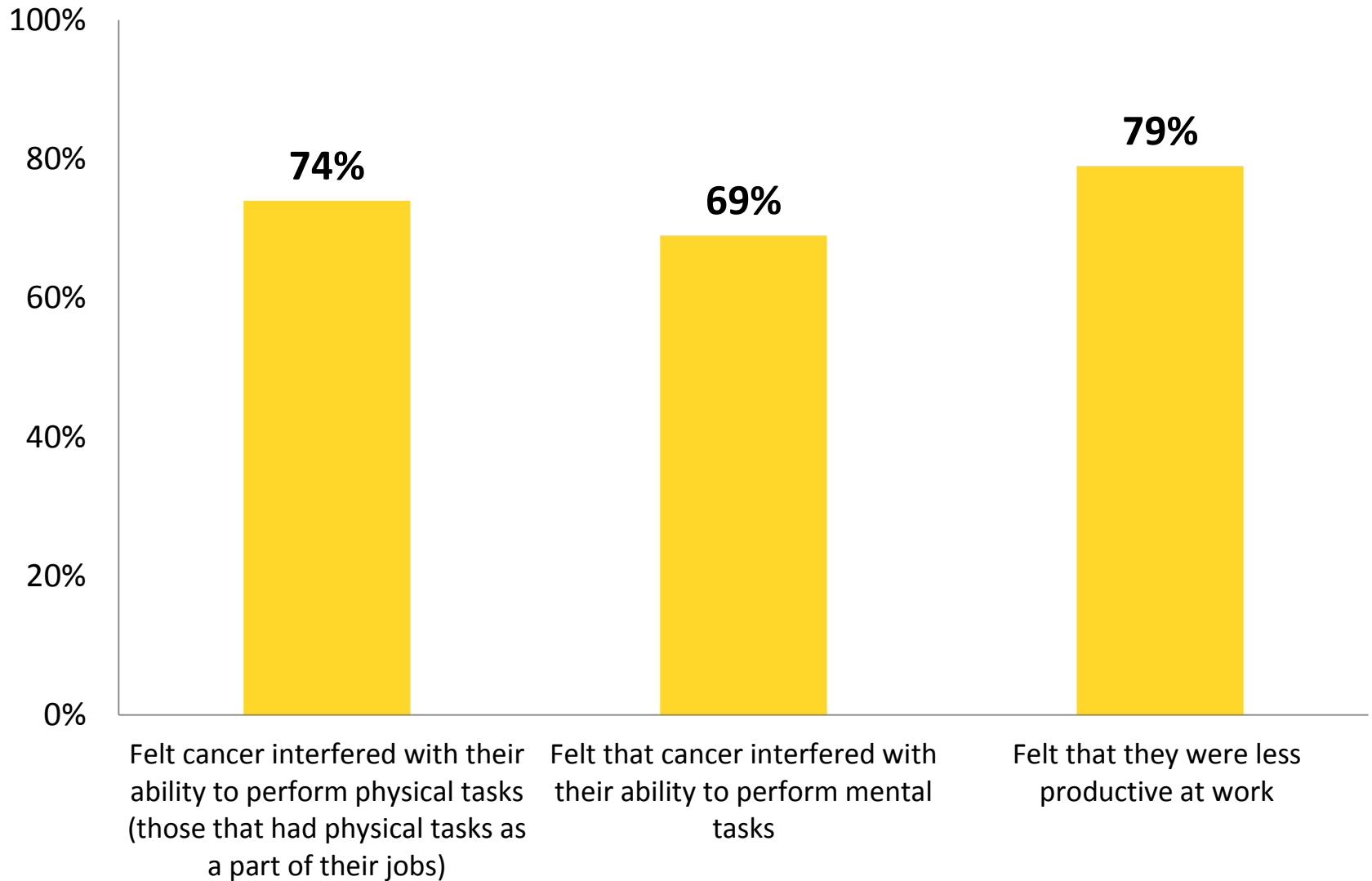
- **7% of AYAs indicated that they had filed for bankruptcy because of their cancer**

