

THE EXPERIENCE OF VIEWING SELF IN THE MIRROR  
AFTER A MASTECTOMY

A DISSERTATION  
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BY  
WYONA M. FREYSTEINSON, M.N.

DENTON, TEXAS

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TEXAS WOMAN'S UNIVERSITY  
DENTON, TEXAS

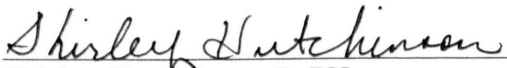
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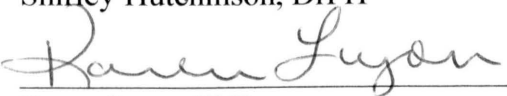
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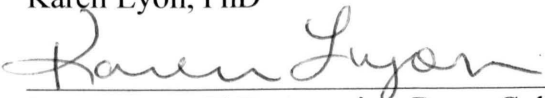
I am submitting herewith a dissertation written by Wyona M. Freysteinson entitled "The Experience of Viewing Self in the Mirror after a Mastectomy". I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy with a major in Nursing Science.


  
Sandra K. Cesario, PhD

We have read this dissertation and recommend its acceptance:

  
Shirley Hutchinson, DrPH

  
Karen Lyon, PhD

  
Karen Lyon, PhD, Associate Dean, College of Nursing

Accepted:   
Dean of the Graduate School



## DEDICATION

To my husband, Tom Zahn,  
thank you for your continuous support, serenity, and love.

To my mother, Lila Freysteinson,  
thank you for always believing in me.

To my sons, AJ, Jordie, Nick, John, and James and your families,  
thank you for your unending love.

To my grandchildren,  
thank you for reminding me to play and have fun.

To my late father, Donald Freysteinson,  
I know you continue to cheer me on.

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My sincere appreciation to my committee members for their candid comments, words of encouragement, and thought provoking questions. Dr. Shirley Hutchinson

helped to ensure a cultural balance. Dr. Karen Lyon's own experience with a family member who had a mastectomy added insight to the project.

Although they remain anonymous, I would like to express my appreciation to the 12 women who participated in this study. Without their honest, often difficult, and thought provoking words on their experiences, this description of viewing self in the mirror would have remained silent. These women hoped this research would help other women in the future. I will work to make their hope a reality.

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## ABSTRACT

WYONA M. FREYSTEINSON

### THE EXPERIENCE OF VIEWING SELF IN THE MIRROR AFTER A MASTECTOMY

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The purpose of this study was to talk with women who have had a mastectomy in order to discern the experience of viewing self in a mirror post-operatively. More specifically, the study sought to describe the experience from both a structural and a phenomenological perspective. The question guiding the study was: What is the experience of viewing self in the mirror after a mastectomy?

Twelve women, who had a mastectomy 3-12 months prior to participation in the study, discussed their experiences of viewing self in mirror in audio-taped conversational interviews. A structural analysis was performed on each transcript, followed by a phenomenological interpretation. A second interview was held with two women to validate the findings.

In the structural analysis, actants, actions, and opposing ideas in the text were uncovered. This analysis revealed the world of the participants. Key actants were: my body, my thoughts, and others in my world. These actants were further broken down into opposing actions: viewing and not viewing my body in a mirror; my energizing and dispiriting thoughts, and supportive and non-supportive others. The phenomenological

interpretation revealed the experience of viewing self in the mirror after a mastectomy from the perspective of a woman looking in a mirror. Four key themes were uncovered: I am, I decide, I see, and I consent. The theme *I see* was further broken down into seeing with the mind's eye, seeing with the eyes, and seeing the meaning. Seeing the meaning is a complex moment of both understanding and explanation.

Implications for nursing practice, education, and research were considered with respect to the results. Understanding this experience of viewing self in the mirror leads to sensitive nursing interventions including: discussion of the impact of the mirror experience before and after surgery; and offering a mirror when changing the dressing and teaching ongoing site and drain care. There is a need to develop educational materials for nurses and patients. This research project simply places a footprint on a vast, largely unexplored, field of nursing, with several opportunities for future research.

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# CHAPTER I

## INTRODUCTION

### **Focus of Inquiry**

The focus of this research project was to explore the experience of viewing self in the mirror after a mastectomy. There are no known published national or international nursing practice guidelines or nursing theories regarding the use of mirrors. A literature review uncovered no research regarding the use of the mirror with women who have had a mastectomy.

The inspiration for this study was derived from a nursing research study of the perceptions of terminally ill women viewing self in the mirror (Freysteinson, 1994). One participant was hospitalized for three weeks following a radical mastectomy. As she did not see her mastectomy site in a mirror in the hospital, she viewed the incision site in a bathroom mirror in her home, alone. When she saw her reflection of the mastectomy site, she felt “a dreadful shock....I felt like running out on the road and screaming. That’s what I felt like doing when I first came home and saw myself in the mirror” (p. 108).

This story raises questions. What should nurses say, if anything, to patients who have had a mastectomy, about mirrors? Should nurses offer a patient who has had a mastectomy a mirror during initial and/or subsequent dressing changes? Are the mirrors in hospitals adequate for viewing the mastectomy site in a mirror? Is a mirror required to teach a mastectomy patient how to care for drains and dressings?

Currently, there is little direction for nurses to any of these questions. Love and Lindsey (2005) suggested to women with mastectomies: 'This is the body you're going to be living with, and you need to see it and accept it' (p.377). They offer no guidance as to how or when women should *see it*. The American Cancer Society (2009) indicated women who have had any type of cancer surgery view the ostomy, scar, or hair loss in a mirror fully clothed, and later with no clothes on. In the Netherlands, mamma care nurses (Freysteinson, 2009a) use mirrors when caring for women who have had a mastectomy. In addition to there being scarce instructions for nurses, there has been no research of these interventions.

Prior to researching interventions regarding the use of the mirror for women who have had a mastectomy, we must first delve deeply into the mirror encounter, and try to understand and describe that experience. Phenomenological hermeneutic methods of inquiry attempt to deal with complex sensitive human experiences. This research methodology uses a data collection process of conversational interviews. The interviews are transcribed. Analysis of the transcribed documents net new insights, understandings, and questions may emerge which may provide fruitful direction for nursing. Should instinct prove to be correct - that this is an emotionally difficult experience - the knowledge gleaned in this study may begin to shape evidence-based healing interventions.

### **Problem of Study/Statement of Purpose**

The focus of this study is to explore the meaning of women's mirror experiences following a mastectomy. Of interest are women's perceptions of viewing the post-surgical site in a mirror the first time after breast cancer surgery, and in subsequent mirror encounters post-surgery. The goal of the research is to establish a conceptual foundation for further research on facilitating acceptance of body image following a mastectomy to promote psychological well-being. In addition, this research may provide direction for future research on the appropriate use and placement of the mirror in clinics, homes, and hospitals where post-surgical care (i.e. initial and subsequent dressing changes) may occur. This study strives to answer the question: What is the experience of viewing self in the mirror after a mastectomy?

### **Rationale for the Study**

The visual field the mirror offers is unique. A mirror is required to view the reflection of one's face, neck, much of the back, and depending on an individual's functional capability, the chest area. This research is grounded in an underlying assumption that viewing oneself in a mirror is a basic human right. "Without mirrors, one is a virtual stranger to oneself" (Freysteinson, 2010a, p.35). In this study, it is assumed that women have the right to choose to view or not view their bodies and mastectomy sites in a mirror. The alternative was to assume individuals do not have the right to view their own bodies. Taking this path may lead to elimination of all mirrors in our health

care environments. This pathway is reminiscent of a time when hospitalized patients were not told their diagnosis or their own vital signs.

The researcher first sought to understand the experience of viewing self in the mirror for terminally ill women (Freysteinson, 1994). In 2006, the researcher returned to graduate school to focus on the study of mirrors in nursing. The mirrors in patient rooms in ten hospitals where women who had a mastectomy may stay following surgery were surveyed (Freysteinson and Cesario, 2008). The rooms in ten nursing homes were also surveyed (Freysteinson, 2010a). Ten healthcare clinicians from eight countries (South Africa, Egypt, Japan, the Netherlands, Panama, Russia, Singapore, and the United Kingdom) were consulted on the use of the mirror in their nursing practice, and available mirrors in their health care environments (Freysteinson, 2009a). Personal experience in the use of the mirror in critical care (Freysteinson, 2009b), a literature review of the therapeutic use of the mirror in healthcare (Freysteinson, 2009c), and a mirror community consultation (Freysteinson, 2010b) was shared with the nursing community. This pursuit of knowledge of the use of the mirror in nursing practice provides the foundation for this study.

The reason for choosing to study the mirror experience for women who have a mastectomy is that women who have had an amputation of a breast may face a mirror everyday. Intuitively we may imagine the experience may be, at least initially, psychologically distressing. A large body of evidence suggests there is psychosocial distress and negative feelings about body image associated with breast cancer (Baucom,

Porter, Kirby, Gremore, & Keefe, 2005/2006; Parker et al., 2007). Qualitative studies suggest living with breast cancer is difficult (Arman & Rehnsfeldt, 2003; Ashing-Giwa et al., 2004; Langellier & Sullivan, 1998).

The literature review consists of two peer-reviewed journal articles. The first article (Freysteinson & Cesario, 2008) that describes a survey study of the mirrors in 10 hospitals in rooms where women who may have a mastectomy may stay after surgery prompted the question: Have we lost sight of the mirrors? The survey indicated a lack of mirrors available for these women. For example, in 7 out of 10 hospitals, there were no mirrors for the bed-bound patient. The survey illuminated the possibility that women who may have wanted to assess if they appeared lopsided in clothing prior to going home, may not have been able to do so, as there may have been no appropriately placed mirror. For example, in some rooms, the mirror was so high on the wall that one would need to be a giant in order to view the chest area. This survey gave credence to the notion that a study of mirrors for this population may be worthy of consideration.

The second article in this review (Freysteinson, 2009c) is a literature review of the therapeutic use of the mirror in health care. An intensive search of the data bases, including abstract searching, uncovered just one mirror article in nursing (Tabak, Bergman & Alpert, 1996). Of interest was the finding that the mirror was used therapeutically in ten fields of medicine. Common elements were identified within these mirror interventions which may be useful in the development of future nursing



interventions regarding the use of the mirror. The lack of research regarding the mirror in nursing gave additional support to the need for this study.

In order to prepare for this study, the researcher used a process of community consultation in pre-research fieldwork. Community consultation is a process, where members of the community who have a common interest are invited to share their opinions and concerns about the research in question. A mastectomy community of 24 breast cancer survivors and 16 health care clinicians were invited to enter into a community consultation project. Over a three-month period, data was collected concerning the potential legitimacy of the study, study benefits, participant protection, and ways in which the community may enter into a partnership with the researcher in formulating the study (Freysteinson, 2010b).

Several community members indicated that although one may strain to look down to see the mastectomy site, a mirror is necessary to visualize the entire mastectomy site, axillary area, dressings, and drains. There was agreement among the majority of participants that “thinking about viewing the mastectomy site is to think of viewing oneself in a mirror” (Freysteinson, 2010b, p. 753). Community members indicated the study was a legitimate project that may help the medical community in understanding the emotions, feelings, and concerns women may have after a mastectomy. The community members provided insight into sample inclusion/exclusion criteria, protection of human subjects, and interview questions.

This study seeks to provide a conceptual framework of the experience of viewing self in the mirror for women who have had a mastectomy. This conceptual foundation may help lead to the development of a mirror theory which may be useful to nursing and other health care disciplines. Questions may emerge from this study which are worthy of future research. Concepts and/or variables, which may be helpful in future interventional mirror research, may also be uncovered. There may be interest in the type, placement, and number of mirrors required in healthcare buildings where women who have had this surgery may have dressing changes post-operatively.

Ultimately, this study may lead to the development of nursing guidelines as to how to use a mirror with women who have had a mastectomy in order to enhance body image. Parse, Coyne and Smith (1985) suggested studies of lived experiences might guide the practice of nursing in simply honoring an individual's values, choices, and ways of being in the world. Van Manen (1990) indicated being aware of the lived experience of another may lead to an increased sensitivity, thoughtfulness, and understanding of other.

### **Philosophical Underpinnings**

Ricoeur's philosophy of phenomenological hermeneutics provided the philosophical foundation for this study (1966, 1974, 1975, 1981, 1992). In an article outlining over 50 years of work, Ricoeur (1975) discussed how his ideas about ontology and epistemology have evolved over time. Ricoeur's (1966) philosophy of the will was written using the existentialism reflective method of Husserl, Jaspers, and Marcel. This

phenomenological philosophy extracts from everyday experiences the essential underlying structures and meaning of experience. This philosophy was the underpinning for the researcher's thesis work on the mirror experiences of terminally ill women (Freysteinson, 1994; Freysteinson & Cesario, 2008).

Ricoeur (1975) recognized a difficulty when he tried to bring the problem of evil (i.e. suffering) into the meaning of experience. Essentially, he found ordinary language is used to describe the phenomenology of simple everyday experiences (i.e. motive, purpose); however, symbolic language is used to describe evil (i.e. spot, stain). Faced with this linguistic perplexity, Ricoeur believed he had to introduce hermeneutics into analysis of reflective thought of symbolic human experience. As such, hermeneutics became a study of symbols, and symbols could be understood using hermeneutics. Over time, however, Ricoeur began to believe that hermeneutics could be extended beyond symbolism to encompass all written language or texts.

At the time of this hermeneutic revelation, structuralism was gaining popularity in France. Ricoeur (1975) found himself merging structural analysis together with his philosophy of phenomenology. It is at this point in Ricoeur's career path that this particular study is grounded.

Ricoeur does not provide a formula or specific methodology for research. This, together with his personal transformation regarding knowledge may provide insight into why nursing scientists have differing opinions on how Ricoeur's philosophy may be used in nursing research (Charalambous, Papadopoulos & Beadsmoore, 2008; Lindseth &

Norberg, 2004; Sander Dreyer & Pedersen, 2008; Tan, Wilson & Olver, 2009; Wiklund, Lindholm & Lindstrom ,2002). Each researcher interprets and chooses a research methodology based on his or her own history of knowledge and, as it is in this case, an understanding of a particular assortment of Ricoeur's work. As such, this study brings a slightly different viewpoint or interpretation of Ricoeur's philosophy and research methodology.

Hermeneutics is the interpretation of texts. "Interpretation...is the work of thought which exists in finding the hidden meaning in the apparent meaning, in unfolding the levels of meaning implied in the literal meaning" (Ricoeur, 1974, p.13).

Phenomenology extracts "from lived experiences the essential meanings and structures of purpose, project, motive, wanting, trying, and so on" (Ricoeur, 1981, p. 316). Ricoeur advocates a reflective phenomenology, where lived experience may only be understood upon reflection.

Ricoeur (1966) establishes his theory of the will, a phenomenological theory of lived experience, on Husserl's notion of *intentionality*. The act, which connects consciousness to the world, is *intentionality*. Intentionality means conscious and non-conscious acts of thinking, perceiving, or remembering are always about some-*thing*. As such, viewing self in a mirror is an intentional act. Two dialectics, distanciation and appropriation, and explanation and understanding, act as keystones in Ricoeur's work.

## **Distanciation and Appropriation**

Ricoeur (1974) grounds interpretation of texts in an ontology of understanding, and asserts understanding a text is a way of understanding a being-in-the-world. There is distanciation between a reader and a text in four ways: (a) the event is passed; (b) the original speaker has vanished; (c) the sociological elements of production (i.e. time) have disappeared; and (d) the original audience is gone. The text is *opened up* to an infinite number of readers. Ricoeur's key hypothesis of interpretation is that a text will not produce one single description. However, the text, although open to many readers and meanings, will have a narrow field of potential interpretations.

A reader is initially distant from a text; however, the reader may orientate self to the text, interpret the text, and through interpretation, appropriate the text to self making it his own. "It is thus the growth of his own understanding of himself that he pursues through his understanding of the other. "Each hermeneutics is thus, implicitly or explicitly self-understanding by means of understanding others" (Ricoeur, 1974, p.17).

## **Explanation and Understanding**

The hermeneutical arc encompasses both explanation and understanding of the text (Ricoeur, 1981). When analyzing the text, one approaches the text from both a structural explanation and a hermeneutic phenomenological interpretation. Reading the text is the dialectic of these two aspects of the hermeneutical arc. The initial analysis is an explanation of the text. To explain a text Ricoeur turns to linguistic theory and its simple system of signs. In explanation analysis, the text is read with no transcendent aim

or psychological considerations. The reader seeks to find the structure of the text. Throughout this process, all statements within the text are moved into action categories, and oppositional units are uncovered. Through this process, the *sense* of the text is explained. The structural interpretation is a phase in between a simple or naïve reading of the text and an in-depth interpretation.

The in-depth phenomenological interpretation provides an understanding of a possible world and *reference* as to the world that the text points to. The text is opened up to the world, so that a reader may “conjoin a new discourse to the discourse of the text” (Ricoeur, 1981, p.158). The world of the text, and that which the text references now become the world of the reader. The text speaks to a reader who becomes the subject in the text. The final product of phenomenological hermeneutics may be represented though ordinary language, poetry, art, or metaphor. Examples of Ricoeur’s descriptions are a phenomenology of the will (Ricoeur, 1966) and ontology of the self (Ricoeur, 1992).

