Transition Challenges in Young Adult Childhood Cancer Survivors and Parents

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Objectives

- Identify the emotional difficulty in transitioning to adult care for young adult childhood cancer survivors
- Address the SMART components influencing the transition success in young adult childhood cancer survivors
- Discuss the facilitators to a successful transition to adult care for the young adult childhood cancer survivors
- Reflect on your own practices in the transition of care of the young adult childhood cancer survivors
  - Remembering the informative years these survivors spent with you!

Background

- Continued efforts to identify the best practices in transition of care for young adult childhood cancer survivors (YACCS)
- One model may not be ideal in all situations for all survivors
- Risk-based surveillance

Background—Review of Literature

- Awareness of psychological factors and transition
  Granek et al. 2012

- Health care insurance (access to care) critical

- Adult provider knowledge of survivorship
  Sakak, Dinofia, & Reaman, 2013

- Family-centered approach to transition
  Schluster, 2014
Review of Literature-cont.

- The Socio-ecological Model of AYA Readiness to Transition is a framework from which to examine transition readiness in this population, their families, providers

  Schwartz et al., 2011

- The components also require exploration on how they influence the process and successful transition to adult services

Framework

METHODOLOGY

- Exploratory qualitative study (as part of a larger study)
- Institutional Review Board approval
- Purposeful sampling using telephone and face to face recruitment of young adults and parents in a non academic affiliated institution
- Audio-taped focus groups
  - At least 18 years of age
  - Cont. care in pediatric survivor program
  - English speaking
Results

**Characteristics (survivors) n=13**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean (range-yrs)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at time of the study</td>
<td>21.8</td>
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<tr>
<td>Age at time of diagnosis</td>
<td>13</td>
</tr>
<tr>
<td>Gender-Female</td>
<td>7 (54)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>6 (46)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>6 (46)</td>
</tr>
<tr>
<td>Biracial</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Living situation</td>
<td></td>
</tr>
<tr>
<td>Live with parents</td>
<td>7 (54)</td>
</tr>
<tr>
<td>Live alone</td>
<td>3 (23)</td>
</tr>
<tr>
<td>Live with significant other</td>
<td>3 (23)</td>
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</tbody>
</table>

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Results

**Characteristics (Parents) n=5**

<table>
<thead>
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<th>Characteristic</th>
<th>Mean (range-yrs)</th>
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<tbody>
<tr>
<td>Age at time of study</td>
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</tr>
<tr>
<td>Gender-Female</td>
<td>5 (100)</td>
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<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
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</tr>
<tr>
<td>Hispanic</td>
<td>2 (46)</td>
</tr>
<tr>
<td>African American</td>
<td>1 (8)</td>
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Results

- **Themes**

<table>
<thead>
<tr>
<th>THEMES</th>
<th>Young Adults</th>
<th>Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of adult provider knowledge/Sensitivity</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Lack of knowledge in adult providers</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Survivors lack of responsibility/independence</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Comfort in Pediatrics</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Transition programs</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Navigators</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
Lack of knowledge/sensitivity

- Feeling that adult providers are incompetent and lack knowledge of late effects of childhood cancer
- Feelings that adult providers will not be attentive to their needs, lack accommodating personalities, and insensitivity
- Not being able to provide level of care that was done in pediatrics (p)

“...You’re a doctor you should know that, what a brain tumor looks like.”
“...They don’t have my treatment plan...they won’t know the specifics of what I went through.”
“...I [created this bond] with my doctor. ‘They’ve known me since I was a child.’
“...I want the doctors to be able to know what he’s been through.” (P)

Comfort/Dependence

- Survivors talked about their comfort in pediatrics and anxiety about leaving
- Had relationships with pediatric specialists

“...it’s like [I’m comfortable here], and [we have a relationship].”
Having to take Responsibility

- Survivors remained dependent upon pediatric specialists & parents
  - Preferred their parents take care of appointments while independently managing rest of life
  - Parents addressed their children’s ambivalence of moving forward/lack of responsibility

“… [we became really dependent] on your guys…”

“I didn’t know all the technicalities…” “[I left that up to my parents…”

“[she’s not ready to take responsibility].” (P)

“my son needs to take responsibility” (P)

Transition Programs

- Survivors were more conceptual and wanted opportunities to meet adult providers and have a collaborative program
  - Ask adult providers about their knowledge
  - Have a workshop(s)
- Parents wanted a transitional unit or clinic-collaborative
- Opportunities to meet the adult provider(s)
“both the pediatric and adult providers are providing the same information…”

“I think a [transition workshop]…was brilliant”

“Why can’t we have a unit that is just a transitional unit.” (P)

“…do you know the doctors that you are going to send my child to?” (P)

Navigators

- Survivors wanted a point person to facilitate the transition
- Survivors also wanted a team or network of people
- One parent had experience with navigators
  - Talked about how helpful they were to her

“[someone behind the scenes] a little bit, where [they kind of bridge the gap], make it smoother”

“I guess you wouldn’t feel like you have to do it by yourself…”

“…it would be comforting to my daughter.” (P)

“I’ve seen that [navigators work] in some situations.” (P)
Summary

- Plans to address each component of the SMART in an intentional manner—transition to adult services
- No participant identified with the pre-existing components and how they influence their transition
  - Access, Insurance, Neurocognition
- When addressing knowledge, skills, expectations, goals, relationships, participants had interesting dialogue on how each component represent them either interpersonally or externally

Limitations/Strengths

- The bonds survivors had with pediatricians were apparent
- Their lack of responsibility and wanting to take responsibility over their cancer surveillance is clear
- All participants feared what adult providers did not know or possibly lack compassion in managing the care of YACCS
  - Wanted competent providers (like pediatrics)
  - Wanted assured collaboration, communication, and consultation between adult and pediatric providers
Implications for Practice

- Nurses can serve as advocates for early transition planning, education, and support for children and adolescent early in the treatment / survivorship trajectory
  - Discuss the transfer of care as part of the phases of treatment-survivorship

- Transition in inevitable for majority of survivors
  - Engage survivors in advocacy training
  - May not be able to ensure adult provider expertise nor compassion
    - Education
    - Support
    - Collaboration
    - Consultation

References