- **83% of AYAs worried about having to pay large medical bills**

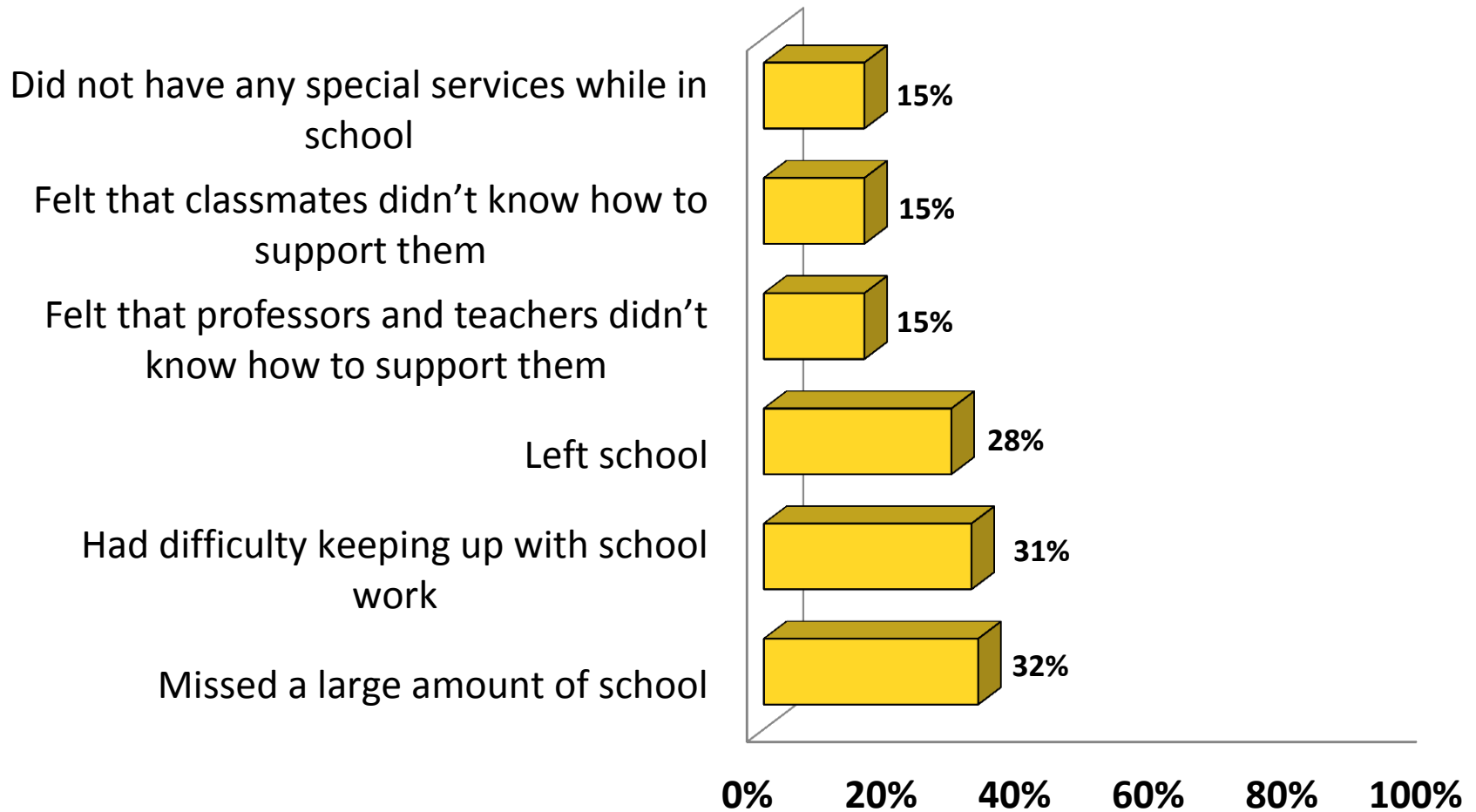
84% of participants made a change to their work since their cancer diagnosis.



