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Seeking a New  
Normal:



*Voices  
of the Cancer  
Experience*

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# Some General Realities About the Cancer Experience

- Psychologically, cancer is regarded as a *relatively* “traumatic experience”
- Highly individualized responses depending on:
  - Age, gender, stage of life, personality, coping styles, physical and/or psychological comorbidities, socio-economic variables
  - Type and stage of cancer
- Inherently high levels of uncertainty and the unknown
- No “right” or “wrong” way to get through it – everyone does the best they can, moment to moment.



# Parameters of the Presentation

- Based on qualitative research done in 2009 and published in 2014
- Participants were breast cancer patients and survivors
- Themes common across all forms of cancer based upon my professional experience
- Does not address unique needs of advanced cancer patients and/or those at end-of-life
- Does not address unique needs of caregivers or family members, i.e., children
- Is certainly not a complete picture
- Suggestions offered – not absolutes



# Movements & Themes in the Research

## NED / Post-Treatment

Themes

- Normalizing the breast cancer experience: Relational bonding, mirroring, & modeling
- Integrating the cancer experience
- Changing my point of view – Accepting & releasing

## NED / “Survivor”

Themes

- Learning to accept & trust my body again
- Searching for meaning
- Enhancing spirituality
- Reassessing values & priorities
- Putting perceptual changes into coping action