### **Summary**

There is little to no literature to guide nurses in the use of a mirror in their day-to-day clinical practice. A study of the experience of viewing self in a mirror after a mastectomy may give an otherwise silent experience a voice, and may provide nursing with new knowledge that may otherwise have been unknown. The researcher brings considerable understanding of the mirror in nursing to this research project.

Hermeneutical phenomenology provides a sensible foundation and research methodology

for this sensitive study. The science of mirrors in nursing appears before us as an unexplored landscape. This study hopes to plant a footprint on that landscape in honor of women who have had a mastectomy. It is hoped the study findings may lead to sensitive nursing practices for these women.

## CHAPTER II

### HAVE WE LOST SIGHT OF THE MIRRORS? THE THERAPEUTIC UTILITY OF MIRRORS IN PATIENT ROOMS

A paper published in *Holistic Nursing Practice* 2010, 22, 317-323.

Wyona M. Freysteinson, RN, MN & Sandra K. Cesario, RNC, PhD

#### ABSTRACT

There is little known research in nursing or in hospital design on mirrors. This article reports the results of a survey of the mirrors in patient rooms in 10 hospitals. The survey focused on the mirrors within rooms where women with breast cancer who have had a partial or complete mastectomy might stay after surgery. Mirrors to view one's full body and mirrors for the bed-bound patient were not available in the majority of hospitals. Privacy to view self in the mirror was also lacking. Viewing self in the mirror is an everyday lived experience for many outside the hospital. This survey points to a need for further research on the mirror in nursing practice and within our healing healthcare environments.

**KEY WORDS:** *mirror, patient rooms*

Florence Nightingale dedicated her life to nursing and to the creation of sanitary conditions within hospitals. She fought for and achieved clean, albeit stark environments. Since Nightingale's time, hospitals continue to change. There has been a metamorphosis away from cold, sterile environments toward environments in which



high-tech mixes with tranquil hotel and home-like elements. Adaptability, flexibility, sustainability, transformability, and universality are the current buzzwords in healthcare design. There is a focus on acuity adaptable rooms, patient- and family-centered care, and bringing the home to the hospital. Computers and numerous other technological devices in patient rooms are attractively enclosed in wooden cabinetry and other hotel-like structures. Patients and families have access to all of the comforts of home, including television, computers, and video games. Gardens, window views, and artwork help promote overall healthcare quality. There appears to be a growing consensus that patient rooms may have the potential to heal and promote well-being.<sup>1-6</sup> In all this commotion, have we lost sight of the mirrors?

### **STUDY INSPIRATION**

The words of one woman provided the inspiration for this study. She viewed her postsurgical mastectomy site in a mirror for the first time alone in her home. Her words were audiotaped by the author and transcribed in a research study on the lived experience of viewing self in the mirror for terminally ill women.<sup>7</sup> Her story of the often agonizing lived experience of viewing self in the mirror, a suggestion of a lack of emotional support from nurses and other healthcare professionals, and a lack of mirrors in her hospital room inspired this study.

I had a mastectomy five years ago. . . . Nobody will know what I went through. It was a terrible mess. I felt like running out on the road and screaming. That's what I felt like doing when I first came home and saw myself in the mirror. All this raw stuff

hanging there. . . . I thought this is it for me, seeing my body all chopped up like that. . . . I'd sit at the mirror. I would cry and say to myself how stupid. It's there and I got to face it. I can't cover up. I can't hide. I just got to face it and that's what I did. . . . I was in the hospital in December. We thought it might be the end. . . . I had brought my own mirror along. I could look if I wanted to but I don't know—maybe some people would be suspicious if they saw you looking in the mirror all the time. People may say: There's that crazy old dame. Why is she doing that?<sup>7</sup>(pp107–109)

This article describes a survey concerning mirrors in single patient rooms in 10 hospitals in the United States. The question giving direction to the survey was what mirrors are available for postoperative women with breast cancer who have had a partial or complete mastectomy?

## **LITERATURE REVIEW**

Cromptvoet's term "breast amputation"<sup>8</sup>(p75) may sound harsh; however, it does describe the partial or complete loss of one's breast or breasts. The impact of breast cancer surgery may be fraught with negative emotions, feelings, behaviors, and symptoms that are similar to traumatic stress.<sup>9</sup> There may be shock, emotional numbness, depression, anxiety, dissatisfaction with body image,<sup>10,11</sup> and a decrease in self-esteem and confidence.<sup>12</sup> Altered feelings of femininity, sexuality, and increased self-consciousness of one's appearance may occur in the society.<sup>13–15</sup> *Suffering* is a word used to describe the existential experience of living with breast cancer.<sup>16</sup> Managing appearances appears to be important to the breast cancer survivor as there appears to be an unspoken urgency

to return to activities of daily life.<sup>17</sup> Immediate reconstruction of the breast appears to decrease but not eliminate the psychosocial impact of losing a breast.<sup>8,18,19</sup>

The literature concerning mirrors in hospitals is limited. Ulrich et al<sup>6</sup> uncovered more than 600 evidence-based practice studies on healthcare design. No mirror studies were found in this project. Similarly, Schweitzer and colleagues<sup>20</sup> in their survey of the research literature on elements of healing in healthcare design, uncovered no mirror studies. The Facility Guidelines Institute makes one reference to a mirror: “Mirrors shall not be installed at hand-washing stations in . . . scrub sinks, or other areas where asepsis control would be lessened by hair combing.”<sup>21</sup>(p111)

Mirrors have been used in the study of disorders. Adolescents with personality disorder may see their mirror images as objects and have difficulty coordinating the object body to self.<sup>22</sup> Mirror exposure for treatment of eating disorders appears to be of value.<sup>23,24</sup> The best mirrors for persons with body dysmorphic disorder may be full-length mirrors rather than imprecise mirror reflections from windows and other shiny or reflective surfaces.<sup>25</sup>

Exercise studies found mirrors may increase one’s self-awareness and/or self-efficacy.<sup>26–28</sup> A randomized control study of mirror therapy in the treatment of paralysis in stroke patients found significant improvement in the mirror group.<sup>29</sup> Body size estimation studies have had inconsistent findings indicating either overestimation<sup>30</sup> or accuracy<sup>31</sup> of body size estimation.

After an extensive literature search, one nursing study on the use of the mirror was found.<sup>32</sup> In this pilot survey study, patients with dementia were observed as they viewed self in the mirror. The nurses suggested the mirror was a medium that one may view and understand the inner world of others. Nurses have antidotal mirror information. Kimlin et al<sup>33</sup> had one research participant who said mirrors may make one wonder if one can accept self. Langellier and Sullivan<sup>34</sup> indicated the mirror may reflect more than just simple image, but a transformation of self. Thomas-MacLean<sup>17</sup> ponders whether or not reflections in a mirror enhance knowing. Madjar and Walton<sup>35</sup> suggest there may be healing value for patients in viewing self in the mirror.

A description of the structure of the lived experience of mirroring for 7 women provides some understanding of viewing self in the mirror.<sup>7</sup> *Viewing self* in the mirror, even in the briefest of glimpses, is an experience of 4 meaning moments: self-decision, self-assessment, self-knowledge, and self-consent. These moments are not moments in time, but rather moments of meaning. Prerequisites to mirroring include accessibility and capability. To view self in the mirror, mirrors must be available and one must be physically capable of viewing self in the available mirror. Women may go to different lengths to get to a mirror: one woman climbed over side rails to get to a mirror in a hospital room.

### **Self-decision**

There is a myriad of reasons to view oneself in the mirror. Deciding to view self in the mirror may simply be a habitual pattern or a willed decision. Checking to

*see what others see*, looking to *see how bad it really is* and simply looking to *see if I am ok* are reasons to look in a mirror. Choosing to view self in the mirror can be a paradoxical experience of wanting and not wanting to look. There is a desire to see self and fear of what one may see.

### **Self-assessment**

One comes to the mirror with an anticipation of what one may see. There may be past mirrored glimpse of self in the mind's eye: one becomes accustomed to seeing one's usual self in the mirror. Or, in the case of a mastectomy site one has not yet seen, there may be dread of what one might see. The counterpart of anticipation is evaluation.

When one sees self in the mirror, there may be neutrality: I look like me. Or, in the case of viewing a mastectomy site for the first time, there may be emotion and a value judgment. One may refer to the mirror image as it, this, or that, suggesting distancing of the body or body part. In distancing, the image in the mirror is remote or alien from oneself. In essence, one does not accept oneself or part of oneself. Referring to the mirror image as I, my, or me suggests appropriation of self. In appropriation, there is acceptance of the mirror image as being oneself.

### **Self-knowledge**

The moment of assessment brings self-knowledge of the image in the mirror. There is a self-explanation: I look like that because I had surgery. One brings to this explanation a way of being-in-the-world, which colors all experience and is one's way of

understanding. One may live, for example, being-in-the-world-gratefully: I am alive. Or, one may live being-in-the-world anxiously with a constant quest for answers: Why me? Every individual has his or her own unique way of being-in-the-world.

### **Self-consent**

Consent to self-knowledge is lived on a horizon of hope to denial and despair. In denial, there is a refusal to accept the image in the mirror. In despair, one accepts the image in the mirror with no possibility of hope for the future. In hope, one sees continued living and possibilities. For example, one may envision that prosthesis may help one look better. One of the women in this study hoped her words would inspire nurses to offer mirrors to those who could not get to a mirror by themselves.

## **METHODS**

An institutional review board approval was not required as no human subjects were used during the course of the research. Mirrors in an empty, single room for patients in each of 10 hospitals in the United States were surveyed. Permission to view the empty rooms was granted by the nursing director of each unit. The empty room was identical to each of the other rooms in the surgical unit (where women with breast cancer might stay postoperatively). As such, 1 unit in each hospital was surveyed. The hospitals ranged in size having from fewer than 200 beds to more than 900 beds. The mix included teaching hospitals, specialty hospitals, community-based hospitals, and hospitals with Magnet status. The oldest hospital was built in 1925 and the most recent in 2002. Total number of mirrors, total mirror coverage, privacy, ability to look in a mirror if bed-bound, ability

to see one's chest, a barrier-free view of chest, and ability to see one's whole body in a mirror were studied. Mirrors were measured for height and width. The distance between the mirror and the floor was measured. Obstructions in front of the mirrors (ie, towel holders) were measured and subtracted from total mirror coverage. Barriers (ie, sinks) were also measured. All measurements were rounded to the nearest centimeter (Appendix).

## **FINDINGS**

In this study, the total number of mirrors in a hospital room ranged from 1 to 4 mirrors with a mean of 2.1 mirrors. Total mirror coverage varied from as little as 0.2 m<sup>2</sup> to as great as 2.1 m<sup>2</sup>. There did not appear to be a correlation between the year a hospital was built and the number, coverage, adequacy, or privacy of the mirrors. A hospital (of Magnet status) built in 1989 had the most mirrors (4), greatest mirror coverage (2.1 m<sup>2</sup>), greatest degree of adequacy, and privacy. The hospital most recently built (2002) had 3 mirrors; however, the mirrors did not allow for a barrier-free view of the chest or the ability to see the whole body. Older hospitals (20%), which had not been renovated within the last 10 years, provided no mirrors for the bed-bound patient or mirrors allowing one to see one's chest or whole body.

### **MIRRORS FOR THE BED-BOUND PATIENT**

Mirrors were not available for the bed-bound patient in 70% of hospitals in this study. In 3 hospitals, the tabletop mirrors were broken off and completely missing. In 3 other hospitals, the tabletop mirrors were extremely difficult to open: the researcher sought

assistance in opening these mirrors. In 2 cases, the assistant also struggled to open these mirrors. In 1 hospital, there was a mirror evident in the overbed table; however, no one was able to open this mirror. Mirrors that were available for the bed-bound patient were found only on overbed tables. Only 3 tabletop mirrors were available and in working order. Two of these available tabletop mirrors were roughly the size of a large envelope ( $24 \times 12$  cm) and as such appeared to allow a partial view of one's face. One of the tabletop mirrors was slightly larger in size ( $24 \times 23$  cm), which appeared to allow for a better view of one's face and neck.

#### **MIRROR FOR THE AMBULATORY PATIENT TO VIEW CHEST**

Mirrors allowing an ambulatory patient the possibility of viewing the chest area were not available in 20% of hospitals in this study. In these 2 hospitals there was 1 small mirror in the room placed high (137–140 cm) on the wall above a sink. One would need to be very tall to see one's chest in this mirror. Ironically, in one of the hospitals with this type of mirror, a glass framed picture allowed for a shadow like reflection of the chest area. Mirrors allowing one to visualize the chest area were found in 80% of the hospitals.

#### **BARRIER-FREE VIEW OF CHEST IN THE MIRROR**

In 90% of the hospitals in this study, there was a barrier of a sink or a counter between a person and the mirror (barriers ranged from 39 to 58 cm). A patient wanting a closer view of self would need to lean across the barriers. Obstructions were obvious in 3



Table 1.

## Hospital Mirror Measurements

Hospital	Built in year	Year of Renovation	No. of mirrors	Total, m <sup>2</sup>	Able to see chest	Barrier-free view of chest	Able to see Whole body	Privacy	Tabletop mirror	Restroom mirror: Measurements within brackets is distance from floor to mirror	Other mirrors: Measurements within brackets is distance from floor to mirror
1	1975	2007	1	0.7	yes	no	no	no	Broken Mirror	None	86 x 114 cm (89cm ) with 381 cm obstruction and 48 cm barrier
6	1950	2006	4	1.3	yes	no	No	yes	24 x 12 cm- Difficult to open	Sink 1, 58 x 89 cm (91cm) with 41 cm barrier. Sink 2: 41 x 36 (91) with 58 barrier.	Mirror with above counter 64 x 91cm (91cm) with 48 cm barrier
5	1959	2006	1	0.4	yes	no	No	no	Broken Mirror	None	Mirror above sink 58 x 78 cm (102 cm) with 56 cm barrier
2	1975	2005	1	0.4	yes	no	no	yes	Unable to open	Sink 58 x 74 cm (102 cm) with 267 cm obstruction and a 41 cm barrier	None
4	2002	2002	3	0.7	yes	no	No	yes	24 x12 cm	Sink 41 x 56 cm (135 cm) with a 41 cm barrier	Mirror above counter 58 x 84 cm (119 cm) with 39 cm barrier
3	1971	2001	2	1.2	yes	no	No	no	24 x 12 cm- Difficult to open	None	Mirror above sink 130 x 104 cm (99 cm) with 2116 cm obstruction and 53 cm barrier
7	1997	1997	2	0.6	no	no	No	no	24 x12 cm	None	Mirror above sink 58 x 89 cm (102 cm) with 56 cm barrier
8	1989	1989	4	2.1	yes	yes	Yes	yes	24 x 23 cm	One full length behind door 183 x 61 cm. Sink 66 x 43 cm (114 cm)	Wooden framed mirror above vanity in room 109 x 58 cm (86 cm) with 53 cm barrier
9	1977	> 10 years	1	0.2	no	no	No	no	Broken Mirror	None	Mirror above sink 38 x 46 cm (137 cm) with 43 cm barrier
10	1925	> 10 years	2	0.2	no	no	No	no	24 x 12 cm- Difficult to open	None	Mirror above sink 43 x37 cm (140 cm) with 56 cm barrier

hospitals and included paper towel holders, soap dispensers, and what appeared to be a sharp's container. One hospital did have a mirror that allowed for a barrier-free view of the chest.

### **WHOLE-BODY VIEW IN THE MIRROR**

The majority (90%) of hospitals in this study did not provide a mirror allowing for a view of the whole body. A full-length mirror was available in one hospital. This was achieved through the use of a full-length mirror placed on the back of the restroom door. It was noted that discretion had been used in the placement of this mirror. The commode was not directly in front of the mirror when the restroom door was closed.

### **PRIVACY**

In 60% of the hospitals in this study, there was no privacy offered to view self in a mirror. Privacy was found only within the restrooms, because the door to the restrooms could be locked by a patient. The doors to the patient rooms could not be locked. In 4 of the hospitals, the mirror was placed directly by the door that led to the common hallway. Even if hospital and nursing administration were able to ensure all healthcare workers waited for an invitation to enter after knocking, they could not ensure all visitors would follow this same procedure. As such, there was no guarantee of privacy in these rooms. The researcher also wondered if these sinks right by the doors to the room might be considered scrub sinks<sup>21</sup> and as such be subject to the no-mirror guideline. Privacy was offered in 40% of the hospitals. In these hospitals, there were mirrors available in the restroom.

## DISCUSSIONS

This hospital-mirror survey has revealed there is little to no congruence among hospitals as to where builders and contractors placed mirrors in rooms where women with breast cancer might stay following surgery. Mirrors for the bed bound, mirrors allowing for a view of the whole body, and privacy were not available in the majority of hospitals in this study. During this survey, informal discussions occasionally surfaced, regarding the mirror with various members of the hospitals' staff. Staff members included nurses, unit clerks, nursing directors, and business administrative staff. A financial officer, a member of one hospital administrative team, asked a poignant question: Do women who have had *that surgery* even want to look in a mirror?

### **Implications for nursing**

Financial officers, hospital builders, and building contractors are not expected to understand the lived experience of viewing a mastectomy site. Nurses, however, may enter into this journey with the mastectomy patients they care for. In offering or having mirrors available, do nurses offer a time for silent reflection, an opportunity to begin to accept an altered body, and a way for the healing to begin? In our quest to bring the home to the hospital, do we dare bring the mirrors too?