AYA's Ability to Perform Tasks



33% of participants attended or made a decision about attending school since their diagnosis (N= 441)

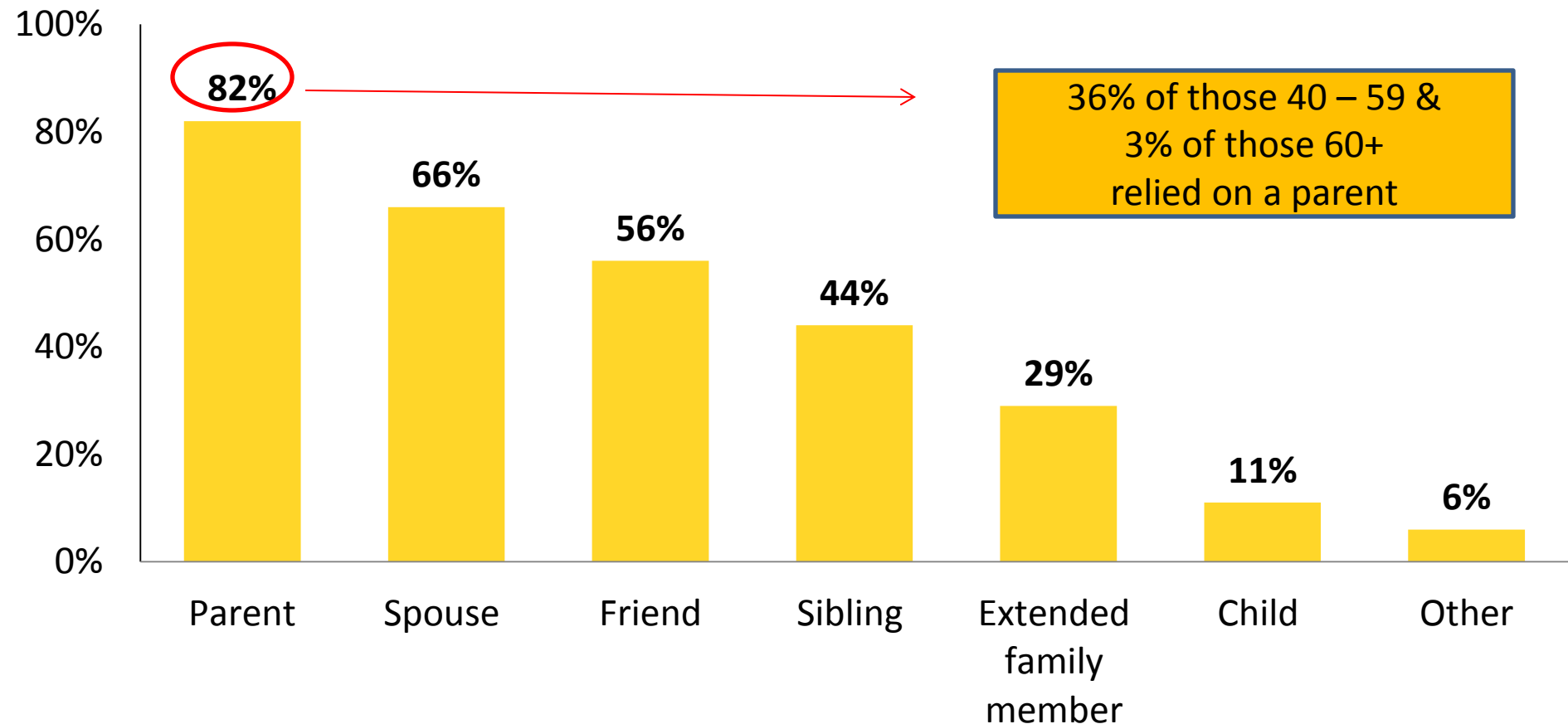


LIVESTRONG®

FOUNDATION

CAREGIVERS

92% of participants had a friend or family member provide care during/after their cancer treatment (N= 1,230)



Those with employed caregivers:

- 54% reported that the caregiver had to **make work changes** because of cancer
- 25% reported that the caregiver had to **make changes for at least 2 months**

