Living with Uncertainty: Young Women and Metastatic Breast Cancer

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“I wish I’d eaten more cheeseburgers. Big juicy fat ones with pickles and ketchup and toasted buns. They represent *joie de vivre*, a laid-back, whatever goes attitude. Something I’d never had. Then, when I was 23, busy plotting my next move, stockpiling my hopes and dreams, I was diagnosed with cancer.”

*My (so-called) Normal Life*  -Erin Zammett
Metastatic breast cancer is rising in patients younger than 40

- Increasing by approximately 2% per year (from 1979-2009) JAMA 2013

- 250 cases in 1979, 850 per year now

- No solid explanation as to why
  - Johnson & Bleyer-2013
Health Disparities

- African American women under 35 have rates of breast cancer 2 times higher than Caucasian women under the age of 35.

- African American women under the age of 35 die from breast cancer 3 times as often as Caucasian women of the same age.
Unique Factors and Specific Issues for Young Adults

🌿 Young adulthood is usually a time of major change, stress, and exploration

🌿 This can complicate adjustment to cancer and coping

🌿 The “delicate interplay” between physical, psychological, and interpersonal factors
Developmental interruption

• Cancer is out of sync with normal development:
  - Identity development
  - Autonomy
  - Search for worldview
  - Spiritual exploration
  - Interpersonal functioning
  - Sexual health and sexual orientation
Psychosocial-Spiritual Adjustments

- Young adults face multiple adjustments such as separating and developing independence
- College/education
- Starting careers
- Relationships and starting families
Young adults with cancer

- Increased risk of suicidal thoughts and a higher risk of depression related to chronic health conditions that affect quality of life

- 16% experience PTSD

- Treatment and “chemo brain”, attention and cognitive function declines—all affect reentry into social circles, school, and the workforce

  Johnson, 2012
Young adults with cancer

- Mental health, mood, psychological well-being affected by cancer

- Mental health symptoms higher

- Greater demands in the area of work and/or parenting and fewer coping skills

Constanzo et al -2009
Young adults with cancer

- Challenged to make sense of diagnosis

- Why me, why now?

- Spiritual development may be incomplete
Relationships and Sense of Self

✨ Out of sync with peers
   ✨ “friends don’t get it”
   ✨ “they’ve completely disappeared”

✨ May increase social isolation and influence whether they participate in normal age-appropriate activities
All these issues are *magnified*

- When a young adult not only has cancer, but has advanced disease

- Impact on day to day living is great (ie: living with chronic pain, fatigue)

- Feeling “old too soon”
Young Adulthood

- Is a time of increased vulnerability and stress

- Alienation from peers can contribute to how the young adult views him/herself

- Can result in lower self esteem

  Zebrack, 2008
Psychosocial Issues

_quality of life_

- Side effects and long-term toxicities higher in this population due to aggressive tx.
- Depression/anxiety higher in young women with breast cancer
- Age related challenges such as career, child-rearing, sexuality and body image
- Relationships with family, partner and friends are affected
Metastatic Disease

- Young women with breast cancer are more likely to present with advanced disease

- 20% of women less than 35 years of age had mets at diagnosis, vs. 3% of older women

  Paluch-Shimon, 2011
Isolation

🌿 From peers

🌿 From the breast cancer community
Unique issues for young women with metastatic disease

- Confronting mortality: facing dying, rather than living at a young age
- Being isolated as a result of being young with breast cancer
- Being isolated even among young breast cancer survivors as a result of having advanced disease
Unique Issues (cont.)

- Getting support is especially important for this population
- Finding ways to link with one another is essential
Unique Issues (cont.)

Insurance and Financial impact

- Even with the Affordable Care Act, the young adult population is one of the most under and uninsured populations in the U.S.
- Reasons: job change, end of college, aging out of parent’s plans
- Lack of insurance makes it harder to obtain care, and adds to higher death rates

Johnson, 2012
Other financial issues:

- Lack of resources to pay rent, utilities, medical bills
- Lack of stable income
- Explaining the employment gap
One program:

- A collaboration between a breast cancer non-profit program and Komen

- A retreat specifically for young women with breast cancer with metastatic disease
Connection…

- All women under 40 years old
- None had met others with advanced disease
- All “felt relieved” to meet one another
One story:

Traci:

- 27 yo at diagnosis: told “don’t worry, you’re young”
- Felt out of place from the beginning
- Single, no children, double mastectomy
- Had her first and last mammogram simultaneously
- Not dating, identity connected with appearance
- “life is over” -sense of aloneness
Traci, (cont.)

- Felt isolated, and alone-being young not acknowledged
- Dx’d with metastatic disease 4 months short of 5 year mark
- Discouraging, felt it was the “beginning of the end”
- With metastatic disease: “you’re not bald, you must be great.” “you are not working-why?”
- “you look great”
Traci (cont.)

