

Specializing Care for Adolescent Oncology Patients

Susan D. Flynn Oncology Fellowship

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Question

Amongst pediatric patients ages 1-18, is the implementation of individualized adolescent psychosocial care more effective compared to standard pediatric psychosocial care in helping adolescent patients cope with the challenges that accompany cancer diagnosis and treatment on a Pediatric Onc/Heme/BMT Unit over an 8 week period?



What is the problem and why is it relevant to nursing practice?

- The problem is that adolescents have unique qualities and needs that are only exacerbated when they are diagnosed with and treated for cancer.
- This topic is relevant to nursing practice because nurses should be providing sensitive and holistic care that includes physical, mental, and emotional.
- There are many barriers and challenges that come with caring for adolescent oncology patients.
- Cancer not only has obvious physical effects, but emotional effects too.

“Where AYAs fit in the healthcare system is another gray area. Sometimes they are treated with pediatric regimens, perhaps even in pediatric centers, although they may not be comfortable walking the halls with animals and balloons painted on the walls. Yet they are not adults. Yet they are not adults. This disconnect may foster a sense of isolation, intimidation, and even mistrust.”

“ Changes in their bodies as well as feelings about these changes need to be explored.”

Infants/Toddlers/School-Aged Children Vs. Adolescents

Infants/Toddlers/School-Aged:

- Some are not as concerned about appearance
- Do not fully understand diagnosis/illness
- Parents are usually assisting them anyway; dependent
- Social aspects not as important
- Infants can't express verbally how they feel but physically i.e. crying



Adolescents:

- Loss of control/independence
- Affects identity
- Challenging developmental stage; "in between"
- Life put on hold; cancer puts future at risk
- Body image/self esteem
- Isolation; risk for increase in depression and anxiety; increase in social pressures; role of social media
- Guilt from dependence
- Stress; resentment
- Mature more quickly
- Relationship issues



Side Effects of Treatment

- Weight change; puffiness
- Hair loss
- Scars
- Amputations
- Fertility issues
- Skin issues (GVHD)
- Isolation precautions
- Nausea/vomiting
- Secondary cancer
- Body image
- Anxiety/depression/nervousness/feeling of hopelessness
- Organ failure



Research

“Compared with age-related norms of functionality, impaired physical functioning strongly correlates with the mental and emotional well-being of adolescents and young adults.”

“Social effects must be considered.”

Research

Total body image scores revealed only 28% of female leukemia survivors had an appropriate body image versus 90% of the healthy control group.

A study done by Williamson, Harcourt, Halliwell, Frith, and Wallace explored adolescent and parental perceptions of appearance throughout cancer treatment. It concluded that appearance changes cause major concern, anxiety, and low self-esteem.

Research

For adolescents in this study, it was vital that family and friends accepted them despite the changes in their bodies that transpired during the cancer trajectory. Previous research has shown that children with cancer want their families and friends to treat them like the same old person even though they endure changes in their lives due to cancer.

Maintaining a balance between regular care and extra special care may be a critical factor to how adolescents adjust to cancer.

https://www.medscape.com/viewarticle/498948_4

From a Patient's Perspective

- ★ Bedside manner is important; patients pick up on it
 - “The only thing I remember about receiving my diagnosis was how cold and blunt the doctor was when he told me. I was just in shock.”
- ★ Diagnosis doesn't set in until you are stuck in a room for weeks at a time
 - “I don't remember anything. All of a sudden it was 7 weeks later and I was still stuck in a hospital room. That's when it finally set in.”
- ★ It helps when healthcare providers are personable, realize patients have a life outside of the hospital and their illness
 - “It helps when doctors and nurses talk to me about things I am interested in and like I am a person instead of treating me like my medical record number or disease.”
 - “The most annoying thing is when they just pop in and ask me to give my pain a number. That's what bothers me the most.”
- ★ Wanting to have some control
 - “Shaving my hair off was the most empowering thing.”
 - “It really helps to have my own stuff here compared to the other kids I see wearing hospital pajamas.”

From a Patient's Perspective

★ Stuck in many ways

- “I was finally able to move out of my small town and into the city for fashion school. I had found myself and was looking forward to starting my new life. Now everything is on hold. Kids can take one day at a time, but adolescents look forward more. I recognize that I am stuck in the present, which makes it harder. We can see the whole picture and how this all affects my whole life.”

★ Friends make a difference

- “I miss my friends and school the most. It I am most looking forward to going back to school. My friends made me a collage which meant a lot.”

★ “I try not to think about it so much. I think I'll be okay.”

How to Improve Care

- Flexibility with appointments (When outpatient)
- ● Technology
- Support groups
- Do not give false hope; Be honest, but know how much
- Validation
- Give patients some control back (ex. Opening meds, I&O)
- Age appropriate communication
- Increase awareness to barriers
- Involve in care
- Create an environment where patients are comfortable to ask questions
- Palliative care team for initial and continuation of care
- Don't always talk to them about something related to cancer
- Anticipatory guidance
- Teen lounge



Research

Zebrack et al³⁹ (USA)

Method: Group interview: “What did people say or do for you that you found helpful while you had cancer?”; and “What did people say or do for you that you found harmful or hurtful?”