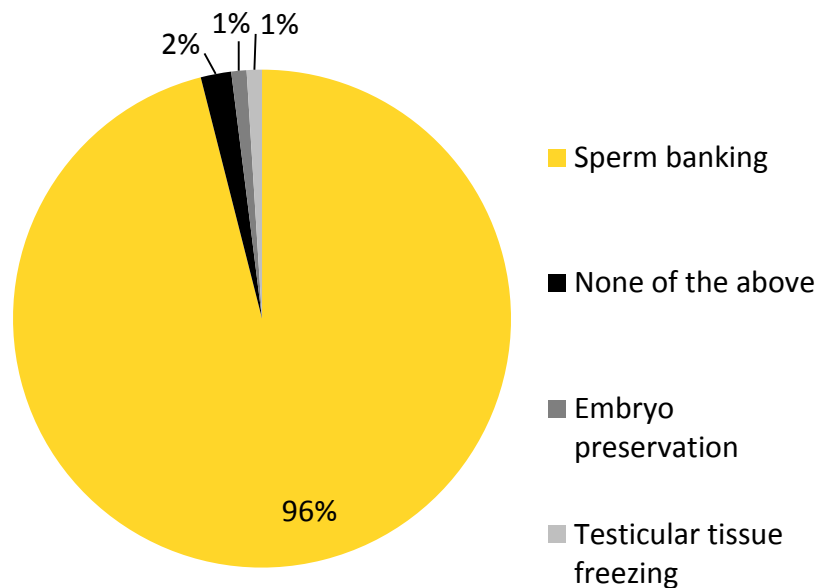
LIVESTRONG®

FOUNDATION

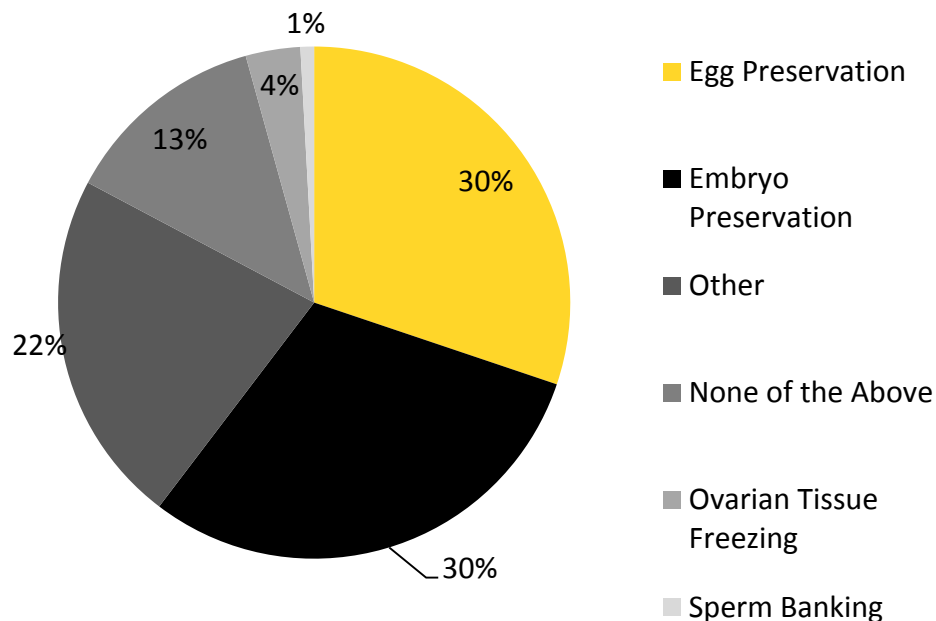
FERTILITY PRESERVATION

- 24% (321 of the 1,333 AYAs) **took steps to preserve their fertility before** their cancer treatment began

