



Transitions to Adulthood

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Transition and the New Normal

I get annoyed when people say, “Well, at least the hard part is over.” Is it? I suppose. But sometimes I feel like now is the hard part. It’s as if you’re thrown into the deep end of the pool for the first time and expected to know how to swim.

-Allie

(excerpted from Planet Cancer)

What is Transition?

- Transition is the purposeful planned movement of adolescents and young people with chronic physical and medical conditions from a child-centered to an adult-oriented health care system.
- Cancer survivors treated in the pediatric setting must be equipped to adapt to a new health care system in a positive manner.

Survivors

- Approximately 1 in 350 individuals in the United States develops cancer by the age of 20.
- More than 10 million cancer survivors currently in the United States, and 270,000 of these survivors received their diagnosis before age 21 years.
- Therapeutic advances have enabled about 80% of pediatric patients with cancer to survive for 5 years, and most are cured.
- Survivors of childhood and adolescent cancer comprise 1 in 570 individuals between 20 and 34 years of age.

Late Effects

- Late effects: Side effects of cancer treatment that appear months or years after treatment has ended. Late effects include physical and mental problems and second cancers and the chance of having late effects increases over time.
- Regular follow-up care is very important for survivors of childhood cancer.
- Good health habits are also important for survivors of childhood cancer.
 - Healthy diet, exercise, regular medical and dental checkups
- Avoiding health damaging behaviors
 - Smoking, excess alcohol use, illegal drug use, sun exposure, not being physically active

The Clinical Situation



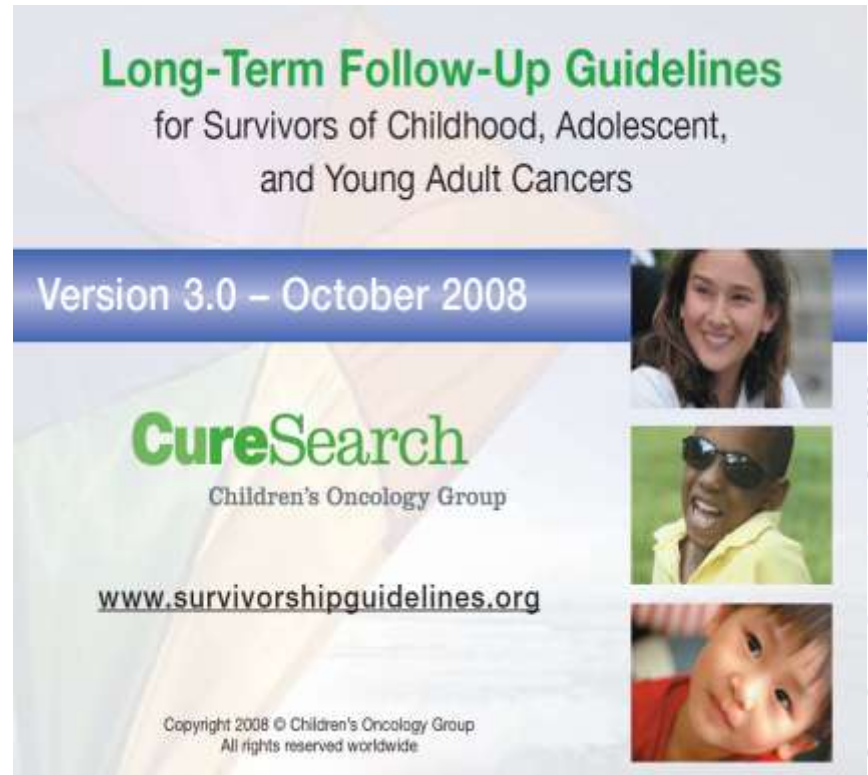
- Issues involved in transition from pediatric cancer care to adult-focused care differ from other diseases.
- Malignant disease itself is no longer a problem
- Greater dependence on pediatric oncology setting may delay transition
- Adverse long-term physical and psychological effects may not manifest until adulthood.

Identifying the Challenges

- Childhood and adolescent cancer survivors are living longer, requiring care in the adult system.
- Adolescence is typically a stressful time for parents and the adolescent.
- Adult health care providers may be unfamiliar with childhood cancers and follow-up management.
- Limited communication between pediatric and adult providers may create gaps.