Patients who have had a mastectomy should not have to wait to view their surgical sites in the mirror when they return home, nor should they have to wait until they can stand on a chair in a hospital restroom to see their chest area. The possibility of negative emotions, shock, and potential of falls is great. In anticipation of this possibility, nurses

may consider gently asking patients whether they wish to view self in the mirror and whether they want to be alone or have the nurse or husband present. A goal may be to have patients view their surgical sites in a mirror at least 1 time before going home, where there are nurses available for emotional support.

Nurses are in a pivotal position to act as mirror advocates for their patients. Mirrors appropriate for a patient room may include tabletop mirrors that are large and easy to open. A full-length mirror may be placed on a discrete wall in the restroom to allow for privacy and a barrier-free view of the whole body. Alternatively, a standing portable full-length mirror may be placed in the patient room. Mirrors should be low enough and large enough for those who need to sit to view self in the mirror. One may want to consider the type of light in the room that may impact the mirror image positively or negatively. High-impact glass in mirrors may provide for an element of safety. Safe, portable mirrors may be helpful to nurses as they care for patients too weak to get to a mirror.

### **Research implications**

Qualitative research on the lived experience of viewing self in the mirror for unique populations may provide a foundation for a mirror theory. The effect of mirrors, if any, on spiritual and cultural care may be of value. Research on mirrors in patient rooms in hospitals may aid in creating optimum healing environments. Knowledge is needed regarding the ideal types of mirror, placement of mirrors, and best light for mirrors. Research on the appropriate use of the mirror with mastectomy patients may help create evidence-based practice guidelines.

## **CONCLUSION**

This article has reviewed the inspiration for the study of hospital mirrors for women with breast cancer who have had a mastectomy. The methodology used to survey a unit within 10 hospitals has been described. The findings have been reviewed. Mirrors that may be appropriate for hospitals have been suggested. This survey points to a need for further mirror research in the field of nursing and within our holistic healthcare environments. We might ask: Would Nightingale have approved of mirrors? With her incredible sensibility and sense of functionality, we wonder if this may be so.

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CHAPTER III

THERAPEUTIC MIRROR INTERVENTIONS: AN INTEGRATED  
REVIEW OF THE LITERATURE

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Wyona M. Freysteinson, MN

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**ABSTRACT**

The mirror is an object that shows one a reflected image of body areas. There appears to be limited nursing literature about the role of a nurse in the use of a mirror. There is, however, literature of the therapeutic use of mirrors in medicine, neurology, psychiatry, psychology, physical medicine and rehabilitation, and rheumatology. The objective of this article is to review the basic elements and the underlying theoretical framework of mirror interventions. In 2007 to 2008, a keyword, abstract, and title search was conducted for therapeutic mirror studies between the years 1998 and 2008. A multidisciplinary, integrated review approach was used when it became apparent that there were limited nursing studies. Qualitative and quantitative strategies for reviewing evidence were used, and a narrative synthesis approach was used to guide the

comprehensive synthesis. Underlying theoretical models were identified, and five elements of mirror interventions were synthesized from the literature.

**Keywords:** *literature review; mirror; reflection*

A mirror is a “glass coated with a metal amalgam that reflects a clear image” (The American Oxford Dictionary, 2002, p. 860). A mirror offers a visual field ordinarily not seen from the standpoint of the first person. Globally, nurses use a mirror when caring for patients. Having had little or no training on the appropriate use of the mirror in their schools of nursing, they are guided by their own experiences, preferences, and assumptions (Freysteinson, 2009). At the national level, there were few mirrors available for women who had mastectomy done in 10 hospitals in the United States (Freysteinson & Cesario, 2008). The words of one woman (Freysteinson, 1994) were the motivation for this article:

I had a mastectomy five years ago. . . . When I first came home it was a dreadful shock. No one will know what I went through. It was a terrible mess. I felt like running out on the road and screaming. That is all that I felt like doing when I first saw myself in the mirror. (p. 108)

We may ask, Had this woman viewed her new mastectomy site in a mirror with the professional guidance of a nurse, would she have had to experience this situation alone in her home? Would she have continued to relive the moment 5 years after the incident? Mirror use is often embedded in the literature and difficult to find. In research articles on body image of advancing age, arthritis, breast cancer, burns, cachexia,

esophageal cancer, and spinal cord injury, antidotal mirror comments were uncovered. These comments were synthesized into three categories: facing the mirror, recognizing the change, and *accepting the change*.

### **Facing the Mirror**

In a descriptive study of 35 burn patients, facing the mirror for the first time was a critical event (Bergamasco, Rossi, da Amancio, & de Carvalho, 2002). This is the moment of looking at oneself and seeing an altered body image. In a hermeneutic study of 10 women who had breast flap reconstruction surgery, one woman was excited to stand in front of the mirror and see her *new* breast: “I couldn’t wait to rip off the bandages and see” (Hill & White, 2008, p.85). Women who have had mastectomies may avoid frontal views in the mirror (Langellier & Sullivan, 1998). Some participants with cachexia, a significant and rapid weight loss, avoided mirrors and expressed feeling such as “people in the concentration camps” (Hinsley & Hughes, 2007, p. 86).

### **Recognizing the Change**

One may need to view one’s self in the mirror several times to fully *see*, *recognize*, and *comprehend* a changed body. A patient who had suffered burns indicated that he had to view his self in the mirror several times when he got home from the hospital as he did not recognize himself (Bergamasco et al., 2002). In a qualitative study of obesity, a woman stated, “I never was a pudgy-faced person. . . . You look in the mirror and it’s like, my God, what happened?” (Blixen, Singh & Thacker, 2006, p. 292).

In a study of esophageal surgery, one man stated, “You get a bit paranoid about your weight; you keep looking in a mirror and say God you’ve lost” (Wainwright, Donovan, Kavada, Cramer, & Blazeby, 2007, p. 763). Interviewees expressed a lack of recognition of their aging faces when asked about the mirror in a study of aging (Paulson & Willig, 2008). In a qualitative study of rheumatoid arthritis, viewing herself in the mirror, for one woman taking prednisone, revealed a “bloated, ugly person” (Plach, Stevens, & Moss, 2004, p. 147).

### **Accepting the Change**

Chau et al. (2008) suggest that learning to accept the change and self may require professional intervention. In a grounded theory study of spinal cord injury, they found that participants generally had negative emotions in the early rehabilitation stages. Some may never fully accept a changed appearance. A woman 17 years post-spinal cord injury confided that she would find herself catching a glimpse of her reflection in a window at the mall and finding it “more of a reality thing” (p. 214). In a qualitative study of 102 women with breast cancer, one woman spoke of the mirror: “The majority of us feel degraded as women as we see ourselves in the mirror and wonder, if we cannot accept ourselves, how can our husbands or partners?” (Ashing-Giwa et al., 2004, p. 422).

There is no known literature to guide nurses in designing mirror interventions for these difficult moments. In the greater health care world, however, there is literature of *mirror therapy* and/or therapeutic interventions using a mirror. This review sought to (a) synthesize the evidence on mirror therapy in its various forms, (b) understand the

theoretical underpinnings of mirror interventions, (c) identify common elements of therapeutic mirror interventions, and (d) offer recommendations for nursing research.

### **Design**

The design was situated in the theoretical assumption that viewing one's self in the mirror may, at times, require a therapeutic mirror nursing intervention. Polit and Beck's (2008) strategies for finding and critiquing qualitative and quantitative evidence were used to gather the data. Popay et al.'s (2006) narrative synthesis approach was used to guide the comprehensive synthesis. A multidisciplinary, integrated review approach was used when it became apparent that there was limited nursing literature.

### **Search Methods**

In the years 2007 and 2008, searches were conducted in Academic Search Premier, CINAHL, CSA Health Sciences, EBSCO, ERIC, MEDLINE, Physical Education Index, PsycINFO, ProQuest Nursing and Allied Health, ScienceDirect, and SCOPUS. Search terms used were *body image*, *looking glass*, *mirror*, *reflection*, *research*, *self-awareness*, *self-image*, and *self-perception*. Terms were searched in keywords, title, and abstract.

Inclusion criteria were peer-reviewed published studies written in the English language between the years 1998 and 2008 concerning a mirror therapy or intervention and any aspect of adult health. Some publications were uncovered through hand searches of citations. The search was limited to the years 1998 through 2008 so as to isolate mirror interventions reflecting current practice. However, as no nursing mirror studies

were found in this date range, the search was expanded to include *all* dates for nursing mirror research. One nursing study was found and is included in the review.

Excluded from the study were research studies on mirrors and animals. Studies concerning children were excluded, as the focus of this review was mirror interventions and adults. Research studies focusing on mirrors in the physical sciences such as transportation mirrors, telescopes, lens, lasers, and x-rays were also excluded.

### **Search Outcome**

The search revealed a paucity of abstracts. For example, using the search terms *mirror* and *research* in CINAHL in the abstract produced 372 titles, as the term *mirror* is frequently used figuratively to suggest something that resembles something else (*The Oxford American College Dictionary*, 2002). Abstract searching netted 142 articles. This number was further reduced to 41 articles by selecting research-based mirror papers. The evidence was further reduced to 25 articles by isolating those papers that considered the use of a mirror therapeutic.

### **Data Abstraction**

A comprehensive Excel matrix was used to abstract the data. Headings included reference, year, keywords, title, journal, country, health care field, study question, independent and dependent variables, conceptual framework, disease/body part, research design, sampling methods, sample, method, mirror intervention, data analysis, findings, major strengths and weaknesses, feasibility, ethical appropriateness, and effectiveness. In



addition, thematic columns were included to capture element and theoretical themes in the data .

### **Quality Appraisal**

Noyes and Popay (2006) suggest that one may retain all applicable studies regardless of appraisal quality. Although all articles were appraised in this review, all applicable research studies, case studies, and pilot studies were retained. Articles that may provide insight into the various types of mirror interventions used by health care providers and the underlying theories supporting the evidence were retained. Key data are summarized in Table 2.

### **Synthesis**

Polit and Beck (2008) use the analogy that synthesis of the literature is not a mechanical straightforward undertaking. Rather, synthesis is much like doing a qualitative study. One must dwell with the data, ruminate over the findings, and at times, one must stand back from the information to *see* the themes within the data.

### **Results**

There is no clear definition of a mirror intervention in the literature. Nor is there a unifying way of naming mirror therapy. Interventions using the mirror have been called *mirror interventions*, *mirror therapy*, or *mirror as therapeutic tool*. Environmental descriptive names include *mirrored environment* and *mirrored exercise environment*. *Mirror confrontation*, *mirror exposure*, *mirror feedback*, *mirror visual feedback*, and *graded motor imagery* are also terms used in describing the therapeutic use of a mirror.

There are also myriad ways in which mirrors are used in a healing, curative, or therapeutic manner. In the following subsections, the many uses of the mirror as a therapeutic tool are described.

### **Dementia**

A nursing pilot exploratory study was conducted (Tabak, Bergman, & Alpert, 1996) to determine the effects of a mirror in 100 patients with dementia. The majority of patients recognized themselves in the mirror. Findings suggested that reactions were positive and included relaxation, enjoyment, and laughter, suggesting a therapeutic response to the mirror. The authors indicated that mirrors helped nurses communicate with the mentally frail by providing a medium through which to explore their internal world. The mirror therapy consisted of placing mirrors of various sizes on the unit.

### **Postcomatose States**

Researchers (Vanhaudenhuyse, Schnakers, Bredart, & Laureys, 2008) believed that without the use of a mirror as a tracking device, several participants in a study sample ( $n = 51$ ) would have been misdiagnosed as being vegetative. Three tracking devices were used: a human being, an object, and a mirror. The mirror intervention consisted of using a round mirror held in front of the patient's face and slowly moving it from the left to right. In the study, 11 participants responded only to the mirror as evidenced by clinical assessment of visual pursuit. They did not visually respond to the object or the human-tracking devices.

## **Body Image Disorders**

Body image mirror interventions are considered “a promising technique to overcome negative body related emotions” (Vocks, Legenbauer, Wachter, Wucherer, & Kosfelder, 2007, p. 231). Mirror interventions were planned, deliberate, and usually involved systematic mirror exposure to one’s body parts. In addition to viewing one’s self in therapy sessions in a full-length mirror, body image therapy was provided by a trained therapist. Studies have indicated that the addition of mirror therapy to nonmirror therapeutic interventions has been successful for women with persistent body image disturbances. For example, mirror interventions have resulted in improved thoughts and feelings about one’s self, decreased frequency of checking one’s body in a mirror, improved body image avoidance, decreased dissatisfaction with body parts, decreased dieting, depression, and improved self esteem (Delinsky & Wilson, 2006; Key et al., 2002; Stewart & Williamson, 2003; Vocks et al., 2007; Vocks, Wachter, Wuchereer, & Kosfelder, 2008).

## **Exercise**

Exercise is considered to be therapeutic in relatively sedentary populations (Martin Ginis, Jung, & Gauvin, 2003). The American College of Sports Medicine (1997) advocates that all exercise classrooms should have mirrors on at least two of four walls to help avoid injury, improve form, and enhance benefits of exercise. Studies found that mirrors increased self-awareness and self-efficacy. Some authors postulated that there may be increased feelings of self-mastery and self-capability (Katula & McAuley, 2001;

Lamarche, Gammage, & Strong, 2007; Latimer & Martin Ginis, 2007; Martin Ginis, et al, 2003; Raedeke, Focht, & Scales, 2007).

### **Hemineglect**

Hemineglect may occur in right-hemisphere strokes. In hemineglect, patients tend to neglect everything on their left side. In case studies, the mirror appeared to accelerate the recovery of patients with left-sided hemineglect (Ramachandran et al., 1999) and unilateral spatial neglect with agnosia (Watanabe & Amimoto, 2007). Mirror therapy consisted of a therapist holding objects close to mirrors. The patients became increasingly improved at reaching for the objects.

### **Cerebrovascular Accident and Brain Damage**

In a case study, a patient with a cerebrovascular accident (CVA; Sathian, Greenspan, & Wolf, 2000) appeared to acquire the ability to pick up small objects and coins after mirror box therapy (see Figure 1). In a pilot study, CVA patients with upper extremity hemiparesis were given limb exercises to do while viewing the reflection of the unaffected limb in a mirror box. Motor extremity recovery appeared to show significant improvement (Altschuler et al., 1999; Yavuzer et al., 2008). In an experimental trial of post CVA patients with lower affected extremities, there was significant improvement in the treatment group receiving mirror therapy as compared with the control group (Sutbeyaz, Yavuzer, Sezer, & Koseoglu, 2007). In all these studies, participants indicated that the reflection of the unaffected limb was like looking at their own affected limb. Similarly, in a study of 10 brain-damaged individuals, looking in a mirror box at the

reflection of the right hand tended to induce a sensation of movement in the left in two of the patients (Zampini, Moro, & Aglioti, 2004). The reflected right hand appeared to look like the left hand.

### **Phantom Pain and Complex Regional Pain Syndrome**

In studies of phantom arm pain, patients reported decreased pain during and after mirror box therapy (Chan et al., 2007; Ramachandran, 1998). Four participants were able to unclench what they believed they had felt as a painfully clenched phantom hand during and after mirror therapy, and in one case, phantom limb pain was totally relieved for the first time in 10 years (Ramachandran, 1998). There was an immediate reduction of perception of pain, and by 6 weeks there was normal functioning for 8 participants with early complex regional pain syndrome who used mirror box therapy (McCabe et al., 2003). Participants ( $n = 13$ ) with upper limb complex regional pain syndrome for more than 6 months duration, caused by a wrist fracture, had significant improvement as measured by the neuropathic pain scale following a 6-week mirror therapy intervention (Moseley, 2004).

### **Balance**

Two studies have indicated that the effect of a mirror on body sway appears to have a stabilizing effect on balance. Some authors theorized that mirrors may help reduce falls in the elderly (Galeazzi, Monzani, Gherpelli, Covezzi, & Guaraldi, 2006; Vaillant et al., 2004).

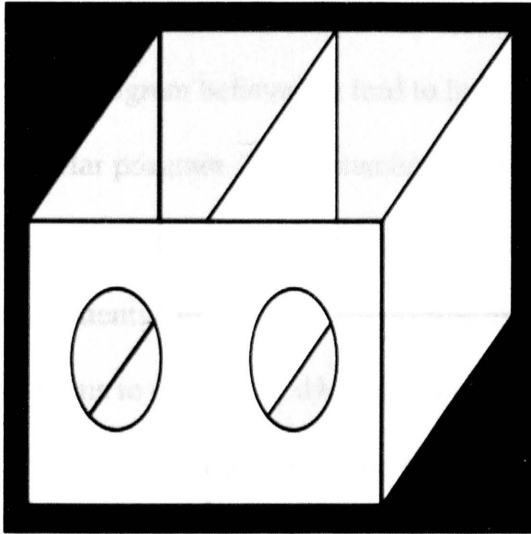


Figure 1. *Mirror boxes*

Note: Mirror therapy boxes are constructed for upper limbs in patients who have suffered a cerebrovascular accident (CVA), phantom limb pain, or complex regional pain syndrome. A mirror is placed laterally into the middle of a box. Upper limbs are placed on both sides of the mirror. The patient looks into the side of the mirror that reflects the unaffected limb. Patients subjectively report being able to almost *see through* the mirror and perceive the reflection they are seeing to be the affected limb. Therapeutic hand exercises of both upper limbs are done while watching the reflected limb. The patient attempts to move the affected limb during these sessions.

