“Mirror, Mirror, on the Wall…”

The Effect of Pre-Operative Education & Self-Reflection on Anxiety, Body Image, Depression & Emotional Well-being of Women Undergoing Mastectomy

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Objectives

1. Discuss how the status of mirrors in health care facilities served as the impetus for a descriptive study about Looking at Self in Mirror After Mastectomy

2. Summarize the collaboration process in the initial mirror study.

3. Discuss the first study to include: type, design, and methodology

4. Describe the ONN experience as a first time co-investigator in a research study.

5. Identify nursing interventions associated with the study

6. Discuss the study entitled: the effect of pre-op education and self-reflection on anxiety, body image, depression and emotion well being of women undergoing mastectomy
Discuss how the status of mirrors in health care facilities served as the impetus for a descriptive study about Looking at Self in Mirror After Mastectomy.

THE HISTORY

WYONA FREYSTEINSON, PH.D., MN
History

- 1960’s Grandma Fannie
- 1970’s Miss Peace
- 1974 Bed Bath Lab
- 1990 Dean says No to Thesis Topic
Seven terminally ill women told their stories of viewing self in the mirror. One woman told the story of viewing her mastectomy site at home, alone.

“I felt like running out on the road and screaming.”

The PhD Nursing Student Journey

- What mirrors are available for postoperative women with breast cancer who have had a partial or complete mastectomy?
- 10 Houston Hospitals
- Short answer: Not many

PICO Literature Review

- Population: In the human population
- Intervention: What is the effect of nurses using a mirror in caring for and/or teaching patients
- Compared: Not using a mirror
- Outcome: On Patient Outcomes

- Short Answer: Nothing!

- Used in post comatose states, CVA, dementia, anorexia, bulimia, phantom and other pain.

I Talked with Nurses by Email

- South Africa
- Egypt
- Japan
- Netherlands
- Panama
- Russia
- Singapore
- United Kingdom
Use of Mirror in Nursing Practice

- Mamma care nurses (Netherlands) use mirrors during initial mastectomy dressing changes. They encourage loved ones to be present.

- Delivery of babies

- Colostomy care, self-catheterization

- Echograms & other procedures

- Children’s port-a-cath

- Self grooming

I Went to Skilled Nursing Facilities

- What mirrors are available to older adults who live in SNF?
- Short answer: Not many!
- Many naysayers!

Naysayers vs One Nervous Student

- Community consultation with 40 people of a breast cancer community

- *Is a research study that asks women to talk about the intimate details of viewing a mastectomy site in the mirror worthy of research?*

- Short Answer: Absolutely!

- Freysteinson, W.M. (2010). The ethical consultation model as preparation for nursing research: A case study. *Nursing Ethics, 17*(6), 749-758.
Community Consultation

- The woman *hoped nurses would have a greater understanding* of the emotions and physical concerns women have when seeing their surgical *incisions, drains, and changed bodies* in a mirror.

- Talking about one’s own experience of viewing self in the mirror may act as a *cathartic moment* and help to bring closure.
Summarize the collaboration process in the initial mirror study.

RESEARCH COLLABORATION ACROSS A HOSPITAL SYSTEM

AMY S. DEUTSCH, DNP, RN, CNS, AOCNS®
Collaborate

- To work jointly with others or together especially in an intellectual endeavor
- To cooperate with an agency or instrumentality with which one is not immediately connected

PhD (student) & DNP: 2 Terminal Practice Degrees

- Doctor of Philosophy (PhD)
  - Research-focused
  - Nurse scientists who develop new knowledge for the science and practice of nursing.
  - Lead interdisciplinary research teams
  - Design & conduct research trials
  - Disseminate knowledge for nursing & related disciplines

- Doctor of Nursing Practice (DNP)
  - Practice-focused
  - Nursing leaders who promote practice excellence through EBP gained from nursing research.
  - Improve systems of care & measure outcomes.
  - Health policy advocates
  - Interdisciplinary collaborators

http://nursing.duke.edu/modules/son_academic/index.php?id=108
Accessed January 17, 2012;
The 1st Meeting

- PhD Student
  - School Requirement – Dissertation
  - Subject Expert – prior research
  - Author
  - History of Mirror Research
  - Body Image r/t Breast Cancer Patients

- DNP
  - Recognized importance of research due lack of evidence & research being a requirement for ACOS COC approved CA progs.
  - Work with CA patients across a hospital system
  - Support EBP
  - Knew types of RNs best suited to assist w/ study – oncology nurse navigators
What is an Oncology Nurse Navigator (ONN)?

