Breast Cancer Survivors

- Breast Cancer Survivorship
  - a “dynamic, life-long process” that starts once a woman is diagnosed with breast cancer (Hewitt et al., 2005; National Coalition for Cancer Survivorship, 1986; Pelusi, 1997).

- Population Prevalent and Increasing
  - 2nd Leading cause of malignancy in women worldwide
  - Population growing, 2.6 million in U.S. in 2011 (Breastcancer.org, 2012)
  - 88% live >5 years (Jemal et al., 2008)

Concern to be Addressed

- Need for greater understanding of the process of transitional breast cancer survivorship from the perspective of women who have completed initial treatment for breast cancer to improve patient outcomes.
- Empirical evidence from breast cancer survivors has revealed
  - there are gaps in treatment
  - the diverse needs of cancer survivors often go unmet.
- (Armes et al., 2009; Harrison et al., 2010; Mao et al., 2009).
- Current survivorship initiatives
  - Healthy People 2020
  - NRC/IOM From Cancer Patient to Survivor: Lost in Transition
Purpose of Research

• Glaserian style qualitative study to generate grounded theory.
• Explore the dynamic process of breast cancer survivorship
• Aid in defining the psychosocial challenges women experience once they have completed breast cancer treatment and enter extended survivorship

Literature Review

• Small sub-set of research
• Breast cancer survivorship (Pelusi, 1997)
• Lack of theoretical framework as evident by the fragmented presentation in the literature.
• Un-met needs
  • Physical, support, psychological, communication, information
  • Evident in both qualitative and quantitative research
• Psychological distress
  • Fear of recurrence, loneliness
• Majority of study participants older, Caucasian
• Age range 26-87 with mean age range 50-60y
• Timeframes in which research conducted varied

Research Questions

• How do women who have been diagnosed with breast cancer process challenges of transitioning into long term breast cancer survivorship once they complete acute and adjuvant care?
• What are the challenges the women themselves identify?
• When does transitional survivorship begin and end for women who have completed initial treatment for breast cancer?
Why Grounded Theory?

- The phenomenon of breast cancer survivorship:
  - Identified with phenomenology
  - Lacked explanatory theory
  - Hypothesized to be a complex social process
- The goal of grounded theory is particularly suited to examine and develop explanatory theory of basic social processes.
- Grounded theory documents and values the perspectives of the people involved in the situation being studied. This allows researchers to understand complex social processes.
- Grounded theory will allow for advancement of breast cancer survivorship theoretically.

Description of Sample and Setting

- IRB-Rutgers & Faxton St.Lukes Healthcare
- Inclusion and Exclusion Criteria
  - 18, speak English, not cognitively impaired
  - Diagnosed and completed initial treatment
- The study took place at public libraries or locations chosen by the participants in Upstate New York.
- Purposive sample drawn from breast cancer survivors in a suburban community.
- Theoretical saturation.

Participants

- 12 women diagnosed with breast cancer and had completed initial treatment
- Age range 39-81
- Mean age 58 (SD=13.37)
- 100% Caucasian
- 2 participants had experienced recurrence (17%)
- 1 confirmed metastatic disease (8%)
- 1 questionable metastatic disease (8%)
Data Source and Collection

- 12 In-depth interviews
- Demographic data form
- Observational notes & field notes

Data Analysis

- ATLAS ti
  - Open Coding
    - Line by line
    - What is going on?, What is the situation?, How is the individual managing the situation?
    - Fractured data into nouns formed from verb or gerund words ending in "ing" to code actions recognized in the data
  - Selective Coding
    - Occurred once core category was identified, researched delimited coding to variables that related to the core category
    - Continued until researcher felt there was saturation of the core variable – Interview 7,8,9
  - Theoretical Coding
    - Codes related to one another as hypotheses to be integrated into theory
  - Memoing
    - Concurrent
  - Theoretical Sorting
    - Outline emergent theory

Rigor

- Trustworthiness
  - Credibility
    - Prolonged Engagement
    - Peer Debriefing
    - Member Checking
  - Transferability
    - Thick Description
  - Dependability
    - Inquiry Audits
  - Confirmation
    - Audit Trail
    - Reflexive Journal
Theory of Negotiating Emotional Order

- Basic social process: Negotiating Emotional Order
- Temporal Aspect
  - Perpetual: “It’s gone but it’s not”
  - Cyclic
- Cutting Points that indicated emotional disruption included
  - 1) Finding an Abnormality,
  - 2) Waiting for Confirmation of Diagnosis,
  - 3) Confirmation of diagnosis,
  - 4) In Treatment,
  - 5) Completing Treatment,
  - 6) Moving On-Accepting what can control and what cannot control.