## **Theory Synthesis**

Perhaps the most perplexing question in this review was, “How can so seemingly unrelated diagnoses benefit from the therapeutic use of a mirror?” “What is the connection, if any, between the use of a mirror for phantom limb pain and body image disturbance?” There appeared to be two major theoretical views in the literature: theories concerning *self* and neurological theories.

### **Self Theories**

In the self-theory cohort, there was a self-presentation model (Lamarche et al., 2007; Raedeke et al., 2007). The authors described this as anxiety over one’s knowledge of one’s own appearance. Mirrors were postulated to increase self-efficacy and/or

mastery in the exercise environment. Self-acceptance was the focus of a mirror body image program believed to lead to healthier mirror habits (Delinsky & Wilson, 2006). In a similar program, “understanding the formation of Body Self” (Key et al., 2002, p. 187) as conceptualized over time was theorized as having cognitive, behavioral, and affective components. In this program, mirror therapy was believed to draw out strong emotional reactions to one’s self, which led to a reconceptualization of self.

Objective self-awareness theory was the underlying theoretical framework for a body image study (Vocks et al., 2008) and exercise studies (Katula & McAuley, 2001; Latimer & Martin Ginis, 2007; Martin Ginis, et al, 2003). Duval and Wickland’s (1972) theory of objective self-awareness postulates viewing one’s self in the mirror is a form of objective self-awareness. When individuals view their self in a mirror, they compare their appearance with an internal standard or anticipated standard. Any discrepancy between an internal standard of appearance and a perceived actuality in the mirror may have a negative or positive effect.

The conceptual framework supporting Tabak et al.’s (1996) research on patients with dementia was to decrease cognitive deterioration of dementia and preserve self-recognition and self-awareness. Vanhaudenhuyse et al. (2008) indicated that patients in a minimally comatose state tend to be more self-aware of their own reflection and will best track their own face.

## **Neurological Theories**

The other major theoretical cohort suggests an underlying neurological mechanism. In limb movement seen in brain damage, researchers suggested that a higher-order, multimodal neurological area concerned with the integration of a unitary body image is involved (Zampini et al., 2004). Neurological changes are also cited concerning hemineglect (Altschuler et al., 1999; Watanabe & Amimoto, 2007), balance (Galeazzi et al., 2006), and hemiparesis (Sathian et al., 2000). Mirror neurons are cited in CVA (Sutbeyaz et al., 2007; Yavuzer et al., 2008) and phantom pain studies (Chan et al., 2007; Ramachandran, 1998) as being the mechanism that is activated when a body part is viewed in a mirror.

The mirror neuron system is believed to include large portions of the premotor and parietal cortex. These neurons were found to be important in action understanding and imitation (Rizzolatti & Craighero, 2004). The neurons discharge when an individual acts or views another individual performing an action. Of the studies in this review grounded in a mirror neuron framework, mirror neurons were believed to fire when an individual viewed a mirror reflection of his or her body part in action. Self-awareness and self-recognition may also be linked to the neurological theories. There is a suggestion in the self-theory literature that one's reaction to one's mirror reflection may be due to an "automatic mindset" (Delinsky & Wilson, 2006, p. 109), neurological structures (Vanhaudenhuyse et al., 2008), and may "be accompanied by a higher



physiological arousal . . . processed by cortical sensory association” (Vocks et al., 2007, p. 148).

Growing bodies of evidence suggest that neurons are vital in generating self-awareness (Uddin, Iacoboni, Lange, & Keenan, 2007), and functional MRI studies have revealed consistent changes in the frontoparietal areas of the brain during a face self recognition study (Uddin, Kaplan, Molnar-Szakacs, Zaidel, & Iacoboni, 2005).

### **Common Elements of a Mirror Intervention**

In the synthesis, five conceptual elements were uncovered in therapeutic mirror interventions (see Table 2). The elements include self-knowledge (participant “sees” reflected image), therapeutic intervention, repetition, homework, and imagery or relaxation.

#### **Self-Knowledge (Participant “Sees” Reflected Image)**

It is not the mirror itself that appears to be central to mirror interventions. Rather, the self-knowledge gleaned from the reflected image is the key element in the studies in this review. In studies where there was an indication of what participants were *seeing* in the mirror, this reflection of self or body part appeared to lead to *self-awareness*, *self-recognition*, or *self-assessment*.

In studies concerning CVA, paralyzed limbs, or painful limbs, there was, albeit false, knowledge that the image of the nonaffected limb was the affected limb. Body and eating disorder studies suggested that the perceived self-knowledge gleaned by viewing one’s self in the mirror prior to intervention was somewhat flawed. Therapeutic

interventions together with systematic viewing of the body lead to healthier notions of self. Exercise studies, although somewhat vague as to what the participants were *seeing* in the mirror, suggested an increased self awareness or knowledge of self, which lead to increased feelings of self-mastery, and so on.

### **Therapeutic Intervention**

There was some form of therapeutic intervention prescribed by a health care professional in the majority (84%,  $n = 21$ ) of the studies in this review. In body image therapy, participants viewed their selves in the mirror and learned therapeutic self-talk exercises. In CVA and limb pain studies, therapeutic limb exercises of the upper and lower limbs were prescribed. In exercise studies, there were prescribed exercises on treadmills, stationary bicycles, and step aerobics. This suggests that a mirror intervention may not work in isolation. Instead, a professional needs to introduce a therapeutic element into the intervention.

### **Repetition**

Hand in hand with therapeutic intervention is the element of repetition (88%,  $n = 22$ ). In many of the studies, exercises of various types were repeated during a session and in subsequent sessions. In body image studies, subsequent mirror viewing sessions were also required.

### **Homework**

In 28% ( $n = 9$ ) of the studies, homework was prescribed. Patients were sent home to do body image work, or in one case a patient constructed his own mirror box so as to

continue his arm exercises. One author was so convinced in the value of homework that he suggested home mirror interventions should be “on par” (Delinsky & Wilson, 2006, p. 109) with in-house therapy sessions. There was an unspoken assumption that mirrors were readily available in the vast majority of homes and that patients complied with homework instruction.

### **Imagery or Relaxation**

In 36% ( $n = 7$ ) of the studies reviewed, there was an element of imagination on the part of the participant. Patients were asked to imagine an affected limb moving. Relaxation exercises were frequently given in body image therapy.

### **Discussion**

In this review, the theoretical underpinnings that may help in understanding the mechanics behind therapeutic mirror interventions were explored. Additionally, the basic elements of a mirror intervention were identified. This review summarized nursing literature on the therapeutic use of the mirror. There was, however, a growing database of therapeutic mirror interventions in several other health care fields.

### **Review Limitations**

This narrative review of mirror interventions has certain limitations. Case studies, pilot studies, and studies that lacked control groups were included in the review. There were few clinical control trials in the review. Compounding this, there was no clear definition in the literature of a mirror intervention.

## **Implications for Nursing**

This review sought to provide a window into the world of the therapeutic use of the mirror. The basic elements of a mirror intervention, uncovered in this review, may conceivably be used in designing nursing mirror interventions.

For women who have had a mastectomy, for example, nursing interventions may be designed for the initial mirror viewing of the mastectomy incision site. For burn or trauma victims, nurse researchers may find the best time and the best way to bring the mirror to the bedside. Phenomenological research on the experience of viewing one's self in the mirror for specific patient populations with recent bodily changes may provide nurses with insight and enhanced understanding.

Research on the use of the mirror as a communication tool in understanding the inner world of patients (Tabak et al., 1996) may be of value. Studies on the effect of a mirror image on phantom or complex regional pain may help substantiate current studies (Chan et al., 2007; McCabe et al., 2003; Moseley, 2004; Ramachandran, 1998). Further research on the mirror as a safety tool in stabilizing balance (Galeazzi et al., 2006; Vaillant et al., 2004) may be of value in decreasing the number of falls in our health care environments. Research on the use of the mirror as a tracking tool in the minimally conscious, and other states of semiconsciousness, may be of value in the appropriate assessment of neurological states (Vanhaudenhuyse et al., 2008). Research may substantiate current findings on the value of mirror therapy for persons with eating and body image disorders (Delinsky & Wilson, 2006; Vocks et al., 2007, 2008).

Nursing studies that delve into the many uses of the mirror may be valuable especially in developing countries where inexpensive tools for health are needed. Research on the appropriate placement of mirrors in health care environments may be of value in creating optimum healing environments. Evidence regarding the therapeutic use of the mirror may provide knowledge in building nursing practice guidelines and mirror theories.

### **Conclusion**

Mirrors are commonplace in the majority of countries in the world, whereas their therapeutic use is not commonplace in the field of nursing. The lived experience of viewing one's self in the mirror for those who have had a surgery, trauma, or other physical change requires a holistic nursing approach. From the knowledge gleaned from the literature, perhaps nursing may venture forward in the use of simple, healing mirror interventions. Possibly nurse researchers may consider researching the mirror as a therapeutic tool in health and illness. Conceivably, nurses, with their unique perspective of persons and the environment, may even untangle the theoretical web supporting mirror interventions. The study of mirrors in nursing science may be envisioned as a series of gaps, which create a landscape, which is wide open for travel. The challenge now is whether or not to begin the journey into a landscape of mirrors.

**Table 2.**

## Characteristics of Therapeutic Mirror Interventions

Reference	Name of intervention	Area of study	Conceptual Framework	Mirror type & placement	Position of subject to mirror	Subject 'sees' (self-knowledge) reflection of:	Therapeutic intervention	Repetition	Imagery or relaxation	Homework
Valliant et al 2004	Mirror feedback	Quiet standing in elderly	Visual target helps body sway	Mirror	Subject stands in front of mirror	Front of body	none	no	no	No
Stewart et al 2003	Mirror exposure	Body image disorders	Systematic desensitization/cognitive behavioral	Mirror	Patient stands in front of mirror during therapeutic session	Body areas	Cognitive behavioral therapeutic exercise	yes	yes	Yes
Lamarche 2007	Mirrored environments	Exercise	Self-presentation /self-efficacy	Mirrored environment	Exercise in front of mirror	Unknown	Step aerobics	yes	no	No
Raedeke et al 2007	Mirror impact	Body image disorders	Self-presentation	2 mirrored walls	Exercise in front of mirror	Unknown	Step aerobics	yes	no	No
Katula et al 2001	Mirrored exercise environments	Exercise	Self-awareness/self-efficacy	Full length mirror	Exercise in front of mirror	Body	Treadmill exercise	yes	no	No

continued

Table cont'd

Vocks et al 2008	Mirror exposure	Eating disorders	Self-awareness/cognitive behavioral	Full length mirror	Patient stands in front of mirror during therapeutic session	Body areas	Cognitive behavioral therapeutic exercise	yes	yes	Yes
Latimer 2007	Mirrored exercise environments	Exercise	Self-awareness	Mirrored environment	Exercise in front of mirror	Unknown	Moderate intensity exercise	yes	no	no
Martin Ginis 2003	Mirrored environments	Exercise	Self-awareness	Mirrored Wall	Exercise in front of mirror	Unknown	Stationary bicycle	yes	no	No
Tabak et al 1996	Mirror as therapeutic tool	Dementia	Self awareness	Mirrors of various sizes	Nurses asked patients to look in mirror. Some patients intentionally viewed self in a mirror	Self	none	yes	no	No
Delinsky et al 2006	Mirror exposure	body image disorders	Self-acceptance/behavioral	Full length 3-way mirror.	Patient stands in front of mirror during therapeutic session	Body areas	Behavioral therapeutic exercise	yes	no	yes

continued

Table cont'd

53	Altschuler et al 1999	Mirror therapy	Hemiparesis	Premotor Cortex Recruitment	Mirror propped up vertically on table on the affected limb side	Paretic arm concealed behind mirror. Non-paretic arm exercises in front of mirror	Non-paretic arm	Bilateral hand and arm exercise	yes	no	No
	Ramachandran et al 1999	Mirror	Hemineglect	None	Mirror propped up vertically on right side of patient	Objects held in front of the mirror	Objects and the world to the left side	Reaching for object exercises	yes	no	No
	Ramachandran 1998	Mirror	Phantom limb pain	Neurons	Mirror propped on table	Phantom limb concealed behind mirror. Normal limb exercises in front of mirror	Unaffected limb	Bilateral hand exercises	yes	yes	No
	Sathian et al 2000	Mirror therapy	Hemiparesis	Neuron activity changes	Mirror box	Affected hand concealed in mirror box. Non-affected hand exercises in front of mirror	Unaffected limb	Bilateral hand exercises	yes	yes	yes

continued



Table cont'd

Watanabe et al 2007	Mirror intervention	Unilateral spatial neglect	Neurological	Mirror propped up vertically on the right side	Objects held in front of the mirror	Objects	Reaching for object exercises	yes	no	No
Galeazzi et al 2006	Mirror exposure	Balance	Neural connection	Full length mirror	Subject stands in front of mirror	Body	none	no	no	No
McCabe et al 2003	Mirror visual feedback	Complex regional pain syndrome	Motor intention/sensory feedback	Mirror positioned between patient's legs	Painful limb concealed behind mirror. Non painful limb exercises in front of mirror	Non painful lower limb	Bilateral lower leg exercises	yes	yes	yes
Chan et al 2007	Mirror therapy	Phantom limb pain	Mirror neuron theory	Mirror placed on side of affected limb	Amputated limb concealed behind mirror. Non amputated limb exercises in front of mirror	Non affected limb	Bilateral limb exercise	yes	yes	No

continued

Table cont'd

Moseley 2004	Graded motor imagery	Complex regional pain syndrome	Mirror neuron theory	Mirror box	Affected hand concealed in mirror box. Non-affected hand exercises in front of mirror	Unaffected limb	Bilateral hand exercises	yes	yes	Yes
Sutbeyaz et al 2007	Mirror therapy	Hemiparesis	Mirror neuron theory	Mirror positioned between patient's legs	Affected limb concealed behind mirror. Non-affected limb exercises in front of mirror	Non affected limb	Stroke program	yes	yes	No
Yavuzer et al 2008	Mirror therapy	Hemiparesis	Mirror neuron theory	Mirror propped on table	Involved hand placed behind mirror	Non involved hand	Stroke program exercise	yes	yes	no

Table cont'd

Zampini et al 2004	Mirror	Brain damage	Higher order, multimodal area	Mirror propped up vertically	Left hand behind mirror	Unaffected limb	Bilateral limb exercise	yes	no	no
Vocks et al 2007	Mirror confrontation	Eating disorders	Cognitive behavioral	Full length mirror	Patient stands in front of mirror during therapeutic session	Body areas	Cognitive behavioral therapeutic exercise	yes	no	no
Key et al 2002	Mirror confrontation	Eating disorders	Body self / cognitive behavioral	Full length mirror	Patient stands in front of mirror during therapeutic session	Body areas	Cognitive behavioral therapeutic exercise	yes	no	yes
Vanhaudenhuyse et al 2008	Mirror	Minimally conscious state	Activation neurological structures	Round mirror	Evaluation of visual pursuit	Unknown	none	no	no	no

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## CHAPTER IV

### PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

#### **Setting**

Multi-site participant recruitment for this research study occurred in three hospitals in the Memorial Hermann Healthcare System (MHHS): Memorial Hermann the Woodlands (MHTW), Memorial Hermann Northwest (MHNW), and Memorial Hermann Northeast (MHNE). These hospitals are located in the Northern region of the greater Houston metropolitan area. In 2009, these hospitals treated 566 women with breast cancer as primary site: NHTW (n = 299), MHNW (N=115), and MHNE (n=152). MHHS is the largest not-for-profit healthcare system in Texas and serves the greater Houston community through 11 hospitals, a vast network of affiliated physicians and numerous specialty programs and services, including a comprehensive range of breast cancer care services. MHTW, MHNW, and MHNE hospital Cancer programs are accredited as Community Hospital Comprehensive Cancer Programs by the American College of Surgeons Commission on Cancer. The Cancer Programs together with the Breast Care Services at each hospital offer advanced diagnostics and dedicated oncology units for inpatient treatment complemented by services such as genetic testing and counseling, nutritional counseling, various support groups, palliative care, cancer registry, community screening programs and sources for cancer resources and education.

Each hospital has an oncology nurse navigator (ONN). The ONNs are expert oncology clinicians who assist patients during much of the entire course of their breast cancer treatment. As a breast cancer patient makes the journey from one physician to another (i.e. gynecologic oncologists, medical oncologists, radiation oncologists, radiologists, reconstructive surgeons, and surgeons), the ONN acts as coach, advocate, and counselor.

The ONN in each of the three hospital study sites, together with the Cancer System Service line nurse practitioner (DNP) were co-researchers for this study. The expertise of these co-researchers lies in the fact that between them, they had cared for hundreds of women who had mastectomy surgery. In addition, the dissertation chair for this study was a co-researcher. The experience of the co-researchers complemented the PI's understanding of hermeneutical phenomenological research.

### **Participants**

Women (12) were recruited from a pool of breast cancer patients who receive care from one of the three MHHS hospitals described above over a nine month period. Based on the literature, a sample size of up to 20 women meeting sample criteria was needed to achieve saturation or redundancy of data in the larger study (Cohen, Kahn & Steeves, 2000). A conservative estimate of the number of potential participants meeting inclusion and exclusion criteria was 75-100 women over a 6-month period. This estimate was derived using the current number of patients (n=566), an estimated .05% growth factor,

and the assumption that 1/3 of patients require a mastectomy and meet inclusion and exclusion criteria.