Population: Age 18–35 years; AYA survivors

Purpose: To identify aspects of behavior that may promote or inhibit healthy psychosocial adjustment for this age-defined population

Method: Participants attending the Young Adult Survivor Conference at Camp Māk-a-Dream, a 4-day retreat for off-treatment survivors of cancers diagnosed in childhood, adolescence, or young adulthood, were offered an opportunity to voluntarily participate in a group interview in which they discussed how having had cancer has affected their lives.

Results: Survivors reported being the recipients of positive and negative communications and behaviors of an informational, practical, interpersonal, and/or emotional character. Most common were comments and actions in the interpersonal realm. More helpful than hurtful comments were reported, except in the informational category, where the “bad news” about cancer and the style of information sharing created hurt.

Survivors had positive and/or negative reactions to the type and degree of communication and support they did or did not receive. They often associated positive comments and actions with useful information that helped them understand their situation and gave them an enhanced sense of control over treatment. Negative comments and actions resulted in feeling uninformed and unable to make critical decisions, overburdened with responsibility, “like a piece of meat”, “just a statistic”, or “like a textbook” rather than a real young adulthood. A simple tabulation of responses suggests the importance of interpersonal support, in that friends and family members, as well as health care professionals, are often positioned to do or say things having significant and meaningful impact for these young people.

Research

Kazak et al³³ (USA)

The BSI-18, the HCBI, the Health Knowledge Inventory

Population: Age 16–30; AYA survivors of Leukemia, lymphoma, and solid tumors

Purpose: To compare AYA pediatric cancer survivors and peers without a history of serious illness on psychological distress, HR-QoL, and health beliefs and examine age at diagnosis and cancer treatment intensity on these outcomes; and to examine relationships between number of health problems and the outcomes.

Method: AYA cancer survivors and controls were recruited during visits to a cancer survivorship clinic and primary care.

Participants completed self-report questionnaires of distress, health problems, and health beliefs. For survivors, providers rated treatment intensity and health problems. The data was collected at or immediately after a medical appointment.

Results: Cancer survivors had fewer positive health beliefs. Survivors diagnosed as adolescents had significantly greater psychological distress and fewer positive health beliefs than those diagnosed earlier. Survivors with the highest level of treatment intensity had greater anxiety and fewer positive health beliefs than those with less intense treatments. Provider report of current health problems related to survivors' beliefs and mental HR-QoL only, whereas patient report of health problems correlated significantly with most psychosocial outcomes and beliefs.

Survivors diagnosed during adolescence and who had more intensive cancer treatments evidenced poorer psychosocial outcomes. Beliefs about health may be identified and targeted for intervention to improve QoL, particularly when patient perceptions of current health problems are considered.

Research

Carpentier et al⁷⁰ (USA)

Semi-structured qualitative interview (impact of testicular cancer on their romantic and sexual relationships)

Population: Age 15–34 years; AYA survivors of Testicular Cancer

Purpose: To examine AYA testicular cancer survivors' subjective understanding of the impact of cancer in adolescence and young adulthood, with a particular emphasis on romantic and sexual relationships.

Method: AYA testicular cancer survivors were recruited from outpatient testicular cancer follow-up clinics and completed a semi-structured qualitative interview that assessed the impact of testicular cancer on their romantic and sexual relationships

Results: The inductive thematic analysis resulted in 18 categories, which were subsequently grouped into four key themes: 1) embarrassment leads to delays in care seeking; 2) testicular cancer makes you feel different from others; 3) being different from others makes you damaged goods; and 4) cancer disclosure is difficult. These four themes were identified as patterned responses or meanings within the data set and captured something important about the data in relation to the research question of interest.

Four themes were identified that reflected survivors' understanding of the impact of cancer in adolescence and young adulthood: 1) embarrassment leads to delays in care seeking; 2) testicular cancer makes you feel different from others; 3) being different from others makes you damaged goods; and 4) cancer disclosure is difficult. As these themes represent important components of being in a romantic/sexual relationship, either currently or in the future, AYA testicular cancer survivors would benefit from the development of tailored interventions focused on improving these relevant domains.

Research

Zebrack et al⁴⁴ (USA)

Method: Three rounds of mailed surveys to AYAs and stakeholders with slightly different wording between groups (biomedical and/or psychosocial needs for AYAs at diagnosis and during treatment and for young adults who are off-treatment survivors, and an idea or vision of what optimal cancer care for AYAs should be)

Population: Age 18–44 years; AYA survivors and stakeholders (oncology health professionals)

Brain tumor, breast cancer, endometrial, germ cell, testicular ovarian, sarcomas, Hodgkin's lymphoma, leukemia, and melanoma

Purpose: To identify important health and supportive care needs for AYA patients and survivors

Results: Over three iterative rounds of mailed surveys, participants identified, rank ordered, and rated the importance of various items. Overall, there was general agreement among health care providers and young adult survivors, with some notable exceptions. Providers and young adult survivors agreed on the relative importance of having adequate health insurance and oncology care that addresses the unique developmental characteristics of this population. Compared with health professionals, young adults ranked the importance of opportunities to meet other young adult survivors at a relatively higher level, and they also ranked those opportunities higher than the importance of support from family and friends.

These findings provide oncology professionals and young adults with insight into the others' values and perspectives. These findings also suggest areas in which to target investments of resources to promote quality health care and appropriate informational and supportive care services and to overcome the deficit in survival improvement that has occurred in young adults and older adolescents with cancer.