Adults vs Children

- Adult survivors of childhood cancers are at a unique disadvantage compared with survivors of adult cancers.
- Goal: to move progressively from complete dependence toward independence
- Children's Oncology Group (COG) guidelines



Childhood to Adolescence to Adulthood

- Passage from each stage is marked by physiologic and psychological growth to develop their own identities and separate from their nuclear family.
- Young adults focus on independent living, intimate relationships, attending college, and pursuing vocational goals.
- Transition from pediatric to adult care is especially complicated for adolescents who are survivors of childhood cancer.

Adolescent's Developmental Norms

- Be more independent and autonomous
- Make decisions and rely on one's own judgment and personal resources
- Have independent relationships with adults outside the home
- Begin intimate relationships

All of these normal changes can be impacted by having had cancer.

Typical Adolescent Behaviors and Feelings



Not feeling understood by parents and other adults

Using friends as confidants (rather than parents/family)



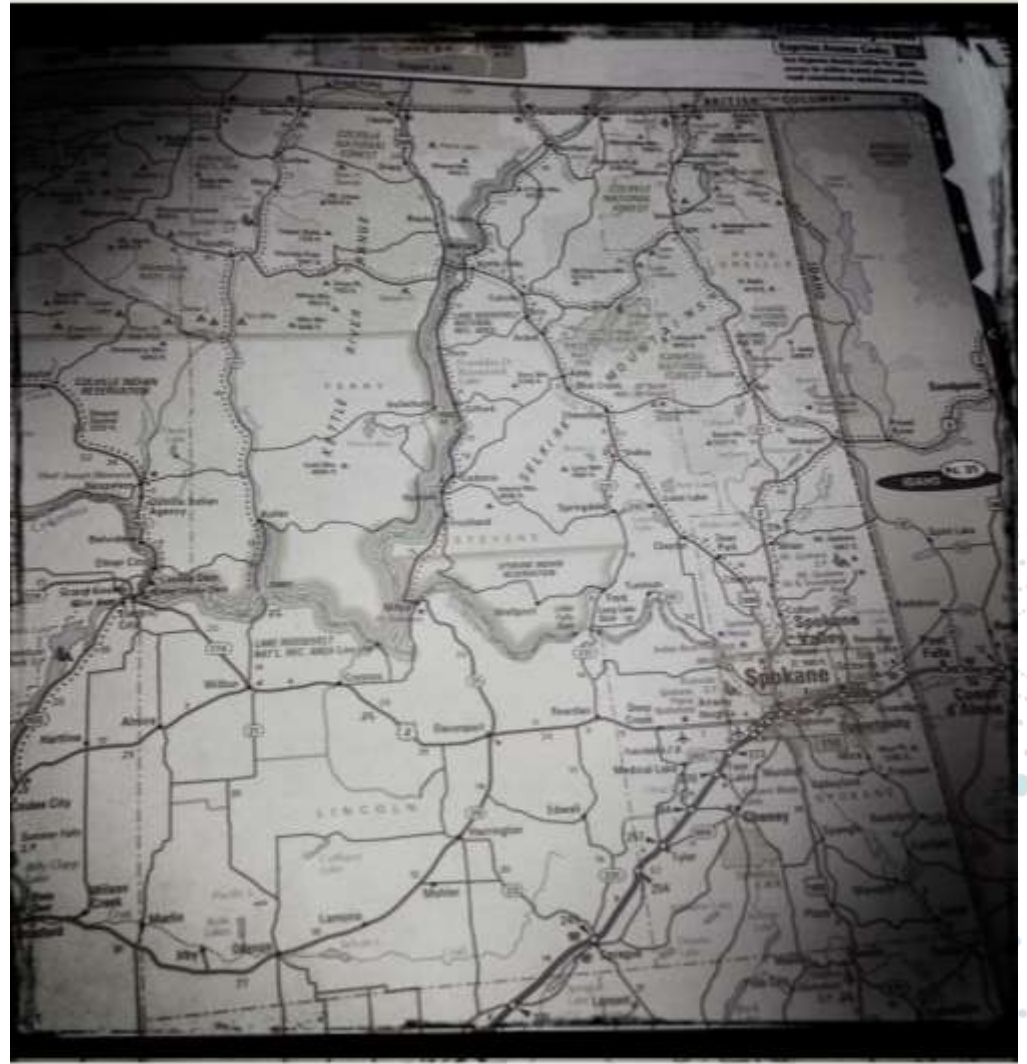
Seeking privacy and a “place of their own”