### **Recruitment of Participants**

The ONNs and Cancer System Service line DNP told women in routine post-mastectomy phone calls about the study (see Appendix A). Of the 20 women approached to be in the study, 12 women participated. One woman who refused indicated she “still could not look at herself in a mirror”. Two women gave no reason for refusing. One woman who had set up a meeting for an interview phoned the PI and indicated she felt too ill to participate due to her chemotherapy symptoms. Another woman had set up an appointment with the PI, but failed to meet the appointment. Three women indicated they would phone the PI, but failed to do so.

Interested participants were given the principal investigator’s (PI) phone number to call if they were interested in learning more about the study. When individuals phoned the PI, the study was described. Sample screening criteria were discussed, and a meeting between participant and PI was arranged. On enrollment to the study, participants were informed they would receive a \$25.00 gift card as compensation for their participation in the study on the day of the interview.

Participants were recruited one at a time. The goal of the PI was to interview, transcribe each interview, and begin a preliminary analysis prior to performing an additional interview. The PI worked closely with the co-investigators on a rotation basis

to ensure only one ONN was discussing the study with potential participants at a time, in order to meet this goal.

Inclusion and exclusion criteria were determined prior to the pilot study, and remained unchanged for this portion of the study.

**Inclusion criteria.** The following criteria were used to determine participant inclusion in the study.

1. Adult woman of at least 18 years of age.
2. Breast cancer surgery resulted in a mastectomy or partial mastectomy (with or without reconstruction).
3. Surgery a minimum of three months and not more than 12 months before first interview.
4. Speak, read, and understand English.
5. Reside in the Greater Houston metropolitan area, defined as the counties of Brazoria, Chambers, Fort Bend, Galveston, Harris, Liberty, Montgomery, Waller, and Wharton.
6. Provide an IRB approved consent form.
7. Willing to attend one interview, and possibly a second interview.

The decision to include women with or without reconstruction was guided by two observations. The co-researchers indicated that a many of their patients tended to have immediate reconstruction. They expressed concern that an adequate sample may be difficult to achieve without this population. In the community consultation, project breast cancer survivors indicated that the experience of viewing self in the mirror after

reconstruction may have just as great an emotional impact as for a woman who had not had reconstructive surgery (Freysteinson, 2010b).

Opting for a time frame of 3 to 12 months post-surgery to interview participants was also guided by the community consultation project. Physicians indicated that at three months optimum physical healing had occurred. Choosing a cutoff point was an arbitrary choice. There was considerable discussion in the community consultation project as to when a woman may not remember viewing self in the mirror post-surgically. Some argued that an individual never forgets that moment even up to ten years later. Other members believed the moment could be forgotten over time (Freysteinson, 2010b).

As the researchers only spoke the English language, and the fact that understanding the text was critical to a description of the experience suggested only English speaking women enter the study. Locations in and around the Houston area were identified as the closest locations for women and/or the PI to travel to an interview.

**Exclusion criteria.** Individuals with the following conditions were excluded from the study.

1. A guardian is responsible for medical decisions.
2. Emotional distress as evidenced by a score of 5 or more on the National

Comprehensive Cancer Network (NCCN) primary screening for distress algorithm (DIS-A) tool (Bultz & Holland, 2006). Women with a score of five or more will be referred to their primary oncology team consisting of the nurse navigator who made



initial contact with potential participants and oncology physician for further follow-up (see Appendix B).

3. Have a diagnosis of body dysmorphic disorder (a severe psychiatric condition occurring in 1-2% of the population in which individuals perceive they have severe face and body defects (Feusner et al, 2009), as determined by an individual stating she has this disorder.

The exclusion criteria were developed to avoid having someone who was cognitively impaired or who had significant emotional distress enter the study. Individuals with body dysmorphic order were considered to potentially have unique mirror experiences.

### **Protection of Human Subjects**

Dual Institutional Review Board (IRB) approval was sought for this study. As the study setting was MHHS, IRB approval was obtained from the Committee for the Protection of Human Subjects (CPHS) at the University of Texas Health Science Center at Houston (UTHSC-H). The study was deemed appropriate for an expedited review. In addition, IRB approval was sought from the Texas Woman's University (TWU) IRB at the expedited level as approved by CPHS UTHSC-H. As this study was very similar to the pilot study, the CPHS UTHSC-H requested that a change request be submitted for the addition of participants, setting locations, co-investigators, interview question additions, and consent changes to reflect the changes. The change request was dually granted by TWU IRB. Approval to initiate the study in the MHHS was granted by the MHHS Clinical Innovation & Research Institute. In May, 2011, the study was randomly chosen

for a monitoring review by CPHS UTHSC (see Appendix C for protection of human subject correspondence).

Participant personal information continues to be kept confidential. A pseudonym name was assigned and the actual age of the participant was attached to the pseudonym (i.e. Mary, 72 years). All consents and paper data were maintained in a locked cabinet at Texas Woman's University. All electronic data was sent via Memorial Herman Health Care System and Texas Woman's University webmail. Electronic data was password protected. All data will be destroyed five years after the completion of the study.

### **Data Collection**

#### **Interview Setting**

Each participant was given a choice of where and when they may want to meet the PI for an interview. Three participants chose to meet the PI in their homes, while nine participants chose to meet the PI at the hospital where they routinely visited the Cancer Clinic. The co-investigators assisted in arranging quiet office areas for these interviews. The PI would meet the participant at the arranged location, obtain consent (see Appendix D), and then administer two instruments.

#### **Instruments**

A demographic collection tool was used to gather data on phone number, age, marital status, race, education and income level, type of mastectomy, radiation, and chemotherapy (Appendix E). The National Comprehensive Cancer Network (NCCN) primary screening for distress algorithm (DIS-A) tool was used after consent, and prior to

an interview to rule out significant distress. This tool is a visual analog screening approach, which rates the perceived level of stress from 0-10 on a picture of a thermometer. This rapid screening tool has been validated in ambulatory settings. The tool also has a series of yes or no questions. These 35 questions are related to practical problems, emotional problems, spiritual/religious concerns, and physical problems (Bultz & Holland, 2006). If a participant scored five or higher on the DIS-A, plans were in place to cancel the interview, and refer the participant back to their physician and ONN. If the DIS-A score was four or less, the PI began the interview.

### **Audio-taped Interview**

The PI and participant settled into chairs. Two tape recorders were used to audio-tape the interviews. One tape recorder was a high-end digital voice recorder. The second tape recorder was inexpensive and acted as a backup. The reason for two tape recorders to ensure the interview was audio-taped was explained to the participant. The tape recorders were placed on the table or chair close to the participant and PI. They were placed on a soft material pad in order to help ensure there was no muffling of sound. The PI did a sound check on each machine prior to starting the interview.

**Interview guide.** A key concept of method of phenomenology is reflection. To learn of an experience as lived, one reflects or recollects on the experience (Ricoeur, 1981). The investigation of experience as lived is best approached by a conversational interview (Van Manen, 1990). In this conversation, the researcher is fully attentive and present, as the participant reflects on her experiences and shares her memories. Although

it may be interesting to delve into causal explanations or generalizations of an experience, this is not the goal of the interview. The goal of the interviews was to stay as close as possible to the experience as a humanly lived. As such, it is impossible to have a long list of ready-made questions. Rather than using interview questions, an interview guide was used to guide the conversation (see Appendix F).

Price (2002) suggests the sequence of probing statements is critical to a successful interview. In pilot interviews, there was initial confusion as to whether or not there was a hospitalization, mastectomy dressing, and if so when and where the dressing was changed. Initial questions were added to the interview guide to orientate the researcher to each participant's unique post-operative journey. These questions also provided a less threatening inroad into each participant's journey of viewing the mastectomy site in the mirror. In addition, the questions and interview statements were laddered in what was believed to be least to most threatening sequence.

**Closing the interview.** At the close of each interview, participants were asked if they had any questions and were thanked for their participation in the study. Each participant was given a \$25 Wal-Mart gift certificate.

### **Data Analysis**

Analysis of data (texts) begins prior to the first interview, in that the researcher explicates any beliefs, biases, theories, or pre-understandings of the phenomenon. This explication is required as it orientates future readers to the researcher's history and initial knowledge of the lived experience under study. This step is the initial step of an audit

trail. Documentation of one's pre-understanding of a phenomenological description is not a form of bracketing. Rather it is a way in which one enters a world and orientates oneself to a world. It is a telling of one's initial notions, explanations, and understandings of a foreign world (Ricoeur, 1981).

### **Researcher's Pre-understanding**

The experience of viewing oneself in a mirror after mastectomy is a mystery. I ask myself: Having suffered no cancer, no radical amputation of a body part, no mastectomy, who am I to understand this experience? I answer my own question: I am a nurse. I believe understanding this experience may, at a minimum, remove some of the mystery, and provide for me a platform on which to guide my actions, interventions, and words.

Living the experience of viewing self in the mirror may be based on Ricoeur's platform of human experience: decision, action, and consent (Ricoeur, 1966). A woman who awaits mastectomy may decide to view her naked body in a mirror pre-surgery. She may see herself as she is now, and at the same time transcend into a future time where she will imagine what she may look like without a complete body. She may struggle between feelings of ridding herself of cancer, and at the same time mourn the imminent loss of her breast. Her consent, ultimately, may be a matter of *so-be-it*. Consent may also contain a dual hope: Hope that the cancer will be eradicated, and hope that in the not too distant future, that she will achieve respectability or normalcy through reconstruction or prosthesis and/or simply through accepting the amputated breast site.

## **Audit Trail**

The researcher maintained an electronic audit trail through to the completion of the project. With each transcript, the researcher's understanding of the data shifted. Pre-understandings were merged with new thoughts, feelings, insights, and emerging concepts. This audit trail was a significant aspect of the analysis of data. All steps taken during the course of the study were outlined in the audit trail.

## **Analysis of the Text**

As each interview was completed, the PI used transcription software to transcribe the audiotapes verbatim. The written transcribed words were the textual data. Where there were significant pauses, an entry was made on the transcription (i.e. pause). If there was significant emotion heard on tape, this was also added to the transcription (i.e. laughter, crying).

Each ONN co-researcher was assigned to read the transcripts of the participants they had recruited for the study. The PI and the Cancer System Service line DNP read all transcripts. Transcripts were emailed using the MHHS protected email network, and then saved to computers using passwords. Co-researchers returned their findings to the researcher in the same fashion using the protected email network. No participant names were included with the management of the transcripts.

Three essential processes were used to analyze the texts: a) naive reading, b) structural analysis, and c) phenomenological analysis. Each analysis step required the

use of an original transcript. Copies of all analysis paperwork was maintained together with the original transcript

**Naïve reading.** A simple reading of the texts was done initially by all researchers. This naïve reading allowed the researchers to become orientated to the world of the text. This reading gave the researchers immediate impressions of the text. Initial understandings and thoughts were jotted on each transcript as the researcher's freely read the transcripts several times.

The co-researchers also used this reading to comment on aspects of the text, describe their feelings regarding the texts, and suggest any nursing interventions that they thought they may have used in each unique transcription situation. These thoughts and opinions helped to formulate the final chapter of this project, and in particular implications for nursing practice, research, and education.

**Structural analysis.** The next step in analysis was for the PI to perform a structural analysis. The PI sought to find the plot, and actions in the text, and in particular opposing actions or actants. Using a word document, all text statements within the text were read, and conceptual headings, which may be indicative of the action or actants, were assigned to each statement. Ricoeur (1981) recommended one use as few categories as possible in the structural analysis, and gives an example of a myth broken down into four categories. After assigning each statement to a concept, the sentences were cut and pasted into groups of concepts. The PI worked with the concepts over the course of the study until as few opposing concepts as possible were uncovered.

The next step was to create a collapsed or smaller text using participant statements which best supported the conceptual headers. This structural analysis was then compared across existing transcripts, and similar plots, actions, and actants were lifted from the text and placed into an electronic file. When concepts were found that were comparable, the PI would collapse the conceptual groupings further. This analysis uncovered common plots or journeys within the texts. In essence, the *sense* (Ricoeur, 1974) of the texts was uncovered. Said differently, the story of each woman was told, and similar elements within each story were identified.

**Phenomenological interpretation.** The PI then performed an in-depth hermeneutical interpretation using an original transcript. The PI looked for statements, which were specifically centered on the phenomenology of the experience of viewing self in a mirror. Using a word document, statements, which were related to the phenomena, were cut and pasted into what appeared to be a corresponding experiential category (i.e. anticipation, hope, etc.). Statements, which did not appear to be related, were placed into a miscellaneous category. The PI returned to the miscellaneous category over and over again to ensure essential elements of the experience of viewing self in a mirror were not symbolically hidden in the text.

When the phenomenological elements of the experience were isolated, the PI returned to the transcript to find the participant statements which best portrayed each element. This created a smaller textual interpretation.



Each in-depth interpretation was then compared across all existing transcripts. With this reading, every miscellaneous category was reviewed for potential experiential categories that may have been missed during a previous analysis.

Ricoeur (1981) likens the actions of the analysis of a text to Gadamer's themes of play. When playing, the world plays us. In other words, when an individual is immersed in play, subjectivity of self is lost, and the project of play becomes a game in which creativity may unfold. Through this process, the preliminary experience of viewing self in a mirror following a mastectomy began to emerge.

### **Confirmation of Findings**

Findings were confirmed as uncovered with the co-researchers. All co-researchers read multiple copies of data analysis with an ongoing audit trail. An ongoing electronic discussion and formal meetings between co-researchers and the PI were used to continuously confirm the findings. After the fifth interview, a description of the experience began to emerge. The PI shared this description with the remaining seven participants after their conversational interviews. The PI also returned to two participants with the description in order to ask: Does this description describe your journey of viewing yourself in a mirror after a mastectomy? Participants who participated in this second interview were selected through a random drawing of names out of a hat. The verification interviews suggested the description was indeed a description of the experience of viewing self in the mirror.

## **Scientific Rigor**

Gold standards for criteria of qualitative research are those outlined by Lincoln and Guba (as cited in Polit & Beck, 2008). Credibility refers to the integrity or believability of the findings. The goal of the study findings was to outline all steps taken in the research process, in addition to providing a description of the phenomenon. Triangulation of data analysis and the use of several co-researchers also aided in confirming credibility.

Dependability refers to the ability of the data to withstand time and conditions. We ask: If a similar phenomenological study were repeated with a similar group of participants, would a similar description be uncovered? A detailed explanation was provided of the data gathering and analysis processes allowing for replication of the research.

Confirmability refers to the objectivity of the data. We wonder: Is the data a reflection of the participants' experience or is the data a figment of the researcher's imagination? To enhance confirmability, there was an explication of pre-understandings and a reflexive audit trail. The description was shared with the co-researchers and participants as it emerged. Two women participated in formal validation meetings.

Transferability refers to the ability of the consumer to transfer the description to other settings. Essentially, we ask: Does the description illuminate the experience of viewing self in the mirror for women with breast cancer beyond the research project? In phenomenological descriptions, transferability is subjectively determined by the reader.

A fifth criteria used in nursing phenomenology research is usefulness. Usefulness is concerned with the applicability the description has for nursing practice. Does this description of the lived experience further guide the practice of nursing in honoring an individual's values, choices, and ways of being in the world? This too is determined by the reader (Parse et al, 1985).

CHAPTER V

THE EXPERIENCE OF VIEWING SELF IN THE MIRROR AFTER A  
MASTECTOMY

A paper

*Submitted to Oncology Nursing Forum, June/July, 2011*

Wyona M. Freysteinson, MN; Amy S. Deutsch, DNP, RN, CNS, AOCNS ;

Carol Lewis BSN, RN, OCN, CRNII; Angela Sisk, MSN, RN, OCN;

Linda Wuest, BSN, RN, OCN and Sandra K. Cesario, PhD, RNC, FAAN

**Abstract**

**Purpose/Objectives:** To describe the experience of viewing self in a mirror following a mastectomy.

**Design:** Ricoeur's hermeneutic phenomenology.

**Setting:** Three hospitals in a non-profit hospital system in the Southwest United States.

**Participants:** Purposive sample of 12 women 3-12 months post mastectomy.

**Methods:** Structural analysis and phenomenological interpretation of audio-taped interviews.

**Main Research Variable:** Viewing self in the mirror after a mastectomy.

**Findings:** Viewing or not viewing one's own body, energizing and dispiriting thoughts, and supportive and unsupportive others helped to explain the world of women who have

had a mastectomy. The phenomenological interpretation yielded four themes: I am, I decide, I see, and I consent.

**Conclusions:** This study offers a portal into and an understanding of this multifaceted experience.

**Interpretation:** Nurses may consider discussing the mirror experience with women who are having a mastectomy pre and post operatively. Nurses may also choose to offer the mirror to their patients when doing the initial dressing change and when teaching wound care. Educational materials are needed for patients and nurses. Further research is needed on the use of mirrors when caring for the patient who has had a mastectomy.

**Keywords:** mirror, mastectomy, breast cancer, body image

Mastectomy continues to be a key treatment option for many forms of breast cancer (Susan G. Komen for the Cure, 2011). Evidence suggests there is psychosocial distress and negative feelings about body image associated with breast cancer (Baucom, Porter, Kirby, Gremore, & Keefe, 2005/2006; Frierson, Thiel & Anderson, 2006, Parker et al., 2007). There may be feelings of altered femininity and sexuality, and an increase in self-consciousness concerning one's appearance (Avis, Crawford & Manuel, 2004). Studies have illuminated the difficult world of suffering with breast cancer (Arman & Rehnsfeldt, 2003; Ashing-Giwa et al., 2004; Langellier & Sullivan, 1998). Although reconstruction may improve body image (Nana, Gill, Kollias, Bochner & Malycha, 2005) for the woman who has had a mastectomy, there may be difficulty adjusting to a changed body image (Crompvoets, 2006; Hill & White, 2008; Morselli & Rossi, 2007).