- The ONN is a professional whose clinical nursing expertise guides patients, families and their caregivers to informed decision-making; collaborating with a multi-disciplinary team to allow for timely cancer screening, diagnosis, treatment, and increased supportive care across the cancer continuum.

They Say a Nurse Wears Many Hats....
“Selling” the Idea: The Research Hat
“Selling” the Idea

- To ONNs (pilot ONN first, then others)
- To Physicians – get MD Champion at each facility (Face to Face, Letters)
- To CNOs - pilot facility CNO first, then others (E-mail, Letters)
- To Cancer Committees at participating facilities - pilot facility first, then others (presentations)
- To System Research – (Phone Call, E-mail)
- To my Boss (Face to Face; Letter/E-mail)
DNP + PhD\textsuperscript{(student)} + ONNs Collaborate

- DNP sets up in-service
- PI conducts in-service for co-researchers (DNP/ONNs)
  - Research study
  - Required on-line education of ONNs (co-investigators) to research (protection of human subjects)
  - Required paperwork for IRB
  - Development of Recruitment Scripting with ONN & DNP participation
- ONNs recruit participants
- DNP & ONNs conduct “1st reviews” of transcribed documents & provide comment
Discuss the first study to include: type, design, and methodology

THE FIRST STUDY

WYONA FREYSTEINSON, PH.D., MN
First Mirror Study

- Research Question

What is the experience of viewing self in the mirror after a mastectomy?
Acknowledgements

- Study Co-Researchers
  - Amy S. Deutsch, DNP, RN, CNS, AOCNS®
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  - Sandra K. Cesario, PhD, RNC, FAAN

- Texas Woman’s University John Winston Carter Small Research Grants

- Houston Affiliate of Susan G. Komen for the Cure® Small Grant
Participants

- 12 women ages: 32 – 76
- 8 Caucasian, 2 Hispanic, 2 American Black
  - ≥18 years of age who had a mastectomy
  - Surgery within 3-12 months of first interview
- Recruited by oncology nurse navigators at three Memorial Hermann Hospitals
Data Collection/Analysis

- Conversational *audio-taped interview*

- The data was analyzed using:
  - Naïve reading
  - Structural approach (empirical science)
  - Phenomenological approach (human science)
Structural Definition

- **My Body**
  - Viewing
  - Not Viewing

- **My Thoughts**
  - Energizing
  - Dispiriting

- **Others in My World**
  - Supportive
  - Unsupportive
My Body: Viewing

- Viewing incision with a health care professional: 1
  - My doctor and the nurse...they said are you ready to see yourself? And my husband was with me ...I was happy for me that it was actually going to be in front of other people.

- Viewing incision for first time at home: 1

- Viewing self with another: 8

- Viewing more often: 5
My Body: Not Viewing

- Three women struggled to view their incision for the first time without a mirror.
  - *I could see the breast was gone but I couldn’t see all this stuff back in under my arm.*
  - *If you’re showing somebody something that’s out of their eye range.... Just to take the mirror and let you just lay down, kind of like soak it in, your body.*
My Body: Not Viewing

- Lack of hospital mirrors, no access, or no recall of mirrors.
  - *I would have liked to see it right away to see what it looked like...in the hospital.*

- Three women avoided viewing self in a mirror for several days.
  - *I wouldn’t look because I just didn’t want to see anything. I wasn’t encouraged to look either.*
My Thoughts: Energizing

- Putting Life into Perspective
  - *Yah, it’s ugly looking and it always will be unless I have reconstruction surgery. But it really doesn’t bother me, because….I was excited to get the Cancer out. It was a tradeoff, it was worth every stitch.*

- Faith

- Helping Others
My Thoughts:  Dispiriting

- Worry/envisioning what others may see

  - At first I thought you know everyone can tell ... I just feel like everybody can see it, even with the bra on and stuff. I still feel like everybody can see or they can tell you know something is off.