## Treatment

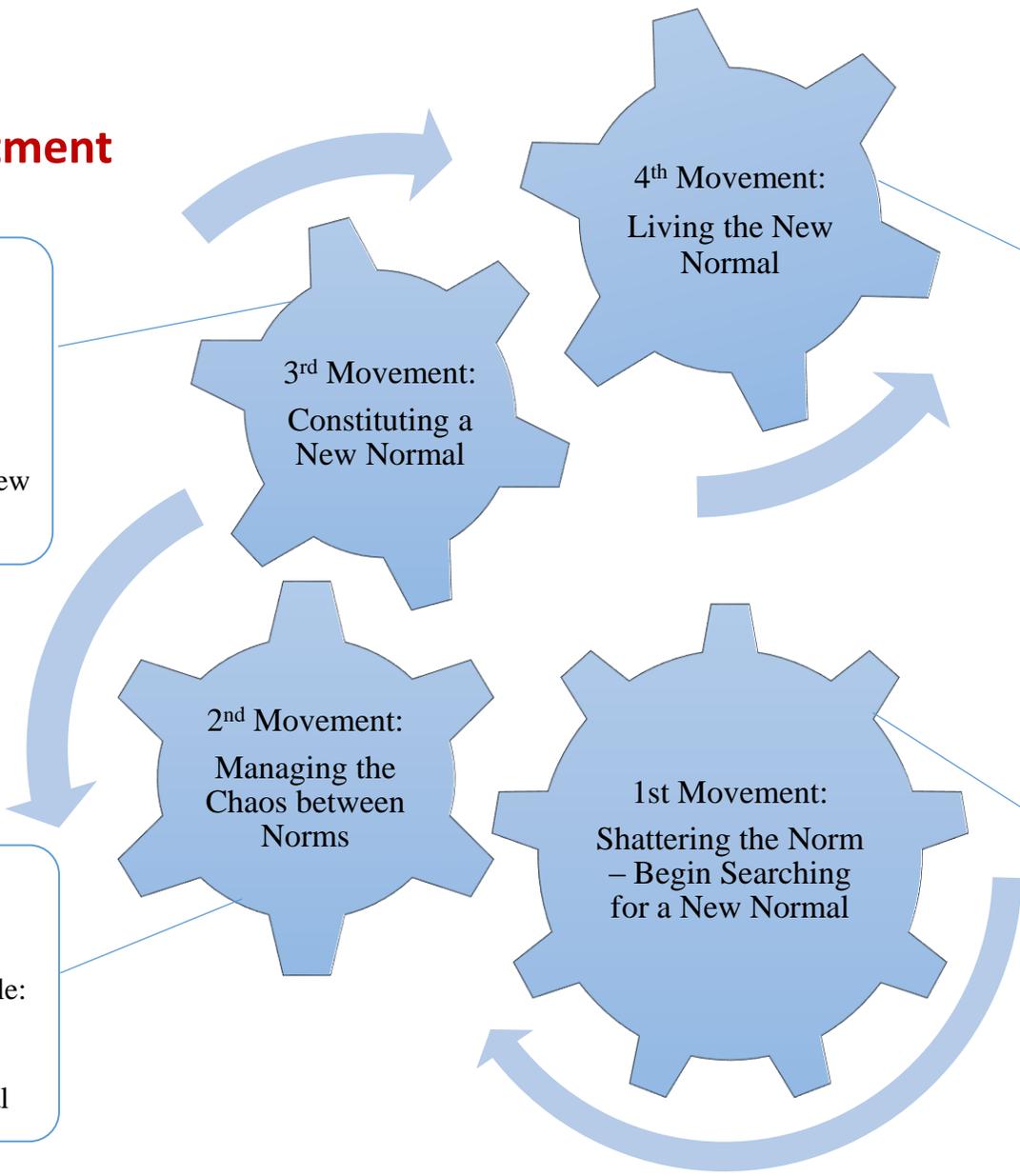
Themes

- Focusing on treatment
- Expanding the support system - Exploring
- Defaulting to coping style:
  - Physical & mental
  - Emotional
  - Religious / spiritual

## Diagnosis

Themes

- Fragmenting of long-held perceptions of normal
- Experiencing death salience
- Struggling with paradoxical norms





# Shattering & Searching: What they had to say about diagnosis

*“When I developed the cancer, it was like a land mine—I say land mine, because I didn’t see it coming. And it blew everything out of the water . . . none of that I used to think or believe was working anymore. You know, blow everything apart and start over with what you think.”*



# Shattering & Searching: What they had to say about diagnosis

*“I was grappling with the fact of—the ambiguity . . . that was pretty hard to deal with. My whole sense of the future was altered. . . . I could live or I could die... and I don’t get to know. Definitely feeling like I was not promised a future.”*



# 1<sup>st</sup> Movement: Shattering Norms & Searching for a New Normal

## Patient's Perspective:

- Shattering the norm
- Facing death
  - Uncertain / unknown
- Caught in-between
  - Life before cancer
  - Life with cancer
- Begin Searching for a New Normal



# 1<sup>st</sup> Movement: Shattering & Searching

## What may be needed during diagnosis:

- Partnership – not alone
- Hope – we will get through this
- Time to process impacts of the diagnosis
  - Communication!!
  - Can be a time of asking “why?”
  - Acceptance of feelings – whatever they are
- Practical advocacy (medical, insurance, research)
- Acknowledgement that cancer impacts the *whole* person and the *whole* family – including primary caregiver
- Encouragement to seek support



# Managing the Chaos: What they had to say about Tx

*“I was very busy, which helped a lot, because then I couldn’t dwell on it.”*

*“I always had a very positive outlook on life, and I approached it head on.”*

*“I could make jokes about it; I could keep it slightly more lighthearted. So, essentially I was able to couch it in different terms.”*

*“I’m a fighter. I’m not going to give up. I simply will not give up to my last dying breath.”*

*“I said to myself: Well, just accept it. There’s nothing else you could do. So you just put one foot in front of the other.”*



# Managing the Chaos: What they had to say about Tx

*“[People would say] Are you keeping your chin up? Are you feeling the power of prayer? No, I’m scared to death - buzz off. It was not very helpful. [It was] undercutting the severity of what was happening to me.”*



# 2<sup>nd</sup> Movement: Managing the Chaos Between Norms

## Patient's Perspective:

- Focus on getting through treatment
- Expanding support system; Exploring
- Default Coping Styles
  - Physical & mental
  - Emotional
  - Religious / spiritual



# 2<sup>nd</sup> Movement: Managing the Chaos Between Norms

## What may be needed during treatment:

- Everything in the previous stage, plus...
- Reinforce empowerment - choices
- Normalizing their experience - talk to other cancer patients who have been through it
- Treat them as a person - not a disease
- Take “cancer breaks” whenever possible
- Find a new “rhythm” – be flexible
- Anxiety is common – explore ways to manage it
- Depression can occur – get help for it
- The hair, and other physical changes – it’s important!