The inspiration for this study was the story of one woman who initially viewed her mastectomy site at home, alone. “I felt like running out on the road and screaming. That’s what I felt like doing when I first came home and saw myself in the mirror” (Freysteinson, 1994. p. 108). In a pre-research fieldwork project, women who had a mastectomy suggested that “thinking about viewing the mastectomy site is to think of viewing oneself in a mirror” (Freysteinson, 2010b, p. 753).

A survey of the mirrors in ten hospitals in which women who have had breast cancer surgery might stay post operatively suggested a shortage of mirrors (Freysteinson & Cesario, 2008). Bedbound patients had no access to a mirror in 70% of the hospitals. For the ambulatory patient, the ability to view one’s chest was not possible in 20% of the hospitals.

No evidence was found which suggested mirrors may be beneficial for the patient who has had a mastectomy. Mirrors, however, may have therapeutic value for patients with diverse diagnoses such as dementia, brain damage, body image disorders, phantom pain, and cerebrovascular accident (Freysteinson, 2009b).

There appear to be no articles in the literature that describe the experience of viewing self in a mirror for women who have had a mastectomy. The goal of this research is to establish a conceptual foundation for future mirror research which may help to promote psychological well-being for women who have had a mastectomy.

## **Methods**

This study is grounded in the assumption that viewing oneself in a mirror is a basic human right. Without mirrors, one is unable to see one's face, back, and much of one's upper body. Ricoeur's philosophy of hermeneutics provides the foundation for this study (1966, 1974, 1975, 1981, 1992). Hermeneutics is a philosophy and theory of analyzing texts. Phenomenology seeks to uncover the motives, actions, thoughts, and feelings associated with everyday experiences.

### **Participants and Setting**

Participants were recruited from three non-profit healthcare system hospitals located in a city in the southwestern United States. Each hospital had an oncology nurse navigator (ONN) who followed cancer patients throughout much of the course of treatment. Women 18 years and older, who spoke and understood English, and who had a mastectomy with or without reconstruction within 3 to 12 months were invited to join the study by ONNs during routine post-operative phone calls. Interested women were given the principal investigator's (PI) phone number and instructed to call the PI. Of the 20 women who were contacted to be in the study, 12 women participated. One woman refused as she could not yet face the mirror. Other women felt too ill, or simply did not phone the PI. Exclusion criteria included the need for a guardian for medical decisions, significant emotional distress, and body dysmorphic disorder (a severe psychiatric condition occurring in 1-2% of the population in which individuals perceive they have

severe face and body defects, Feusner et al, 2009). Institutional review board approval was secured for this study.

### **Data Collection**

After informed consent, participants completed the National Comprehensive Cancer Network (NCCN) primary screening for distress algorithm (DIS-A) tool (Bultz & Holland, 2006). Permission was granted by NCCN for the use of this tool. All participants scored four or lower on this scale. Scores of five and above would have been indicative of too much distress for the participant. Participants completed a demographic form (see Table 3). Data was collected in audio-taped conversational interviews (see Figure 2) lasting approximately 30 minutes.

### **Data Analysis**

The audio taped interviews were transcribed verbatim by the PI. The texts were then analyzed in a naïve reading, a structural analysis, and a phenomenological interpretation. In addition, a metaphor which may help to convey the experience was conceived (Ricoeur, 1974). The naïve reading was done to obtain a general understanding of the text. The structural analysis was an explanation of the text. Using linguistic theory, the text was analyzed for actants, actions, and oppositional units. Through this process, the *sense* of the text was explained. The goal of the phenomenological interpretation was to illuminate that which the text *references* regarding the experience of viewing self in the mirror after a mastectomy and to “conjoin a new discourse to the discourse of the text” (Ricoeur, 1981, p.158). Each line of each



text was studied for phenomenological themes. As new themes were uncovered, the PI returned again and again to previous interview texts in search of these new themes. With each analysis of an interview, a new word document was created. Early interview texts had as many as five and six analysis documents. A final document emerged where salient quotations from each text were paired with a corresponding theme.

### **Study Rigor**

Lincoln and Guba's gold standards for criteria of qualitative research were used to enhance study rigor (as cited in Polit & Beck, 2008). Credibility, dependability, confirmability and transferability were enhanced by the use of triangulation of analysis and a team of co-researchers skilled in caring for women with breast cancer. A reflexive audit trail was woven directly into each interview analysis by all researchers in the naïve reading, and the PI continued this practice in the subsequent textual analyses. Emerging descriptions were shared with participants at the conclusion of each conversational interview. Formal validation meetings were held with two participants.

### **Findings**

In the naïve reading, the text was read and analyzed by all researchers. The PI did the remaining analysis of the texts, with input from all co-researchers. The results of the structural analysis helped to make *sense* of the data. The analysis described the world of the women who participated in this study. Three key actants were uncovered: my body, my thoughts, and others. These actants were further broken down into oppositional units.

## **Structural Analysis**

**My body.** When viewing the post-operative site initially without a mirror, three women talked about struggling to see their chest area. Judy would have preferred the nurse use a mirror when she changed the dressing, and instructed her on wound care. “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.”

All but one participant initially viewed her mastectomy site in a mirror in her own home. Many women were alone and some had a loved one with them for this initial difficult mirror experience. Eight women suggested that initially or in subsequent encounters in viewing self in the mirror, they were with a loved one or friends (see Table 4). Ellie was the only participant to initially view her mastectomy site with health care professionals. A full length mirror was used. “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.”

After the initial viewing of the mastectomy all participants continued to view their post-operative sites in a mirror, and with time, viewing became somewhat easier. Participants also discussed viewing face, hair, skin and weight in the mirror. Five participants indicated they viewed themselves in a mirror more frequently. Mary said, “When I went through my radiation I was in the mirror constantly.”

There were two key reasons for not viewing oneself in a mirror. The first was a lack of or no recall of mirrors in hospitals, clinics, and physician offices. The second

reason for not viewing self was avoiding the mirror. Three women avoided a mirror for days after their surgeries due to fear as to what the mirror would reveal. Lisa tried to convey that the thoughts she had running through her mind as she avoided the mirror were worse than viewing herself.

If I could, you know, I would have look at myself in the mirror, like right away.... Just to be avoiding more expectations or your mind saying....Like how will it look like?....Seeing myself in the mirror is confronting it like, yah, it is confronting, and I think if I could confront that sooner I can sooner start dealing with it.

**My thoughts.** One's thoughts after a mastectomy may be classified as energizing or dispiriting. Thoughts such as putting one's life into perspective, having faith, and thinking of ways to help others are positive and help one to keep moving on in life. Eleven women talked about ways in which they put life into perspective. Battling Cancer was a way of putting life into perspective for many of the participants. Sarah declared. "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."

All twelve participants indicated faith was essential to helping them view self in the mirror. Angie said it best for all participants. "Somebody up there is giving me the strength. That's all I can say. It is not just me." Finding ways to help others was a third way in which eight of the participants expressed having an energizing attitude.

Dispiriting thoughts concerned the mastectomy site. Eight participants expressed concern that loved ones may not accept the surgical site. Joanie wondered, "You think is this going to interfere with my sex life or is my husband going to accept me?" Nine women worried or wondered if people would know they had a mastectomy, even with the use of prosthesis, checking one's appearance in a mirror, and/or careful choice of clothing. Ericka said:

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.

**Others.** Other people in the world may be classified as supportive or unsupportive throughout the mastectomy journey. All participants had family and/or friends who were considered helpful. Jamie professed, "My husband is wonderful. Ah I can tell him everything I am feeling... I remember saying to him gosh it's really hard to look in the mirror." Mary said, "My husband helps me all the time now. I'll stand in the mirror and see if I'm crooked. I'll ask him if I'm straight and he'll tell me yah you gotta straighten it you know."

Many nurses and/or physicians were perceived as being compassionate and having given good care. Nine participants felt the ONN was the only medical person who really cared about them. Joanie stated, "But I am talking about in the entire medical world she's the only contact I had." Seven participants found support groups, written information, and/or computer website communication helpful.

Many friends and/or relatives simply could not help due to their own troubles including terminal illness, advanced age, and/or work schedules. Some family and/or friends were perceived to be rude, squeamish, or not caring. Jane said some people could even be “hurtful.”

The unplanned medical journey was frustrating for eight of the participants. Joanie called it the “domino effect.” Insurance concerns were at times exasperating for some of the participants. Some individuals in the medical world were perceived as being rude, lacked communication skills, and/or provided poor care. Ericka offered the following suggestion:

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.

### **Phenomenology Interpretation**

Viewing oneself in the mirror, if even for a moment, is filled with layers of meaning. The role of the researcher is to tease those layers of meaning out from each other, and create a novel discourse or description. Throughout this process, four key phenomenological layers emerged: I am, I decide, I see and I consent.

***I am.*** Each participant said in her own way *I am* me. One’s way of being in all experiences, decisions, and actions, including viewing self in a mirror is the constant that allows oneself and others to recognize who *I am*. Each person approaches the mirror, and

finds meaning in the experience in a unique and individual way. Heredity, environment, and life experiences may help to create this unique way of being in the world. For example, Sarah claimed, "I'm a tough old bird." Sandy indicated she was Scandinavian. "We're just not an emotional bunch of people."

***I decide.*** One decides to view self in the mirror based on one's own motives. Curiosity as to what one looks like is a key reason for viewing self in the mirror after a mastectomy. One simply wants to look and see "what it looks like." Jamie said, "I didn't know if I wanted to look at it or not but a natural curiosity overcomes you...you have to take a breath and swallow and say this is going to be OK."

A second motive in deciding to view self in the mirror is the necessity of having to care for the mastectomy site and drains. Lisa had a very difficult time looking in the mirror initially. "I mean sooner or later I needed to do it (look in a mirror).... I had the drains so I needed to, to see where they were...and clean the area."

The third motive to view self in the mirror is to care for one's appearance. The mirror is needed to put on make-up, fix one's hair or wig, and ensure one looks symmetrical. Angie stressed:

I don't care how bad, or how ugly, or how gray I'm looking. If I put my face on, I feel like a million dollars....The mirror makes you think how you need to improve yourself, what to do with yourself.

Seeking and ensuring one's body appears symmetrical was important for all participants. Some women were having or were considering reconstructive surgery.

Other women had or were going to get prosthesis. Several participants talked about how they had to be careful in their choice of clothing. Mary suggested one has to be resourceful.

You become very creative after you have this surgery... putting my bra on and having to put my socks in (while viewing self in the mirror). Make sure I am you know ...not lopsided or one's bigger than the other and stuff like that.

*I see.* One sees in the mirror in three ways: seeing with the mind's eye; seeing with the eyes; and seeing the meaning. An individual brings to the mirror a picture in her mind's eye as to what the mirror image may reflect. This mental image may be accompanied by apprehension, expectation or hopefulness (see Table 5). While the entire experience of viewing self in the mirror takes varying degrees of effort, seeing with one's eyes is relatively effortless unless you have low vision. Helen had macular degeneration and she discovered she needed a magnified mirror in order to see.

Seeing the meaning of what one sees in the mirror is a two part construct of understanding and explanation. One initially understands what is reflected in the mirror and one then explains to one's self the reason for what is seen in the mirror. Mary describes how the mirror changes one's meaning of the mastectomy site.

If you just look down you kind of see it but you're not really putting two and two together... but when you look in the mirror you see like your whole self. And it's just boom, there it is.... Your whole self.

Each woman expressed a different meaning or understanding of what was seen in the mirror. All women in this study understood part of their bodies to be disfigured, fat, bald, and/or ugly in some way when viewing self in the mirror. This disfigurement was accompanied by a host of emotions and feelings: shock, surprise, unworthiness, disgust, frustration, anger, fear, hurt, sadness, relief and/or happiness (see Table 6). Ericka confided, “Actually, honestly, sometimes I would feel like less of a woman.”

All participants in this study used terms such as *it* or *that* when talking about the mastectomy site. For example, Jane said, “You’re seeing *that* every time you stand in front of the mirror. *It* was not a pretty site.” These words may be evidence of distancing of body to self. Some of the women occasionally used words like *my*, *I*, or *me* to refer to the mastectomy site. This language suggests there is appropriation of the mastectomy site to the self. Helen asserted, “I don’t think that I want implants anymore and *I am satisfied with the way I am.*” Angie was the only participant who referred to her mastectomy site using the word *my*. “*My scar* is not healed.”

Where there is understanding, there is explanation. Each woman had her own perception or reasons as to why the mastectomy site looked as it did. For most of the women, that reason was medical in nature. However, for some women the reason was theological or societal (see Table 6).

***I consent.*** Consent to what one has seen in the mirror is to suffer, acquiesce, and/or thrust forward into the future. Suffering was associated with grief, sadness, hurt, frustration and sorrow. Angie said, “It hurts very deeply, very deeply.” Jamie confided,



“I sat there in that tub and I cried like a baby. Just cried, and I prayed.” One has no choice but to eventually accept or acquiesce to seeing one’s mastectomy site in a mirror. Joanie explained, “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.” Lisa expressed that, “Somehow I kind of need to start loving that part of myself again. OK. It’s a mastectomy. ... that’s the reason why I see (look at) myself in the mirror.”

Even as one views self in the mirror, one may thrust forward into the future in one’s mind. For example, there are visions of what the scar may look like when it fades. There are decisions made as to whether or not to get reconstruction or a prosthesis. Ellie tells us,

It’s not the end of my story. I’m still in the middle of it. It’s not going to be what I am going to look like in a year from now, but it is what it is. So I finally had my mind set of you know I’ve got to get over this....I’m not going to look like this for the rest of my life.

## **Metaphor**

In dwelling with the textual data, the metaphor *battle spot* was created. Sarah’s words speak for many of the participants regarding winning the battle with Cancer. “I was going to win no matter what.” The mastectomy scar, however, is not always understood to be an honorable badge. Jane calls it a “spot” and Judy states, it is “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.

### **Discussion**

To our knowledge, this is the first description to be published of the experience of viewing self in the mirror after a mastectomy. The structural analysis described the world of women who have had a mastectomy as one which is focused on one's body, one's thoughts, and others. The phenomenological interpretation described the experience from the viewpoint of a woman viewing herself in a mirror.

The fact the participants could not recall seeing a mirror in the hospital helps to corroborate Freysteinson & Cesario's (2008) survey on the lack of mirrors on breast cancer hospital units. The study description of initially viewing the mastectomy site in a mirror as opposed to attempting to view the post-operative area by looking downwards helps to substantiate breast cancer survivor's feelings that a mirror is needed to view the post-operative area (Freysteinson, 2010b).

Initially viewing the mastectomy site in a mirror alone, with a loved one, or with a health care professional brings a perspective of the mirror not previously published. Support from family and loved ones, and having a strong faith is echoed in Ashing-Giwa et al's (2004) multicultural qualitative study of women with breast cancer. In this study, the women found the ONN to be helpful. Swanson (2010) found that patients who have an ONN may have lower distress scores.

The phenomenological interpretation is one description of the experience of viewing self in the mirror, and is similar to a framework of viewing self in the mirror for terminally ill women (Freysteinson, 1994): I decide, I see, I know, and I consent. The interpretation stresses that each woman creates her own meaning or understanding and explanation of what she sees in a mirror. Collie and Long (2005) suggest the meanings women give to breast cancer may be different than meanings ascribed by health care professionals. Feelings of disfigurement, deformity, and fear were also uncovered in Avis et al's (2004) work. The need to seek symmetry is alluded to in research on reconstruction and body image (Baucom, et al, 2005/2006; Cromptvoets, 2006; Parker et al., 2007; Morselli & Rossi, 2007; Nana et al, 2005).

### **Limitations**

This study is limited by a small sample size and setting. The relatively small sample size of 12 participants were women, many of whom were married, and living in a Southwestern United States city. Only three of the participants were under the age of 50 years and eight of twelve women were Caucasian. The setting was unique as all participants were from a non-academic community based hospital, and received care from an ONN. These factors do not allow for generalizability to a larger population. In addition, reflecting on one's thoughts and feelings is the methodology used in phenomenological research, and yet those memories of past events may be influenced by time and other variables.

### **Implications for Nursing**

The use of the mirror in nursing may be likened to an unexplored landscape. As nurses journey into that landscape, they need to begin by being aware that the mirror is a tool that may be used to view one's mastectomy site. Emphasis should be placed on the uniqueness of individuals and the need for there to be personal choice as to whether or not to use a mirror.

Nurses may choose to prepare patients for the impact of the mirror experience. Discussing the mirror experience with women pre-operatively may allow patients to voice their pre-understandings of what they believe they may see in the mirror. Education as to what the post-operative area will look like may help to alleviate unrealistic expectations, hopes and fears. Gently encouraging women to discuss their thoughts of viewing self in the mirror post-operatively may allow for a reflective healing moment. Nurses may consider carrying a mirror in their pocket, and offering the mirror when teaching post-operative incisional site and/or drain care. In the Netherlands, the nurse discusses the mirror with patients prior to mastectomy surgery. After surgery, the nurse offers a small, medium, and larger mirror for looking at the mastectomy site. The goal of the mirror intervention is that a woman may view her post-operative site at least one time in one mirror prior to discharge (Freysteinson, 2009a). *Mirror talk* may be of value.