Engage in risk taking behaviors (as defined by adults) or...trying new and different things (as defined by adolescents themselves)

Life Transitions

So many transitions:
education, employment,
frequent relocation,
relationship and family-
related issues

Cancer survivor
transitions interact to
create a “perfect storm”



SEP 82

Multiple Cancer Transitions

Diagnosis

- Orientation of the medical system
- Education about diagnosis, planned therapy and long term risks of therapy
- Discussion about future fertility
- Education and support to promote self care
- Understand impact on education and future occupation

End of Therapy

- Review of treatment exposures and risks
- Education about recommended screening and surveillance
- Education about healthy lifestyle choices
- Support and referral to ensure psychosocial health

Entrance to LTFU

- Provision of treatment summary
- Developmentally appropriate review of information shared and end of therapy
- Explanation of long term follow-up process and preparation for eventual transfer to adult care

Transition of Adult Care

- Identify adult LTFU program and/or primary care provider to assume responsibility for care
- Treatment summary and care plan provided to new care provider
- Ensure survivor has required knowledge of their cancer history, treatment exposures, long term risks, and recommended surveillance.
- Support for future academic and vocational endeavors
- Support for obtaining health insurance / other financial needs
- Emphasis on the importance of life-long survivor care, even if no current late effects of therapy.

Adolescent's Concerns

- May feel abandoned by pediatrician or pediatric oncologist/care team
- Hard to develop trust in a new physician-adult system- abrupt and may seem less caring
- High value placed on privacy
- Not used to taking control of own health care-dependent on parents and pediatrician
- Unfamiliar with new hospital or surroundings

Parental Concerns

- Fear of letting go/loss of control
- Sense of “starting over”
- Concerned for their child’s well being
- Not included in information sharing, feeling left out of the loop
- Guardianship issues



Financial Challenges

- Young adults age 18-34 are the most uninsured segment of the US population



The Gap

- Many survivors leave the cancer center without having consistent follow-up into adult health care.
- CCSS survey found that fewer than half reported having cancer-related outpatient follow-up during the previous 2 years since their last follow-up visit, and fewer than one-third reported follow-up at their cancer center.



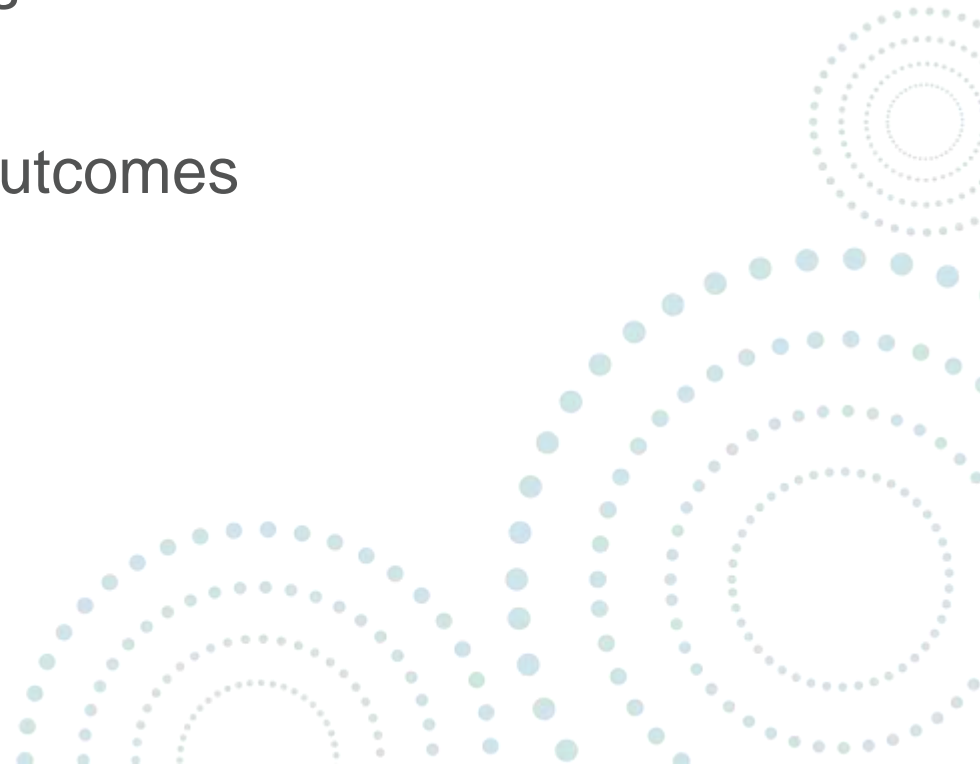
Transition by default

- Simply aging out of pediatric care leads to severe attrition in follow-up
- Unplanned
- Involved little or no communication among providers
- Poor surveillance
- Reactive medical care