- Timing is terrible, angry at God
- Angry at doctors
- Now what?
- Heightens every fear, including mortality
At the retreat:

- Normalized the experience
- Felt less isolated
- Faith/family/friends fed one’s soul
- “I want to fight”
- So tired of treatment, side effects, cancer directing ones’ life, activities, and even what you eat
At the retreat:

“we had fun!”
“we laughed and laughed!”
“we jumped on our beds!”
“we climbed trees!”
“others ‘get’ it!”
Message to other young women with metastatic disease

“There is hope and you do not have to give up!”

“Stay away from the internet!”

“Get good information, and find good support.”
Message to providers:

・“Talk to us about our options! (including fertility)”
・“Tell us about resources”
・“Put a little more heart in it!”
・“Hold hope with us”
Important resources:

- Cancer and Careers
- Patient Advocate Foundation
- Cancer Legal Resource Center
- LBBC-Annual conference for women living with metastatic disease
Living Well with Advanced Cancer

- Literature is sparse

- “you are cured, or you are dying”

- Little research about the “middle ground” of living with advanced cancer, much less living with it at a young age
Living well: (cont.)

- Some people with a terminal diagnosis will live for a long time
- “uncharted territory” : not healthy, not well, but not dying in the immediate future
- “living past my expiration date”
Challenges:

- Living with uncertainty
- Making sound decisions
- Trying to maintain a balanced and positive daily view
- “the struggle to be a participant in one’s own life”
The conditions:

- Trying to live a normal life
- Learning to live with powerlessness
- Finding the courage and strength to continue

Thomsen et al, 2011
Psychosocial issues

- Depression is most common symptom, followed closely by anxiety

- Most people with Stage 4 disease are not clinically depressed

- They ARE, however, sad, scared, and unsure how to think about their lives/future
Normal Crisis Points

- Diagnosis of metastatic disease
- The most intense experience settles after 6-8 weeks
- May take several months to a year to be “comfortable”
- When treatment is no longer working or must be changed
- The decision to stop treatment ("when is enough enough?")
Women with Advanced Disease

- Women with advanced disease will experience physical and psychological distress

- Hope is essential!

- Sharing the burden, holding hope, and maintaining non-abandonment are also essential
Survivorship Issues

PTSD

Limited research, however some studies indicate that younger age, lower income and less education are risk factors for PTSD

Cordova et al, 2007

PTSD: more prevalent in patients with advanced disease, longer hospitalization, duration and intensity of treatment

Weiner et al, 2006
Risk factors and Warning Signs

- Isolation
- Avoidance of positive experiences and activities
- Hyperarousal
- Heightened anxiety
- Emotional states that impede sleep, work and productive activities
Interventions:
- Relaxation
- Desensitization
- Cognitive behavioral techniques
- Medication
Adherence: How can we keep young adults engaged?

- Young adults want information on disease, treatment, what to expect before, during, and after treatment.
- Speak their language—don’t use medical jargon.
- Find creative ways to communicate with young adults.
Adherence: (cont.)

- Find creative ways to communicate:
  - Provide multiple ways to access information: websites, email contacts, books, blogs, peer support/referral
  - Find alternative modes of communication: social media, texting, treatment or side-effect reporting apps
  - Utilize social networking in your institution and possibly a separate platform for young adults
Adherence: (cont.)

- LBBC: closed Facebook group, and peer-support helpline, including young women living with metastatic disease
- Connect with peers who “get it” (Young Survival Coalition, Imerman Angels, etc)
- Start a young adult group or refer to one
- Consider retreats for young women with metastatic disease
Normalize

- Acknowledge the emotional and physical implications of “life being turned upside down”

- Assess psychosocial spiritual well-being at regular intervals

- Develop a treatment plan to address these concerns
Resources:

- Have a list of community resources and professionals comfortable and skilled with young adult survivors
- Gynecologists/endocrinologists/urologists/psychiatrists
- Counselors/therapists/oncology social workers
- Websites
- Survivorship care plans
What can we do better?

- Unique programming
  - Support groups
  - Web/media resources
  - Retreats
Take homes:

The diagnosis of cancer in early adulthood is untimely and challenges developmental progression, adaptation, and self-esteem in ways that require making group, individual, and programmatic interventions readily accessible.
Take homes:

- Young adults with cancer experience higher risks of mental health symptoms, including anxiety, depression, PTSD, and suicidal thoughts than do older cancer patients.

- These symptoms appear to be related to advanced disease, longer hospital stay, duration/intensity of treatment, lower income, and less education.
“We don’t heal in isolation, but in community.”

S. Kelley Havell