The mirror talk, in my practice, usually came only when I saw a patient pre- and immediately post-operatively..... I offered to help them and to "take a look" with

them, if they wished. Some took me up on that offer; others preferred to be alone, or to be with their spouse/partner. Since women are discharged so early these days....The dressing change may occur in the surgeon's office a few days after discharge; in that case, it's the surgical nurse who may have the window of opportunity for the mirror talk (S. Moore, personal communication, May 6, 2011).

Home health care nurses may also have a window of opportunity to offer and/or discuss the mirror. Developing awareness of the language patients use may help the nurse assess whether there is distancing or appropriation of body parts (i.e. my scar vs. that scar). Questions about the mirror and body image may need to be developed and incorporated into baseline psychosocial assessments and body image questionnaires. Nurses may use the mirror as a discussion topic for breast cancer support group meetings. A small mirror may be appropriate in tote bags or with other gifts given to women who have had or will have mastectomy surgery. Nurse administrators in clinics and hospitals may choose to survey existing mirrors for appropriateness for use by bedbound, wheelchair bound, and ambulatory patients.

Educators may consider including the mirror in patient and caregiver educational materials. Education for nurses who work with patients who have had a mastectomy is needed on awareness of and the experience of viewing self in the mirror, and the use of the mirror.

Research is needed on the appropriate use of the mirror with women. The effect of mirrors on patient satisfaction; patient/loved one relationships; and acceptance of body

image may also be of value. Of interest may be the effect of mirrors on spiritual and cultural care. Research is needed on ideal types of mirrors, mirror placement, and mirror lighting for this patient population.

In conclusion, this study brings a unique perspective regarding the experience of a woman who has had a mastectomy. When we try to peer through her eyes into the reflection she may see in a mirror, we are brought one step closer to understanding her world. Usefulness of descriptive research (Parse, Coyne & Smith, 1985) is concerned with the applicability the description has for nursing practice. Essentially the reader determines if the description may help to guide the practice of nursing in honoring an individual's choices and meanings regarding the mirror.

## Opening Statement

If at any time during the discussion you want to stop participating, you may do so. You are under no obligation to continue in this discussion for any reason. This will not be a simple matter of me asking you questions. Rather, in this discussion, you are free to share your stories and memories of what it is like for view to yourself in a mirror since your breast surgery.

- Tell me about your surgery.
- Did you have a dressing (bandages) and/or drains (tubes)?
- Tell me about an experience of looking in a mirror.
- Tell me about the first time you saw yourself in a mirror.
- How did you come to decide to look in the mirror?
- Was someone with you?

Figure 2. *Examples of the Conversational Interview Questions*

**Table 3.****Participant Demographic & Clinical Characteristics**

<b>Characteristic</b>	<b>N</b>
<b>Age (years)</b>	
Range = 32-76	-
<b>Race</b>	
American Black	2
Caucasian	8
Hispanic	2
<b>Marital Status</b>	
Married	9
Widow	2
Single	1
<b>Education</b>	
High School Diploma	7
2 years College	4
Bachelor's Degree	1
<b>Annual Income</b>	
Declined to Answer	1
Less than \$18, 000	2
\$18,000-\$30,000	3
\$31,000 - \$50,000	3
\$76,000 - \$100, 000	2
More than \$100,000	1
<b>Mastectomy Type</b>	
Simple	8
Radical	4
Bilateral	3
Previous Mastectomy	2
<b>Time from Surgery to Interview</b>	
3-9 Months	-
<b>Current Treatments</b>	
Chemotherapy	5
<b>Past Treatments</b>	
Chemotherapy	1
Radiation	2
Chemotherapy & Radiation	3
<hr/> <b>N = 12</b>	



**Table 4:****Selected Examples of Actants, Opposing Actions, and Supporting Statements**

<b>Actants and Opposing Actions</b>	<b>Subthemes</b>	<b>Supporting Statements</b>
Viewing My Body	Viewing without a mirror for the first time	I could see the breast was gone but I couldn't see all this stuff back in under my arm.
	Viewing incision in a mirror for first time at home alone	When I saw myself in the mirror I have that feeling like I was mutilated. OK. And um it is kind of like how did this happen to me?
	Viewing the incision in a mirror with another	One or two of them (girlfriends); they looked in the mirror with me...they're in shock....But they try not to let it show on their face, but you know I can still see it...you know they feel bad for me.
	Viewing oneself more often	When I went through my radiation I had to I was in the mirror constantly.
Not Viewing My Body	Lack of or no recall of mirrors in hospital, clinics, or physician office	I was only there that morning and then I left the next day and I got up and I used the restroom....I don't remember seeing no mirror. I really don't.
	Avoiding the mirror	I wouldn't look because I just didn't want to see anything. I wasn't encouraged to look either.

**Table 5****Selected Examples of Seeing with the Mind's Eye**

<b>Phenomenological Construct</b>	<b>Subthemes</b>	<b>Supporting Statements</b>
Seeing with the Mind's Eye	Apprehension	The first time I looked in the mirror, I was afraid to look into the mirror, because I didn't know what it would be like to have a portion of your body removed.
	Expectation	This, these scar is uglier than I thought it would be. I thought it would be a little bit prettier. A little nicer looking.
	Hope	I think I look more...with the hope to think that things are going to change.

**Table 6:**  
Selected Examples of Seeing the Meaning

Phenomenological Construct	Subthemes	Supporting Statements
Understanding	Deformed	I do feel deformed when I look in the mirror....And I wonder is this normal, and you keep thinking is this normal?
	Shock/Surprise	I was in shock. I was in shock. I started crying. Wondering why .... Why, why, why. ...Cause at first it was, it was just unbelievable.
	Disgust	I looked like a burn victim....(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.
	Unworthiness	Some people may even feel like I 'm unworthy....because I don't have the beauty of both breasts.
	Anger/Frustration	I went into the bathroom, and go aah. What is this you know and then I felt around it and I thought can you believe they did this to me?
	Fear	Well I am not as scared of it (the mastectomy site) as I was.
	Sadness/Hurt	When I looked, it looked bad, and I did cry some.
Explanation	Relief/Happiness	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! So for me, I guess that's where my story is a little bit different because every time I got stitched up I was ecstatic, like it was ridiculous, like look at it, it's closed! It's closed!
	Medical	I thought it might have been a little bit nicer looking but then it's not plastic surgery, it was just surgery.
	Theological	It's like the devil's trying to get to you....You know that's the devil in there.
	Societal	My hair is just a big problem for me because... it's noticeable.

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## CHAPTER VI

### SUMMARY OF THE STUDY JOURNEY

This journey began when one woman confided that she wanted to run out on to a road screaming when she initially saw her mastectomy site in a mirror (Freysteinson, 1994). My own practice of nursing had been to carry a mirror in my pocket and when doing initial dressing changes on mastectomy sites or other areas of the upper body, I would offer the patient a mirror in order for her to view herself. Some patients refused, but the majority would want to see their changed bodies (Freysteinson, 2009b). I wondered why this woman had to endure viewing her mastectomy site alone. I asked myself: Where was her nurse?

A survey of the mirrors in ten hospitals where a woman may stay after breast surgery suggested a lack of mirrors for the bedbound, wheelchair bound, and for 20% of the ambulatory patients (Freysteinson & Cesario, 2008). An extensive search of the literature uncovered only one previous nursing study on mirrors and elderly patients with dementia (Tabak, Bergman, & Alpert, 1996). The literature contained a curious mix of studies of unrelated diagnoses where the mirror is used therapeutically. The theories underlying these studies are self or cognitive and neurological theories. The interventions share common elements such as repetition, homework, and relaxation or imagery (Freysteinson, 2009c). A pre-research fieldwork community consultation project suggested that research on this topic was needed (Freysteinson, 2010b).

The literature review led to the realization that prior to researching interventions regarding the use of the mirror for women who have had a mastectomy, we must first try to understand and describe that experience. Without description, the experience of viewing self in the mirror for someone who has had a mastectomy may lay silent. We, perchance, think we may almost see the experience in our mind's eye, and yet when asked to describe the experience, we find we are at a loss for words. This kind of silence is what philosophers call an epistemological silence. In this silence, we confront the unspeakable. The goal of this research was to walk directly into that silence, and attempt to find words that would help convey that experience to the nursing community. The research question was: What is the experience of viewing self in the mirror after a mastectomy?

Twelve women who had a mastectomy were invited to participate in the study. The data was collected in conversational interviews and transcribed verbatim. The resulting textual data became the focus of analysis.

Ricoeur's work (1966, 1974, 1975, 1981, 1992) was the foundation for this study. The resulting mirror description correlates closely with Ricoeur's philosophy of phenomenology and hermeneutics (1966, 1981, 1992). An analysis was done to provide a structural viewpoint of the findings. The actants: my body, my thoughts, and others are, for Ricoeur (1992), a "triad of passivity" (p.318). Essentially, individuals are not in immediate possession of self. One's own body in relationship to oneself may be like that of a dancer, an effortless extension of self. And yet, that same body can become foreign



when there is physical suffering, changing the meaning one has of one's self. One's own thoughts and other people in one's world color and may also affect one's understanding of self.

In 1966, Ricoeur developed an overarching phenomenology of the will: I decide, I act, and I consent. This phenomenology closely resembles, and may ground the phenomenological moments uncovered in this description: I am, I decide, I see, and I consent.

A relationship was uncovered between Ricoeur's (1981) hermeneutic method of analyzing a text and the experience of viewing self in the mirror. When analyzing a text, there is initial distancing of the text to the reader. With time and analysis, the reader appropriates the text to self and creates a new discourse of meaning (Ricoeur, 1981). In a similar fashion, when viewing self in the mirror after a mastectomy there is distancing of the changed body to the self as is indicated by the words used to describe the mastectomy site (i.e. that, it). With time, there is appropriation of the physical self to the self, together with a new meaning of one's self (i.e. my, me).

An interpretation of a text also calls for explanation and understanding. The structural analysis provides an explanation of the text, whereas the phenomenological interpretation seeks to understand that which the text references. In this description of viewing self in the mirror, women understood the image in the mirror, and gave personal meaning to that reflection. Women also explained that meaning using medical, theological, or societal reasons. In other words, the hermeneutical concept of explanation

and understanding may extend to the experience of viewing self in the mirror. Said differently, interpreting a text is much like interpreting a reflection in a mirror. This journey into the philosophy of Ricoeur may be considered a continuation of the reflective audit trail which links my appropriation of the data to my pre-understandings of Ricoeur's work.

The nursing implications which were conceived because of this project are simple, and in retrospect may almost be considered to be common sense. However, prior to this research, nurses had no knowledge of the experience of viewing self in the mirror on which to build sensible interventions. With this description, nurses may begin to build the simple gentle scripts as to how to offer a mirror to women who have had a mastectomy during the initial dressing change. Mirror talk scripts may be designed which help nurses discuss the impact of the mirror experience pre and post -operatively. Nurses may be inspired to include the mirror in written and web based communications which discuss body image and mastectomy.

Researching the mirror in nursing may be likened to a vast silent landscape. This project has put one footprint on that landscape. The possibilities for research may be vaster than we currently can comprehend. Research is needed on the appropriate use of the mirror with women who have had a mastectomy, the effects of mirror interventions on body image, self-image, self-esteem, self-confidence, relationships, and patient satisfaction. Cultural meanings individuals have of the mirror image are desperately needed, so that culturally appropriate mirror interventions may be developed.

Research is also needed on the best kind, placement, and lighting of mirrors in hospitals, clinics, and homes where medical care is carried out.

A rich description of the experience of viewing self in the mirror has been uncovered. The metaphor *battle spot* arose from the text. Sensitive nursing mirror interventions have been suggested, and possibilities for future research have been offered. The journey continues.

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## APPENDIX A

### Telephone Screening Guide

## Telephone Screening Guide

1. The MHHS ONNs (co-researchers) will tell women who meet sample-screening criteria in routine post-mastectomy phone calls about the study. The ONN will ask: Are you interested in hearing about a research study? Interested women will be told:

The research is called, “The Experience of Viewing Self in the Mirror after a Mastectomy”. Wyona Freysteinson, a PhD nursing student at Texas Woman’s University is doing the research together with five co-investigators.

The purpose of this research is to understand what it is like to view self in a mirror following a mastectomy. Understanding this experience may help nurses understand and honor individual’s values and choices concerning mirrors.

If you choose to be in this research study, there will be one to two audio tape-recorded interview sessions. You will be asked to share your stories and memories of what it was like for you to view your surgical site for the first time after surgery, and on other occasions when you looked in a mirror.

2. Interested participants will be given the PI’s phone number (281-433-5365) to call if they are interested in learning more about the study. The PI will say:

The research project is called, “The Experience of Viewing Self in the Mirror after a Mastectomy”.

The purpose of this research study is to understand what it is like to view self in a mirror following a mastectomy. Understanding this experience may help nurses understand and honor individual’s values and choices concerning mirrors.

This research may also provide direction to future research studies about the use and placement of mirrors in hospital rooms, clinics, and homes where women may look in mirrors after mastectomy surgery.

If you choose to be in this research study, there will be one to two audio tape-recorded interviews. I will ask you to share your stories and memories of what it was like for you to view your surgical site for the first time after surgery, and on other occasions when you looked in a mirror.

Your words will become part of a paper, which may be published.

The time for the first interview will be approximately 1 to 1½ hours. You may be asked to participate in a second interview, which will be 30-45 minutes. This time does not include travel time.

You will receive a \$25 gift card for your time and travel for each interview.

You may receive no direct benefit from being in this study; however, your taking part may help patients get better care in the future.

The setting where this research will take place will be a *quiet place* that is most convenient for you.

3. The PI will review sample-screening criteria, and arrange with the ONN a meeting room in which to meet with potential participants.

## APPENDIX B

Verification of Permission to use The National Comprehensive Cancer Network (NCCN)  
primary screening for distress algorithm (DIS-A) tool



National  
Comprehensive  
Cancer  
Network®

275 Commerce Drive  
Suite 800  
Fort Washington, PA 19034  
215-690-2280  
Fax: 215-690-2281  
For Clinicians: NCCN.org  
For Patients: NCCN.com

William T. McGee, PhD  
Chief Executive Officer  
mcg@nccn.org

October 12, 2010

Wyona Freysteinson, MN  
Texas Woman's University  
15819 Mesa Gardens  
Houston, TX 77095

Dear Ms. Freysteinson:

On behalf of the National Comprehensive Cancer Network ("NCCN") I am writing to grant you permission to reproduce the **Distress Thermometer Screening Tool FIGURE (DIS-A)** from the NCCN **1.2010 Distress Management** Guidelines as described in your original request for use to screen potential participants for a dissertation qualitative research study: **The Experience of Viewing Self in the Mirror after a Mastectomy**. Permission is granted solely for the purposes described herein, which you represent and warrant to be for non-promotional educational use only. The following qualifications also apply to the permission granted by this letter:

1. You agree to include a citation giving full credit to the NCCN for these Guidelines as follows:  
Reproduced with permission from The NCCN **1.2010 Distress Management Clinical Practice Guidelines in Oncology**. ©National Comprehensive Cancer Network, 2010. Available at: <http://www.nccn.org>. Accessed [Month and Day, Year]  
To view the most recent and complete version of the guideline, go online to [www.nccn.org](http://www.nccn.org)
2. Permission is granted solely for the purposes described within your original request and expires after one year. An extension on your permission request may be requested at that time.
3. You must initial this letter to denote your acceptance of the terms/stipulations in this letter, and fax it back to NCCN at 215-690-0283 to the attention of Nicole Fair.
4. You agree that you will not translate, change, adapt, delete, extract portions, or modify the content of the NCCN **1.2010 Distress Management** Guidelines, unless explicit permission is provided above.
5. Permission is for reproduction of the Guidelines in print media only. **No Electronic Rights** (including CD-ROM and Internet) are granted. Reproduction of the Guidelines into any other medium, including but not limited to electronic media, is explicitly prohibited. You further agree that any reproduction of the Guidelines will include NCCN's URL address [www.nccn.org](http://www.nccn.org), to link to the most updated version of the NCCN **Distress Management** Guideline.