Transition by design

- Systematic
- Offers the possibility of more effective communication
- Better monitoring, early detection, and intervention
- Preventive / wellness focus
- Less attrition
- Ability to study long term outcomes



Adult care is different

- Relies more consistently on patient initiative
- Has the potential to be more collaborative and empowering vs nurturing and prescriptive
- Medical decision making is the domain of the patient vs parent/family.

The goal of health transition is to provide care that continues to be medically and developmentally appropriate for the maturing survivor.

End of Therapy and Beyond

- Long-term follow-up (LTFU) programs have been developed in the past two decades in many cancer centers.
- These programs should assist with transition from pediatric oncology to adult medicine.



Care Tools

- Survivor's potential late effects/complications require risk-based follow-up care dedicated to the screening, prevention, and treatment of late effects throughout the life span
- The Institute of Medicine (IOM) published recommendations for follow-up care for all cancer survivors and that survivorship care plans be developed to assist survivors and their care providers.

Seattle Children's / SCCA Survivor Program

- Transition programs for pediatric cancer survivor require experts who are knowledgeable regarding the long-term follow-up needs of childhood cancer survivors and who can provide a bridge between pediatric oncology and primary care that is risk based.



Requirements for Transition

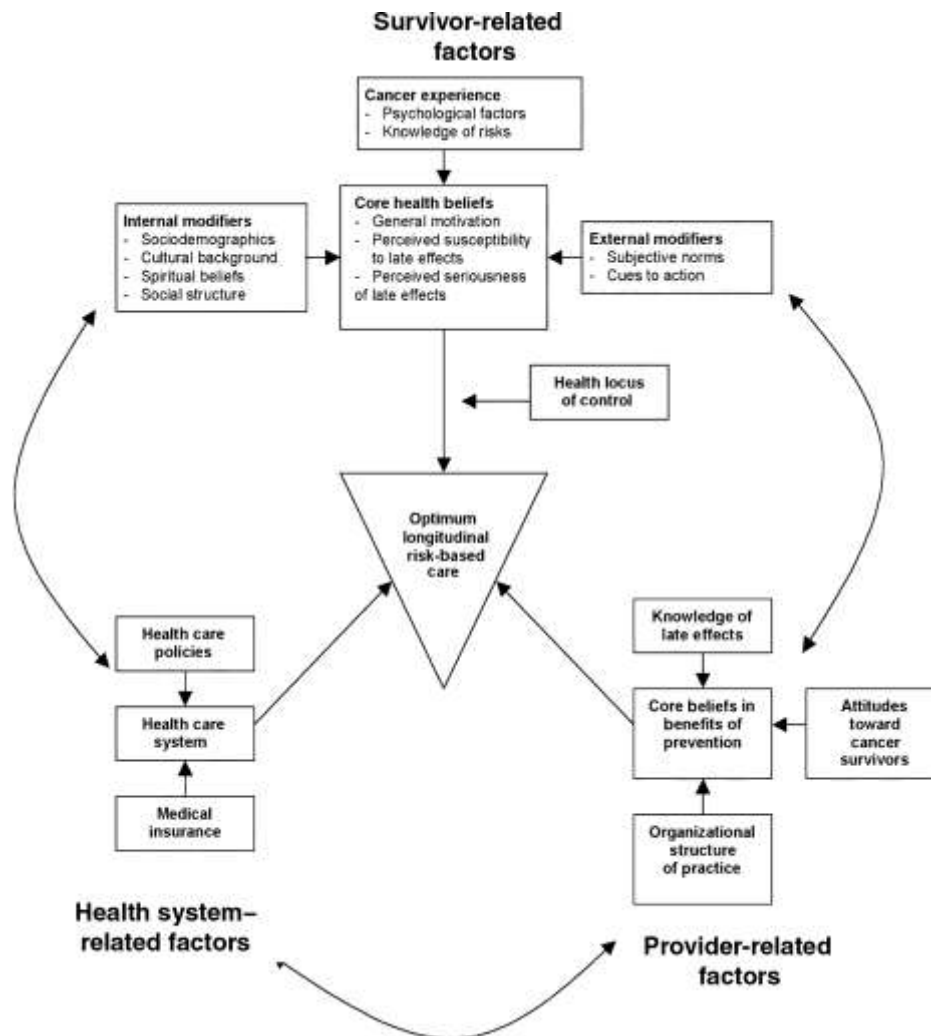
- Education of survivors and providers regarding long-term health risks is necessary for a successful transition.
- Process should be gradual to address the educational needs of survivors, families, and health care professionals, and determine “readiness” for transition
- Transition process must address financial and insurance concerns