- Concern loved one will not accept me.
Others: Supportive

• Family/Friends help me
  ◦ My husband helps me all the time now. I’ll stand in the mirror and see if I am crooked. I’ll ask him if I’s straight and he’ll tell me yah you gotta straighten it you know.

• Support Groups, Nurses/ONN/doctors

• Website/books/pictures
Others: Unsupportive

- Family/Friends have their own troubles.
- Family/Friends may be rude or squeamish
- Unplanned Medical Journey (*Domino Effect*)
  - Insurance concerns
  - Rude, poor, or lack of communication
Phenomenological Interpretation

- Four key meaning moments emerged in the interpretation of viewing self in the mirror:
  - I am
  - I decide
  - I see
  - I consent
I Am

- Genetics, life experiences and environment help to create a unique way of being-in-the-world.

I am self-conscious.

I am wise.

I am very blessed.

I am Scandinavian.
I Decide

- **Curiosity**

  *I think it is just a natural curiosity to look and see what’s happening to you.*

- **Medical Care**

  *I thought that (bathroom) was the most logical place (to change the dressing).*

- **Keeping up Appearances**

  *You make your self look better (with the mirror) by using prosthesis or whatever means there are for beauty.*
I See: With my Mind’s Eye

• Apprehension

_ I was going to have a mastectomy so I used to see myself in the mirror, and try to imagine how I would look._

• Expectation

_ This scar is uglier than I thought it would be. I thought it would be a little bit prettier._

• Hope

_ I used to imagine before I went to the mirror that my breast would still be there, that this has all been a dream._
I See: With my Eyes

*It depends on how your eyes are I guess because my eyes aren’t good either.*

Also I’ve got macular degeneration and I’ve already had glaucoma …One side (of the mirror) is magnified and the other one isn’t. So I really can get a good look.
I See the Meaning: Understanding

- All women understood part of their body to be unattractive, unsightly or repulsive.

- Many emotions accompanied this understanding: shock, surprise, disgust, unworthiness, anger/frustration, fear, sadness, relief & happiness.
I See the Meaning: Understanding

(I was) looking in the mirror constantly. . . . It was gross, it was so disgusting. I couldn’t hardly face myself or look at it because it was so disgusting.

But I was so ecstatic that it (mastectomy incision) was closed! See the attitude change? I’m like look at this, it’s stitched closed!
I See the Meaning: Understanding

- **Distanciation**

  You’re seeing *that* every time you stand in front of the mirror.

  *It looks real ugly.*

- **Appropriation**

  *My scar is beginning to fade.*
I don’t know how to explain what I am talking about. It is like they (doctors) took a lot of flesh off of me.

You know that’s the devil in there.

You’d be surprised what men say about this, this surgery. They can’t cope with it.
I Consent

• Suffer

You have your days where you could sit there and have a pity party.

• Acceptance/Acquiesce

I still do look in the mirror and wish I had more you know up there but may have to learn to accept it, the way it is.

• Thrust Forward into the Future

It is crazy, but what keeps me going is knowing that these ... old breasts are going to be replaced.
Metaphor: Battle Spot

- The battle with Cancer.
  - I was going to win no matter what.

- The mastectomy scar is not always understood to be an honorable badge.
  - A spot.
  - My secret.

- The mastectomy site is a spot which is at times unbearable to view in a mirror. It is a spot which all participants expressed needed to be hidden, reconstructed, or disguised.
Describe the ONN experience as a first time co-investigator in a research study.

THE ONN EXPERIENCE

CAROL LEWIS, BSN, RN, CRNI, OCN
The New Researcher

- The initial meeting
- Clinical vs Research experience
The ONN Research Experience

- Pre-Study
- During the Study
- After the Study
Identify nursing interventions associated with the study.

