Trajectories of Identity Development in Adolescents with Cancer

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Objectives

• Describe the dual trajectories of adolescent and cancer identity development across the first year following cancer diagnosis.

• Discuss the implications that these dual trajectories have on the care of adolescents to promote optimal health and development
Background

• 78,325 adolescents (10-19 yrs old) diagnosed in the United States (1999-2010)
• Difficult to have good numbers in this age group across the world
  – hard to separate from children and adults
• Really a distinct age group
  – Specific needs
  – Specific developmental tasks
Sample

- 15 adolescents with cancer
  - 10 Female
  - 5 Male
- Sequentially approached as diagnosed-no potential participant declined participation
- Age from 12-17 years, (mean 13.9 yrs, median 13 yrs).
- Race:
  - 14 Caucasian
  - 1 African American
Sample

- **Diagnoses** (typical for adolescent cancer): Total n=15
  - Acute Lymphoblastic Leukemia (n=3)
  - Hodgkin Lymphoma (n=3)
  - Acute Myeloblastic Lymphoma (n=2)
  - Ewing’s Sarcoma (n=2)
  - Brain Tumor (n=2)
  - Wilms Tumor (n=1)
  - Chronic Myelogenous Leukemia (n=1)
  - Osteosarcoma (n=1)
Consolidated Standards of Reporting Trials (CONSORT) diagram

Eligible
N=15

Enrolled
N=15

Interview 1
N=15

Interview 2
N=11

Interview 3
N=9

Interview 4
N=5

2 missed interviews

2 missed interviews

2 missed interviews

2 withdrawals (relapse/death, lack of interest)

1 withdrawal - death

1 transfer to adult care, 1 lost to f/u

2 missed interviews

2 missed interviews

2 missed interviews

2 missed interviews
Methods

• Longitudinal Qualitative Approach
• 4 “quarterly” interviews starting within 2 months of diagnosis
• Interviews conducted with AWC alone
• Place and time convenient and comfortable to AWC
• Interview questions focused on present situation related to cancer and life in general. Questions also followed up on where AWC had been in previous interviews
Methods: Analysis

• Transcribed verbatim and checked for accuracy
• Coded each interview individually
• Then placed in a matrix with other interviews with same participant so that common processes and themes could be identified and compared
• Then compared over time and both within and across participants
Illness trajectory

Managing how I see myself

Managing how others see me

Negotiating present and planning for future

Hair
Friends
Peers & Others
Family
Results

• Adolescent Identity and Cancer Identity Development:

• Core processes:
  – managing how I see myself
  – managing how others see me
  – negotiating the present and planning for the future
Processes linked to identity development

Adolescent Identity & Cancer Identity
Managing how I see myself

• **Hair**
  “losing my hair. That was tragedy….I lost it right after Christmas, I was like, Merry Christmas…I wanted to have my hair on Christmas…So I wore a hat and then I wore a headband. When I took it off it was like chunks were kind of coming out” (P7, T1)

• **Friends**
  “the risk of it coming back again and stuff like that….I just don’t feel like talking about it really…with my friends.” (P6, T4)

• **Peers and others**
  “when I talk to them (other adolescents with cancer), they tell me their stories and like what they’re going through. And just like knowing there’s someone else out there” (P15, T1)

• **Family**
  “My dad’s feeling sorry for me and he wants to spoil me but he doesn’t want to spoil me too much. I had to make that decision. Do I want to get spoiled or do I not want to get spoiled?…It’s like in between the middle. I want to get spoiled but I don’t …I don’t like it.” (P9, T1)
Processes linked to identity development

Managing how others see me

• **Hair**
  “I’ll just feel happy when I have hair again…And just be able to say I’m normal.” (P14, T3)

• **Friends**
  “my best friend’s been really, you know, she’s been pretty much the same throughout all of it.” (P8, T2)

• **Peers and others**
  “when I was on chemo, when I was on radiation, I left that hour every day at school so I wasn’t a full time student….these kids were like, why is she leaving all the time and staring at me….whispering and I could tell they were talking about me.” (P14, T3)

• **Family**
  “I definitely know cancer doesn’t just affect me. It affects my brothers, it affect my parents. It definitely affects my little sisters” (P8, T3)
Processes linked to identity development

Negotiating the present and planning for the future

• **Hair**
  “we’re having a remission party for my birthday and that’s in July so I’m hoping by then I have a little bit of hair to do something with it.” (P7, T3)

• **Friends**
  “I mean, you obviously don’t talk to them as much but they’re still there, so…they just tried to keep it regular like they would if I was home….Just calling and talking and stuff on the phone….I live an hour and a half away. They just kept me up with what was going on in town and stuff.” (P11, T4)

• **Peers and others**
  “Some kids have come around and I’m like, You were mean before, don’t try to be nice now” (P1, T1)

• **Family**
  “I just wanted to get back to normal so they wouldn’t worry…my parents…had a really hard time in the hospital of trying to cover it up, being worried.” (P2, T1)
Discussion

- Erikson: primary developmental task of adolescence is identity formation
- Not all adolescents (with OR without cancer) do well with this task
  - AWC have additional identity to assimilate
  - Threat to identity development
- Cancer diagnosis triggers an identity disruption
  - Formation of cancer identity/integration of cancer identity into adolescent identity/self identity
Discussion

- Individuals (including AWC) actively play a role in constructing the reality within which they live (Berzonsky, 1993)
- To be useful, it has to make sense within world around it
- Needs to be monitored, evaluated and often revised in adolescence (cancer notwithstanding)
Discussion

- So how do we support AWC?
- Recognition of their situation
  - Adolescent Identity development
  - Cancer Identity development
- These are not static with regard to each other
  - Each AWC decides how much they overlap at any given time
Illness trajectory

Managing how I see myself

Managing how others see me

Negotiating present and planning for future

Hair
Friends
Peers & Others
Family

Adolescent
Identity
Work

Cancer
Identity
Work

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Implications for Practice

• Opportunities for friend/peer interaction
• Opportunities for interaction with other AWC
• Education
  – AWC
  – Parent
Implications for Future Research

• Validation with more diverse sample
• Intervention development that involves friends and other AWC specifically since maintaining that support is key to perception of "normal"
Questions?