Life After Cancer

Psychosocial Health in Cancer Survivors

Joanna Thome Patten, PsyD
Attending Psychologist
Seattle Children’s Hospital
Discussion Topics

- What does the research say about psychosocial health in cancer survivors?
- Developmental considerations
- Life after cancer
- Areas of difficulty to address
- Resources and recommendations
What does the research say?

- Survivors are generally resilient and may experience positive outcomes related to enhanced coping abilities and “posttraumatic growth.”

- However, having been treated for cancer increases risk of psychological distress, somatic symptoms, cognitive late-effects, developmental deviations.

- Psychosocial health often affected by physical health.
Developmental Considerations

- Impact of developmental stage at time of diagnosis and treatment, and current developmental stage.

- Consider degree of independence and engagement in:
  - Self care activities and household responsibilities
  - Social activities (friends, romantic interests, hobbies, clubs)
  - School

- Developmental Stages
  - Early Childhood: bonding, separating, early emotion regulation skills and independence
  - School Age: interests, friendships, school, natural consequences
  - Adolescence: peers, identity development, preparing for future

https://www.healthychildren.org/English/ages-stages/Pages/default.aspx
http://www.zerotothree.org
+ Typical Development

<table>
<thead>
<tr>
<th>Independence</th>
<th>Child</th>
<th>Pre-teen</th>
<th>Teenager</th>
<th>Young Adult</th>
</tr>
</thead>
</table>
Developmental Disruption

Cancer Diagnosis

Usual

Independence

Child  Pre-teen  Teenager  Young Adult
Nobody said this would be easy....

- Adjustment around time of diagnosis
- Adjustment to major stressors of treatment
  - Hair loss, NG tube placement, port access, extended admissions, hospital food, etc.
- Adjustment to unexpected or unplanned (negative) events
  - Recurrence, adverse event, permanent effect of treatment, etc.
- Adjustment to ongoing treatment
  - “I’m sick of this already”
  - “I didn’t plan on missing 8th grade graduation”
- Adjustment to life after cancer
  - Getting back to “normal”
Adjusting to Life After Cancer

- How do you fit back in with your family?
- How do you fit back in with your friends?
- How do you regain independence and build more independence?
- How do you go back to school?
- How do you go back to not being in or at the hospital all the time?
- How do you build health behaviors and life habits?
What to expect and what can help

- Expect a that adjustment will take some time

- Facilitate adjustment with conversation and preparation
  - Spending time with a few friends prior to larger social gatherings
  - Going to school to meet with teachers prior to returning to school

- As health improves, set developmentally appropriate expectations with graded support as needed
  - Independence (sleeping, going places, ordering for self, hygiene behaviors, etc.)
  - Household duties (chores, behavior, participation, etc.)
  - School

- Do fun things!
  - Social activities
    - Camps!!
  - Active activities
Increase Health Literacy

- Get familiar with the “End of Therapy” summary and keep notes from Long Term Follow Up clinic in 1 binder/folder.

- Encourage developmentally appropriate independence in transitioning knowledge from parent to child. For children who were treated when they were young, develop a concise narrative that includes treatment essentials.

- Encourage developmentally appropriate independence in monitoring health, scheduling follow-up visits, refilling current medications, etc.

- Regular discussions of health promotion and risk behaviors
  - Primary prevention (use sunscreen, avoid drugs/alcohol, eat well, exercise, safe sex practices, etc.)
  - Secondary prevention (BSE and TSE, other screening/labs).

http://www.gottransition.org/
When to consider mental health support:

- Persistent sadness or worry
- Persistent difficulty integrating with friends and peers
- Risk behaviors
- Significant effects of treatment, requiring more extensive support
  - Academic issues
  - Mobility or sensory impact of treatment
  - Medical complications requiring ongoing management
  - Transition support to address academic, occupational, and independent living needs. http://www.gottransition.org/
When discussing mental health services, use a helpful framework:

<table>
<thead>
<tr>
<th>Common Misconceptions</th>
<th>Helpful Reframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>I don’t want to be <em>forced</em> to talk about this</td>
<td>A therapist is like a “talking doctor”</td>
</tr>
<tr>
<td>The therapist will <em>fix</em> this</td>
<td>A therapist will teach me specific skills to make life easier, less uncomfortable.</td>
</tr>
<tr>
<td>I don’t want to be <em>analyzed</em> or <em>judged</em></td>
<td>A therapist will help me think through and “process” my thoughts and feelings about what happened or what is happening</td>
</tr>
<tr>
<td>What did I say that made my doctor place the referral? Do they think I’m crazy?</td>
<td>I don’t have to protect mental health providers from my sad or worried feelings</td>
</tr>
<tr>
<td></td>
<td>We can all learn new ways of coping, communicating, working together, etc.</td>
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<td></td>
<td>It is normal for people who have been through extremely stressful circumstances to talk to a mental health provider.</td>
</tr>
</tbody>
</table>
Mental Health Interventions: What (usually) works?

Good Rapport → Evidence Based Interventions → Good Outcomes
Cognitive Behavioral Model: Teaching Concepts, Skills, and Strategies

- Thoughts
- Feelings
  - Physiological
  - Emotions

Actions
Cognitive Behavioral Model

- Thoughts
  - Detective Thinking
  - Self Coaching
  - Validation

- Feelings
  - Physiological
  - Emotions

- Actions
Cognitive Behavioral Model

Thoughts

Feelings

- Temp Change
- Intense Exercise
- Prog. Relaxation
- Paced Breathing Skills

Actions
Cognitive Behavioral Model

Thoughts

Actions
- Wellness Toolkit
- Distraction
- Positive Activity Scheduling

Feelings
- Physiological
- Emotions
Therapy services at SCH

- Joanna Thome Patten, PsyD, Outpatient Psychiatry
  - Individual therapy
  - Consultation and referral
  - Transition planning

- Possible expansion of social work

- Group Therapy
  - Life After Cancer: Group for patients 12-14 years old who have completed treatment for cancer, concurrent group for parents
  - AYA Group: Group for 17-23 year olds who have or have had cancer.
Evidence Based Services available at Seattle Children’s Hospital

- Outpatient Psychiatry:
  - Reorganized into specialty clinics
    - Mood and Anxiety Program
    - Pearl Clinic (ADHD and Disruptive Behaviors)
    - Transgender Evaluations
    - Substance Abuse
    - Training Clinic
    - Neuropsychological Consultation Service
    - Integrated Psychiatry
    - Early Childhood Clinic
Finding Support

- Call your insurance carrier and ask them to help you find a therapist with specific experience working with children with medical conditions.

- If they cannot find someone in their network, ask them if they will create a single case agreement with an out of network provider with this experience.

- Intervention through research or training programs

- Ask your communities for recommendations
Children’s Hospital of Philadelphia (CHOP) has a variety of resources, including podcasts, support groups, videos, websites, coping tools, books, camps, and other resources on their website: http://www.chop.edu/centers-programs/oncology-psychosocial-services-program/health-resources#.V_QN7aKUJZ8

Other resources?
Questions and Discussion

- What services would you like to see here at SCH?
- For how many of you is distance a barrier to obtaining appropriate mental health services?
- Pie in the sky ideas to support cancer survivors at SCH?