**NURSING INTERVENTIONS**

CAROL LEWIS, BSN, RN, CRNI, OCN
Nursing Interventions

- Pre-op education which includes an accurate visual understanding of the incision site needs to be developed with a focus on:
  - alleviating inaccurate anticipatory expectations, fears, and hopes.
  - Offsetting emotions of shock, surprise, and/or anger.
Nursing Interventions

- Post-op care should include offering a mirror to the patient for the initial viewing of the incision site.
Nursing Interventions

- Mirror Talk

- I think you nurses should let women talk about this stuff (the mirror). Not that “how you doing today stuff” cause we are just going to say “fine thank you”….You know, you should say to women, “how you really doing, how you really feeling” and then give folks a chance to say what’s really on their minds.

- Discussions can be:
  - 1:1
  - Loved ones present
  - Breast cancer support groups
Clinical Nursing Interventions

- Mirror education for hospital, clinic, and home health nurses

- Assessment of the adequacy of mirrors in hospital rooms, clinics, and patient homes:
  - Are there more mirrors in the elevators than in patient rooms?
  - Do the over bed table mirrors work?
Clinical Nursing Interventions

- Altered body image
- Removing the dressing
  - Challenges
  - Timing
Clinical Nursing Interventions

- Emotions
  - Anxiety
  - Fear
  - Depression
- Significant Other Involvement
- Women vs Men
Discuss the study entitled: the effect of pre-op education and self reflection on anxiety, body image, depression and emotion well being of women undergoing mastectomy.

THE SECOND STUDY

WYONA FREYSTEINSON, PH.D., MN
The Second Study: PICO

- **Population:** In women > 18 years of age who are scheduled for a mastectomy,

- **Intervention:** What is the effect of pre-operative mirror education

- **Comparison:** As compared to no education

- **Outcome:** On anxiety, body image, depression and emotional well-being?
The Second Study

- The purpose of this study is to evaluate the feasibility of a nursing mirror educational intervention and determine if it is of potential value for women scheduled for a mastectomy.

- Results from this pilot study will help determine whether the research design, setting, sample, instruments, data collection and data analysis are appropriate and practical for a larger study.
Methods

- Randomized control trial
- Population of 20 women from five MHHS hospitals
- Intervention group (10)
  - ONN education on mirrors
  - Mirror
- Control group (10)
  - Usual care
Why ONN’s

- ONN’s see patients throughout the entire breast cancer journey.
Study Tools

- **Demographic Form.**

- **Body Image Scale (BIS).** 10-item scale measuring affective, behavioral, and cognitive aspects of body image in patients with breast cancer.

- **Hospital Anxiety and Depression Scale (HADS).** 14-item self-reported screening tool to evaluate anxiety and depression.

- **MOS 36-Item Short Form Survey (SF-36) emotional well-being subscale.** 5-item scale.

- **Functional Assessment of Cancer Therapies (FACT) emotional well-being scale.** 6-item subscale to measure well-being designed specifically for cancer patients.

- **Researcher constructed structured questionnaire.** A structured questionnaire on the use of mirrors will be administered at the post-operative time point.
When do we start?

- Initial IRB approval has been received from UT and TWU.
- However, a change request is pending approval.
- Anticipated start date July/August 2012
Why a Change Request?

- Dr. Michelle Fingeret has been added as a Co-PI to the study.

- Assistant Professor Department of Behavioral Science with joint appointments in the Departments of Plastic Surgery and Head and Neck Surgery at the University of Texas M. D. Anderson Cancer Center.

- Dr. Fingeret is a licensed psychologist and has developed an innovative line of research centering on body image issues for oncology patients.
What happens Next?

- After this pilot, refine the study.
- Possibly add MD Anderson and other hospitals as study sites to existing five MHHS sites.
- Submit an application for national funding.
Research Needs

- What is the role of other nurses in the care of a patient who has had a mastectomy?
  - Surgical hospital nurses
  - Clinic nurses
  - Home health nurses

- What symptoms may constitute a nursing referral to a psychologist?
Research Needs

- Appropriate use of the mirror with other patients who have suffered disfigurement after surgery or other trauma:
  - Head and neck
  - Burns
  - Spinal cord injury

- The effect of mirrors on spiritual and cultural care.

- Ideal types of mirror, placement of mirrors, and best light for mirrors.
Research Needs

- Body image after disfiguring surgeries and trauma is essentially an unexplored field.

- Currently we do not know how many questions there are and what those questions may be.
Questions & Comments