Obstacles to Transition

- Fewer than 20% of adult survivors have reported receiving follow-up care at a cancer center, and a significant proportion of them are not receiving appropriate risk-based screening.



Optimal risk-based care model.



Henderson T O et al. Pediatrics 2010;126:129-136

Survivor Factors

- Lack of knowledge of treatment and risk
- Lack of insurance
- Psychological barriers
 - Overdependency on families, anxiety, or lack of trust in caregivers
 - Posttraumatic stress disorder
 - Avoidance
 - Cognitive and developmental delays
- Relationship with pediatric oncology providers

What Do Survivors Know??

- Many adult survivors of childhood cancers are now at increased risk for ???
- Childhood cancer survivors transition to adulthood and will manage their own health care and require accurate information in this role.



Provider Factors

- Uncomfortable caring for survivor over the age of 21
- Ambivalence to transition due to intense bond with survivors
- Adult providers may provide inadequate surveillance or subject patients to inappropriately excessive monitoring.
- Adult providers wanted: a patient-specific referral letter, printed recommendations, expedited routes of referral, and expedited access to investigations for suspected cancer recurrence.

Healthcare Factors

- Health Care Costs a Major Barrier
 - Survivors much more likely to forgo care
- Insurability
- Coverage limitations
 - Limitations in suggested tests
 - Limitation in covered physicians



Optimal Transition Process

- Begin early
- Gradual
- During the “readiness” window
- Include active participation of the family and patient in the process
- Explore fears and anxiety related to transition
- Introduction to adult care prior to transition

It should consider the patient individually, realistically, and positively, encouraging functional independence and appropriate attitudes toward self-worth and interpersonal relationships.

Step 1



Important first step in transitioning survivors is to address knowledge deficits about long-term risks among both providers and survivors by providing a comprehensive medical summary

Step 2

- Appropriate psychological services available to enable young adults to better adapt maintaining care independently



Step 3



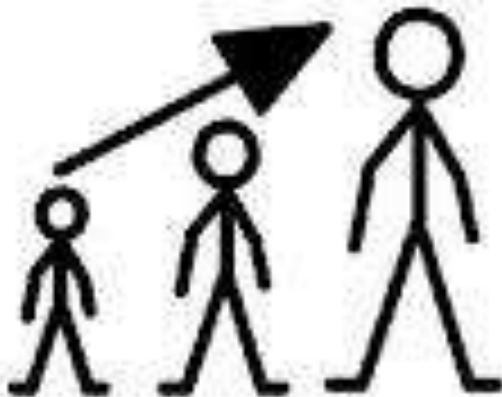
Barriers intrinsic to our health care system need to be addressed.

Keys to successful transition

- Building bridges between pediatric and adult health care providers
- Strengthening adolescents' independence without undermining parental involvement
- Proactive conversation regarding transition to adult care during the survivor's period of readiness
- At each routine visit, the survivor should expand his or her medical knowledge and self-management skills by discussing
 - diagnosis
 - medication and treatments
 - preventive interventions

Conclusions

- Providing a smooth transition for survivors to age-appropriate risk-based health care is a priority and can only occur by actively addressing the barriers in survivor, providers, and the health care system
- We hope that once these barriers are overcome childhood cancer survivors will live healthier, longer lives.



Transition is Hard

When I was finished with treatment, I felt like my life just suddenly started right back up again without me. Everything went “back to normal”, only I wasn’t normal anymore. It takes time to digest these big lessons.

-Shanti

Welcome to the New Normal



Congratulations!?

You have been tagged as someone whose every health issue deserves a little bit of extra scrutiny. So if something unusual does pop up, the likelihood is that you will catch it early and tackle it fast.

(Planet Cancer)



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