**Fertility Preservation Methods Used
by AYA Males**

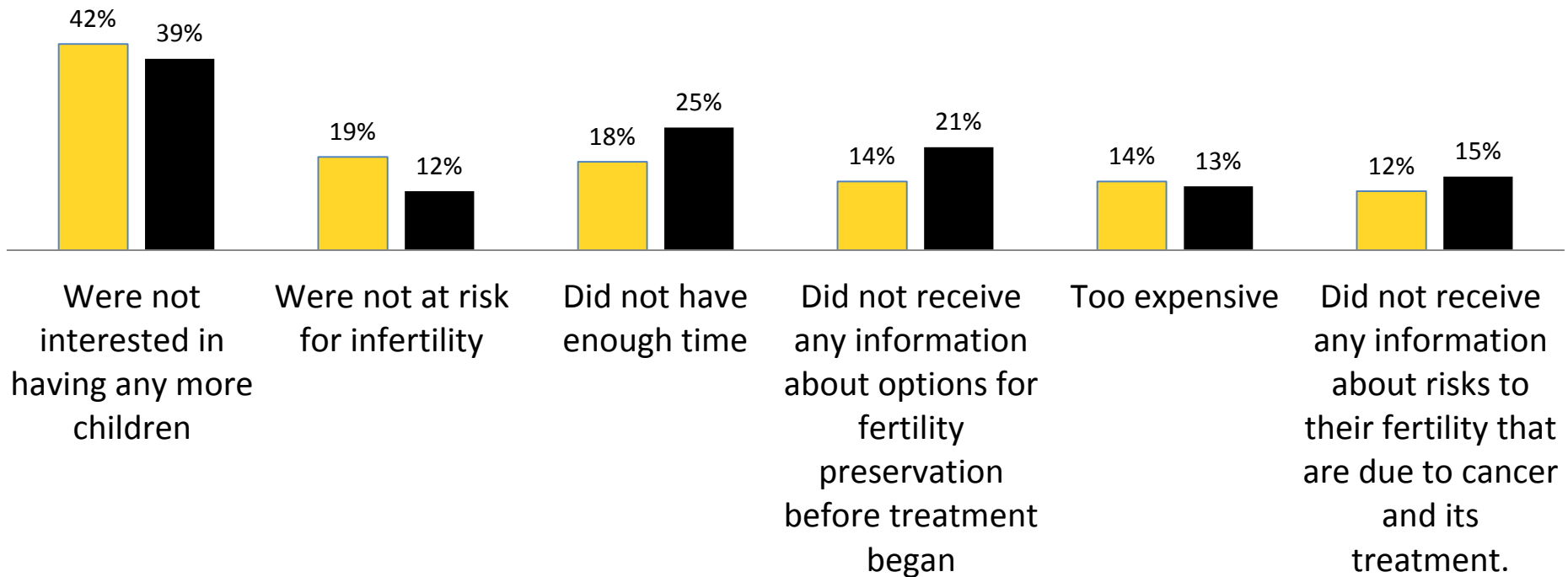


**Fertility Preservation Methods Used by
AYA Females**



Reasons for not using Fertility Preservation

■ Male ■ Female



- Findings indicate AYA survivors are experiencing significant burden of practical concerns after a diagnosis
- AYAs are often relying on a parent as a caregiver
- Caregivers are acquiring debt and reducing work as a result of their loved ones diagnosis

LIVESTRONG®

FOUNDATION

Future Directions

- **Manuscript** of findings on AYAs from 2012 LS Survey
- **LSSCOE Network Young Adult Survivorship Study**
 - Tests *feasibility* of recruiting YA Cohort (18-39)
 - Tests the *effectiveness* of the Essential Elements of Survivorship Care on improving health outcomes & health-related quality of life
 - Sending out the **LIVESTRONG** Survey
- **NCI AYA Oncology Workshop** Sept 2013
- **2014 LIVESTRONG Survey**
- 2014 release of **2012 LS Survey Dataset** for public use

- **LIVESTRONG** Research & Evaluation Team (Stephanie Nutt, Sarah Arvey, Melissa Dockery)
- RTI International (Carla Bann and Linda Squiers)
- **LIVESTRONG** Survivorship Centers of Excellence Network
 - Abramson Cancer Center, University of Pennsylvania
 - Dana-Farber Cancer Institute
 - Fred Hutchinson Cancer Research Center
 - Memorial Sloan-Kettering Cancer Center Survivorship Program
 - UCLA Jonsson Comprehensive Cancer Center
 - University of Colorado Cancer Center
 - University of North Carolina at Chapel Hill, Lineberger Comprehensive Cancer Center
- National Cancer Institute
- Office of Behavioral and Social Sciences Research
- American Cancer Society
- Centers for Disease Control and Prevention
- Agency for Healthcare Research & Quality

ACKNOWLEDGEMENTS

LIVESTRONG

FOUNDATION

LIVESTRONG®

FOUNDATION

Questions or Participate:
research@livestrong.org