Theory of Negotiating Emotional Order

- Emotional Modifiers
  - Spirituality
  - Humor and Positive Outlook
  - Information
  - Interpersonal Influences

Stage I
Losing Life Order
- Threat Becomes Reality
- Losing Control; the Group 
- Uncontrollable Family Order

Stage II
Assisted Life Order
- Treatment as Sanctuary
- Family in Experience

Stage III
Assuming Life Order
- Managing: Where do we go?
- Living in each day, living on from here

Stage IV
Accepting Cannot Control Threat
- Chap of Returning
- Living with Reminders
- Living with Society

Stage V
Creating Emotional Order
- Controlling
- Rebuilding
- Emotions
- Rebuilding the self
Stage I
Losing Life Order
• Treatment as a Sanctuary
• Loneliness in Experience

Stage II
Assisted Life Order
• Remapping: Where do I go?
• Getting on with Life: Moving on from Fear

Stage III
Assuming Life Order
• Fear of Recurrence
• Order versus Control
• Living with Reminders
• Physical, Body Image, Diagnostics, Society Cancer Awareness

Stage IV
Accepting Cannot Control Threat
• Compartmentalizing
• Social Comparison
• Benefit Finding
• Planned Helpfulness

Stage V
Creating Emotional Order
Negotiating Emotional Order
Discussion

• Gap in nursing literature reporting un-met needs consistent with report of HCP not addressing psychological aftermath of breast cancer
• Sherman, Rosedale, & Haber, 2012
• Transitional Survivorship Identified-Stage III Assuming Life Order
• Redefinition of the Stages of Breast Cancer Survivorship as compared to Mullan (1985) Seasons of Survivorship
• Fear-
• Control-catalyst shaping decisions and actions of participants

Strengths/Limitation of the Study

• Strengths
  ▪ Findings grounded in the narratives expressed by women who had completed treatment for breast cancer
  ▪ Range of years of survivorship allowed a wide representation of the phenomenon over time
  ▪ Realistic view of the population of interest

• Limitations
  ▪ Sample not diverse
  ▪ Novice researcher
  ▪ Population Specific

Implications for Nursing Practice

• Understanding the Theory of Negotiating Emotional Order allows for nurses understand their role as powerful interpersonal modifier
• Assist nurses to support, educate and encourage breast cancer survivors as few theory based interventions for counseling women with breast cancer exist (Lev & Owen, 2000).
• Assist nurses to acknowledge informational needs and periods of emotional loss of control: diagnostics, health care visits and encourage nurses to inquire about psychological wellness
• Implement communication and assessment of psychological well-being.
Lessons Learned: Timing

• Basic social process: Negotiating Emotional Order
• Temporal Aspect
  • Perpetual: “It’s gone but it’s not”
  • Cyclic
• Cutting Points that indicated emotional disruption included
  • 1) Finding an Abnormality,
  • 2) Waiting for Confirmation of Diagnosis,
  • 3) Confirmation of diagnosis,
  • 4) In Treatment,
  • 5) Completing Treatment,
  • 6) Moving On-Accepting what can control and what cannot control.

Lessons Learned

• Timing
  • Immediacy-Time is of the essence
  • Diagnostics: Routine and emergent
  • Results of diagnostics
  • Weekends, holidays, and answering services

Lessons Learned: Emotional Modifiers

• Emotional Modifiers
  • Spirituality
  • Humor and Positive Outlook
  • Information
    • Web MD
    • The internet is a scary place
  • Interpersonal Influences
Lessons Learned: Communication

- The Hidden Conversation
- Listen

Lesson Learned: Emotions

- Fear
- Uncertainty

Stage I
Losing Life Order
- Lose autonomy, reality
- Losing balance, self-care tools, community or sudden family order

Stage II
Assisted Life Order
- Treatment as necessary
- Lovers in experience

Stage III
Assuming Life Order
- Managing, where do I go?
- Lovers in experience
- Living in fear

Stage IV
Accepting Cannot Control Threat
- Fear of recurrence
- Losing balance, living with reminders
- Living with reminders
- Disease, stage, diagnostics, society, cancer awareness

Stage V
Creating Emotional Order
- Compartmentalizing
- Planned helpfulness
- Social comparison
- Benefit finding
- Planned helpfulness
Lessons Learned: The BC Experience

• Everyone does things differently
• Not everyone thinks PINK!

Recommendations

• Replicate the study in other ethnic groups
• Replicate the study indifferent cancer populations
• Explore BCS that fall into the cutting points uncovered in this study to further expand theory

“Apprehension, uncertainty, waiting, expectation, fear of surprise, do a patient more harm than any exertion” (p.25, Nightingale, 1859/2003).