# Constituting a New Normal: What they had to say at end of Tx

*“There’s a process going on here that I don’t think I’m paying enough attention to — that it’s never over. When my primary treatment was over, that was another phase of kind of strange disbelief in a way, because, Oh, gee, the radiation is finally over, isn’t that wonderful? It’s all over now, right? And, it’s not right—it’s never over. It’s never going to be over.”*



# Constituting a New Normal: What they had to say at end of Tx

*“...the whole cancer treatment is such a physical experience, and you’re so exhausted that it’s hard to figure out your emotions - what else is going on with you.”*

*“For me, making peace with this whole thing was adjusting to the fact that I am powerless over the cancer and accepting that. At any point in time, you do the very best you can, then you just have to let go. But getting to that place took a lot of work when I was dealing with a potentially life-threatening situation.”*



# 3<sup>rd</sup> Movement: Constituting a New Normal

## Patient's Perspective:

- Another change – another disconnect
- Integrating the cancer experience
  - Emotional backwash
  - Accept / release
- Trying on new ways of being in the world
- Will it come back?
  - Triggers



# 3<sup>rd</sup> Movement: Constituting a New Normal

## What may be needed shortly after treatment:

- Realize emotions may surface suddenly: depression, grief, anxiety, anger, etc. Get help to work through them.
- Accept that getting back to the life you had together before the cancer may not be entirely possible.
- Communicate, be flexible, give lots of time for all of you to figure out a “new normal” that includes:
  - Physical and functional changes and limitations
  - Differences in priorities, values, need for legacy or meaning
  - Possible impacts to sexual intimacy
- Learning to manage responses to triggers such as “scanxiety”, new body aches/pains, smells, tastes, sounds, locations, etc.



# Living a New Normal: What they had to say about “surviving”

*“You can never go back—cancer changes you, and it changes you for good, and there’s no going back. And people that haven’t experienced cancer think that, Oh, once you get through this, you’re going to go back and be the way you were before—be whole again, well, we have a new normal. And it’s not the way we were before. We think about our bodies differently, we think about our relationships differently, we think about our life differently.”*



# Living a New Normal: What they had to say about “surviving”

*“Through this cancer experience, I realized that I’m no longer superwoman. But, I just can’t mentally acknowledge that I’m not superwoman; I have to do something about it. I have to give myself a higher priority.”*



# Living a New Normal: What they had to say about “surviving”

*“I feel that I am changing, but the people around me aren’t. I’m trying to be more tolerant or understanding towards my family. But, it seems that there is a lack of understanding on their part. So it’s a two-way thing. It’s like we have to go through this process where things need to be balanced out between us.”*

## Patient's Perspective:

- Accepting my body
  - Limitations, changes
  - Trust
  - Physical triggers
- Meaning & purpose
  - “Now what? How do I want to live the time I have?”
- Reassessing values & priorities
- Establishing new habits

## **What may be needed long after treatment:**

- Be patient – there is no specified time in which to “get over” cancer.
- Physical changes and limitations may affect relationships.
  - Functional, physical, and aesthetic / cosmetic
- Self-care may take on new importance for them.
- Accept that cancer may be a transformational experience for your loved one; they may be different because of it.
- Your loved one may view life differently now.
- With this new outlook on life, a new career, or life purpose may emerge for them.
- The changes may not be over yet – for them or you!



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# Questions? Thank You!

  
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