City of Hope  
Comprehensive Cancer Center

Dana-Farber/Brigham and  
Women's Cancer Center /  
Massachusetts General Hospital  
Cancer Center

Duke Comprehensive  
Cancer Center

Fox Chase Cancer Center

Huntsman Cancer Institute  
of the University of Utah

Fred Hutchinson Cancer  
Research Center /  
Seattle Cancer Care Alliance

The Sidney Kimmel  
Comprehensive Cancer Center  
at Johns Hopkins

Robert H. Lurie Comprehensive  
Cancer Center of Northwestern  
University

Memorial Sloan-Kettering  
Cancer Center

H. Lee Moffitt Cancer Center  
& Research Institute

The Ohio State University  
Comprehensive Cancer Center  
James Cancer Hospital and  
Solove Research Institute

Roswell Park Cancer Institute

Siteman Cancer Center at  
Barnes-Jewish Hospital and  
Washington University  
School of Medicine

St. Jude Children's Research  
Hospital/University of  
Tennessee Cancer Institute

Stanford Comprehensive  
Cancer Center

University of Alabama at  
Birmingham Comprehensive  
Cancer Center

UCSF Helen Diller Family  
Comprehensive Cancer Center

University of Michigan  
Comprehensive Cancer Center

UNMC Eppley Cancer  
Center at The Nebraska  
Medical Center

The University of Texas  
M. D. Anderson Cancer Center

Vanderbilt Ingram  
Cancer Center

6. Permission is granted for reproduction in the English language only.
7. You acknowledge that the NCCN is sole owner of the Guidelines, and any derivative works created from the Guidelines. You further acknowledge that the NCCN is the owner of the name "National Comprehensive Cancer Network, Inc.®," and "the NCCN®" and any derivatives thereof (the "Marks"). You agree that you shall not use the Marks in any manner or for any purpose other than to acknowledge ownership of the Guidelines by the NCCN as described in this letter. Your use of the Marks and/or Guidelines for the purposes described herein in no way constitutes an endorsement of your works or opinions by the NCCN. You acknowledge that use of the Marks and reprinting of the Guidelines pursuant to the permission granted hereunder shall not create in your favor any right, title, or interest in or to the Marks and/or the Guidelines. The permission granted hereunder is for a one-time use of the Marks and/or Guidelines. You agree that each use of the Marks and/or the Guidelines by you, beyond or in addition to that described herein, shall require written approval by the NCCN.
8. Your use of the Marks and/or Guidelines as described herein shall signify your acceptance of the terms and conditions of this letter. The NCCN reserves the right to at any time revoke the permission granted hereunder if, in its discretion, the NCCN determines that you have violated or are in violation of the terms of this letter of permission.

Thank you for your interest in the work of the NCCN.

Sincerely,

Nicole Fair  
CME Specialist  
NCCN



## APPENDIX C

### Protection of Human Subject Correspondence



**Office of Research**

6700 Fannin Street  
Houston, TX 77030-2343  
713-794-2480 Fax 713-794-2488

August 24, 2010

Ms. Wyona M. Freysteinson  
College of Nursing - Sandra Cesario Faculty Advisor  
6700 Fannin Street  
Houston, TX 77030

Dear Ms. Freysteinson:

Re: *"Experience of Viewing Self in Mirror After a Mastectomy"*

Your application to the IRB has been reviewed and approved.

This approval lasts for one (1) year. The study may not continue after the approval period without additional IRB review and approval for continuation. It is your responsibility to assure that this study is not conducted beyond the expiration date.

Any changes in the study or informed consent procedure must receive review and approval prior to implementation unless the change is necessary for the safety of subjects. In addition, you must inform the IRB of adverse events encountered during the study or of any new and significant information that may impact a research participant's safety or willingness to continue in your study.

The signed consent forms and final report must be filed with the Institutional Review Board in the Office of Research, IHS 10110, at the completion of the study.

Sincerely,

*Carolyn Kelley*  
Carolyn Kelley, PT, DSc, NCS  
Institutional Review Board - Houston



THE UNIVERSITY of TEXAS  
HEALTH SCIENCE CENTER AT HOUSTON

The Committee for the Protection of Human Subjects  
Office of Research Support Committees

6410 Fannin, Suite 1100  
Houston, TX 77030

Wyona Freysteinson, MN  
UT-H - GEN - Default Department Code

**NOTICE OF APPROVAL TO BEGIN RESEARCH**

July 30, 2010

HSC-GEN-10-0230 - Copy of The Experience of Viewing Self in the Mirror After a Mastectomy

PROVISIONS: This approval relates to the research to be conducted under the above referenced title and/or to any associated materials considered by the Committee for the Protection of Human Subjects, e.g. study documents, informed consent, etc.

APPROVED: By Expedited Review and Approval

REVIEW DATE: 7/29/2010

APPROVAL DATE: 7/30/2010

EXPIRATION DATE: 6/30/2011

CHAIRPERSON: Anne Dougherty, MD

Subject to any provisions noted above, you may now begin this research.

CHANGES: The principal investigator (PI) must receive approval from the CPHS before initiating any changes, including those required by the sponsor, which would affect human subjects, e.g. changes in methods or procedures, numbers or kinds of human subjects, or revisions to the informed consent document or procedures. The addition of co-investigators must also receive approval from the CPHS. **ALL PROTOCOL REVISIONS MUST BE SUBMITTED TO THE SPONSOR OF THE RESEARCH.**

INFORMED CONSENT: When informed consent is required, it must be obtained by the PI or designee(s), using the format and procedures approved by the CPHS. The PI is responsible to instruct the designee in the methods approved by the CPHS for the consent process. The individual obtaining informed consent must also sign the consent document. Please note that only copies of the stamped approved informed consent form can be used when obtaining consent.

HEALTH INSURANCE PORTABILITY and ACCOUNTABILITY ACT (HIPAA):  
The study must meet all HIPAA research requirements. For compliance guidelines see details on the Committee for the Protection of Human Subjects website at:  
[http://www.uth.tmc.edu/ut\\_general/research\\_acad\\_aff/orsc/cphs/guidelines/hipaa.htm](http://www.uth.tmc.edu/ut_general/research_acad_aff/orsc/cphs/guidelines/hipaa.htm)

UNANTICIPATED RISK OR HARM, OR ADVERSE DRUG REACTIONS: The PI will immediately inform the CPHS of any unanticipated problems involving risks to subjects or others, of any serious harm to subjects, and of any adverse drug reactions.

## APPENDIX D

### Consent Form

**THE UNIVERSITY OF TEXAS HEALTH SCIENCE CENTER - HOUSTON**

**The Experience of Viewing Self in the Mirror after a Mastectomy**

**HSC-GEN-10-0230**

**INFORMED CONSENT TO JOIN A RESEARCH STUDY**

You are being invited to take part in a research study called, "The Experience of Viewing Self in the Mirror after a Mastectomy", conducted by:

Wyona M. Freysteinson, MN. Wyona is the main researcher and a PhD nursing student at Texas Woman's University (TWU)..... 281-433-5365 or [wfreysteinson@mail.twu.edu](mailto:wfreysteinson@mail.twu.edu)

Sandra K. Cesario, RNC, PhD is a professor at TWU and a co-investigator and advisor on the study:..... 713-794-2110

Other co-investigators are oncology nurses who work at Memorial Hermann Healthcare System hospitals:

Amy S. Deutsch, DNP(c), RN, CNS, AOCNS.....	281-627-2257
Angela Sisk, MSN, RN, OCN.....	713-867-2062
Carol Lewis, RN, BSN, OCN, CRNI.....	281-364-4668
Linda Wuest, RN, BSN, OCN.....	281-540-7905

Your decision to take part is voluntary and you may refuse to take part, or choose to stop taking part, at any time. A decision not to take part or to stop being a part of the research project will not change any services that are available to you from your health care providers. You may refuse to answer any questions asked or written on forms.

This research project has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston as HSC-GEN-10-0230.

Up to 25 women from three Memorial Hermann Healthcare System Hospitals: Memorial Hermann The Woodlands; Memorial Hermann Northwest; and Memorial Hermann Northeast, will be enrolled into the study.

Women who are at least 18 years of age and have had a total or radical mastectomy may be enrolled into the study/project.

**DESCRIPTION OF RESEARCH**

The purpose of this research study is to understand what it is like to view self in a mirror following mastectomy surgery. Understanding this experience may help nurses understand and honor individual's choices concerning mirrors.



This research may also support research on helping women accept their body following a mastectomy. It may also help in research on the best use and placement of mirrors.

In this study, you will share stories of your experiences of viewing yourself in a mirror with the researcher. There will be one to two interviews. You will be asked to share your stories and memories of what it was like for you to view your surgical site for the first time after surgery, and on other occasions when you looked in a mirror. If you join this study you will be asked questions about viewing self in the mirror with and without clothing.

1. In the first interview, and after this consent is understood and signed, some basic facts about you (i.e. age, type of mastectomy and any related treatments) will be obtained. You will also complete a simple (paper and pencil) stress test. If the test score shows you have too much stress, the researcher will not proceed with an interview. If this happens, the researcher will refer you to your oncology nurse and physician.
2. The interview will be audio tape-recorded.
3. After the interview, the words on the audio tapes will be typed onto paper. The researcher will read the audiotaped words of your interview, and the audiotaped words of all the women in the study.
4. The researchers will create a story of the experience of viewing self in the mirror after a mastectomy from the interview words.
5. The main researcher will then return to up to six women to ask them if the story describes the experience correctly.
6. Some of your words (or story) may become part of a paper that may be published which will help other people understand this experience.

#### **TIME COMMITMENT**

The time commitment for the first interview, together with consent and demographic consent will be approximately 1 to 1½ hours. There may be a second interview. The time commitment for a second interview will be 30 -45 minutes. This time does not include any travel time.

#### **BENEFITS**

You may receive no direct benefit from being in this study; however, your taking part may help patients get better care in the future.

#### **RISKS AND/OR DISCOMFORTS**

You may become upset talking about sensitive issues. If at any time you want to stop participating in the study, you may do so.

### **ALTERNATIVES**

The only alternative is not to take part in this study.

### **VOLUNTARY PARTICIPATION**

Your participation in this study is completely voluntary. You are under absolutely no obligation to continue in an interview for any reason. You might want to stop talking about this experience; or you may feel there is no point in the study or in participating. For whatever reason you choose to stop, you may do so. You do not have to explain your reason to the interviewer.

### **STUDY WITHDRAWAL**

The researcher may choose to stop an interview, and withdraw you from the study, if it appears that there is significant emotional suffering.

### **IN CASE OF INJURY**

The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

If you suffer any injury as a result of taking part in this research study, please understand that nothing has been arranged to provide free treatment of the injury or any other type of payment. However, all needed facilities, emergency treatment and professional services will be available to you, just as they are to the community in general.

You should report any injury to Wyona M. Freysteinson (24 hour telephone number: 281-433-5365) and to the Committee for the Protection of Human Subjects at 713-500-7943. You will not give up any of your legal rights by signing this consent form.

### **COSTS, REIMBURSEMENT, AND COMPENSATION**

You will receive a \$25 gift card for your time and travel for each interview.

### **CONFIDENTIALITY**

You will not be personally identified in any reports or publications that may result from this study. Any personal information about you that is gathered during this study will remain confidential to every extent of the law. A special number will be used to identify you in the study and only the investigator will know your name. The Committee for the Protection of Human Subjects and the researcher may review your research records for the purposes of verifying research data, and will see personal identifiers.

### **SIGNATURES**

Taking part in this study is your choice. If you sign this form, it means that you understand the information given to you about the research and choose to take part. Make sure that any questions have been answered and that you understand the study.

If you have any questions or concerns about your rights as a research subject, call the Committee for the Protection of Human Subjects at 713-500-7943. You may also call the Committee if you wish to discuss problems, concerns, and questions; obtain information about the research; and offer input about current or past participation in a research study.

If you decide to take part in this research study, a copy of this signed consent form will be given to you. If you have any questions or concerns about the research study, please contact Wyona Freysteinson at 281-433-5365 or [wfreysteinson@mail.twu.edu](mailto:wfreysteinson@mail.twu.edu).

Participant Name (Printed): \_\_\_\_\_

Participant Signature: \_\_\_\_\_ Date: \_\_\_\_\_ Time: \_\_\_\_\_

Researcher Name (Printed): \_\_\_\_\_

Researcher Signature: \_\_\_\_\_ Date: \_\_\_\_\_ Time: \_\_\_\_\_

### **CPHS STATEMENT**

This study (HSC-GEN-10-0230) has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston. For any questions about research subject's rights, or to report a research-related injury, call the CPHS at 713-500-7943.

If you would like to know the results of this study tell us where you want them to be sent:

Email: \_\_\_\_\_

or

Address: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_





## APPENDIX E

### Demographic Data Collection Form

## Demographic Data Collection Form

### Demographic Information

Date \_\_\_\_\_

Study ID#: \_\_\_\_\_ Phone (\_\_\_\_) \_\_\_\_\_ Cell Phone (\_\_\_\_) \_\_\_\_\_

The best time to contact me is: \_\_\_\_\_ ☐ A.M. ☐ P.M. On my ☐ Home phone ☐ Cell phone

Age: \_\_\_\_\_

Check Appropriate Box:

Marital Status ☐ Married (1) ☐ Single (2) ☐ Widowed (3) ☐ Separated (4) ☐ Divorced (5)

Race: ☐ Caucasian (1) ☐ African American (2) ☐ Hispanic (3) ☐ Native American (4) ☐ Asian (5) ☐ Other (6)

Education Level: ☐ < 10 years (1) ☐ 10-11 years (2) ☐ High School Diploma or GED (3) ☐ 2 years college (4)

☐ Bachelor's Degree (5) ☐ Master's Degree (6) ☐ PhD/MD/JDS (7)

Income Level: ☐ < \$18,000 (1) ☐ \$18,000 – 30,000 (2) ☐ \$31,000 - 50,000 (3) ☐ \$51,000 – 75,000 (4)  
☐ 76,000 – 100,000 (5) ☐ > 100,000 (6)

Medical History pertinent to this study:

Year diagnosed with breast cancer: \_\_\_\_\_

Type of mastectomy ☐ Right (1) ☐ Left (2) ☐ Bilateral (3) ☐ Total (4) ☐ Radical (5)

☐ Immediate reconstruction (6) Is this your first mastectomy surgery? ☐ Yes (1) ☐ No (2)

Other treatments for breast cancer ☐ Currently receiving Chemotherapy (1) ☐ Currently receiving Radiation (2) ☐ Chemotherapy in the past (1) ☐ Radiation in the past (2)

Researcher Code: \_\_\_\_\_

## **APPENDIX F**

### **Interview Guide**

## Interview Guide

An opening comment will be made by the researcher as to the date, and willing participation of the participant in the study. The researcher will state to the participant:

If at any time during the discussion you want to stop participating, you may do so. You are under no obligation to continue in this discussion for any reason. This will not be a simple matter of me asking you questions. Rather, in this discussion, you are free to share your stories and memories of what it is like for you to view yourself in a mirror since your breast surgery.

The researcher will use the following statement and prompts to orientate herself to the participant's hospitalization and post-operative dressing care.

(1) Tell me about your surgery.

Were you hospitalized for your surgery? If so, for how long?

Did you have a dressing (bandages) and/or drains (tubes)?

What type of care did nurses or physicians do for your dressing and/or drains after your surgery in the hospital or at your physician's office?

What type care did you and/or your caregiver have to do for your dressing and/or drains after your surgery?

The researcher will use the following statements to initiate discussion, and prompt questions as appropriate in order to extract a rich description.

(1) Tell me about an experience of looking in a mirror since your surgery.

(2) Tell me about the first time you saw yourself in a mirror since your surgery.

(3) Tell me about the first time you saw your incision.

(4) Tell me about your experiences of looking in the mirror a day or two before your surgery.

Additional prompts will be used in order to continue the flow of discussion and understand an experience or meaning more fully.

Did this occur when you were or someone else was providing post-operative care?

How did you come to decide to look in the mirror?

Was someone with you?

What was your self-talk before/during/after you looked in the mirror?

Would you have preferred this experience had been different?

Techniques such as silence and repetition may be used, together with simple prompt statements:

How did you feel about that?

In what way?

What was it like?

Can you tell me more?

Can you give me an example?

Do you have another story or memory of looking in the mirror?

## APPENDIX G

### Co-authorship Permissions

**RE: Co-author Permission**

Cesario, Sandra

**Sent:** Friday, July 08, 2011 6:16 PM

**To:** Freysteinson, Wyona

Dear Dr Freysteinson and other parties of concern,

As a co-author of the articles listed below, I grant you permission to use the articles in your dissertation and for the prospective publication of your dissertation by ProQuest through its UMI® Dissertation Publishing business.

Sincerely,

Sandra K. Cesario, PhD, RNC, FAAN  
PhD Program Coordinator and Professor  
College of Nursing, Texas Woman's University  
6700 Fannin Street, Houston, TX 77030-2343  
713-794-2110

**From:** Freysteinson, Wyona

**Sent:** Friday, July 08, 2011 5:19 PM

**To:** Cesario, Sandra

**Subject:** Co-author Permission

Good Afternoon Dr. Cesario,

I would like to deposit the full text of the following articles in my dissertation to meet the graduate requirements at the Texas Woman's University, Denton, Texas.

HAVE WE LOST SIGHT OF THE MIRRORS? THE THERAPEUTIC  
UTILITY OF MIRRORS IN PATIENT ROOMS  
A paper published in *Holistic Nursing Practice* 2010, 22, 317-323.  
Wyona M. Freysteinson, RN, MN & Sandra K. Cesario, RNC, PhD

THE EXPERIENCE OF VIEWING SELF IN THE MIRROR AFTER A MASTECTOMY  
*Submitted to Oncology Nursing Forum, June/July, 2011*  
Wyona M. Freysteinson, MN; Amy S. Deutsch, DNP, RN, CNS, AOCNS ;  
Carol Lewis BSN, RN, OCN, CRNII; Angela Sisk, MSN, RN, OCN;  
Linda Wuest, BSN, RN, OCN and Sandra K. Cesario, PhD, RNC, FAAN

I am contacting you as a co-author in order to seek your permission to do this. The requested permission extends to any future revisions and editions of my dissertation and to the prospective publication of my dissertation by ProQuest through its UMI® Dissertation Publishing business.

I would be grateful if you could return this email to me with your permission to use the articles. Thank you for your attention with this and I look forward to hearing from you.

Yours sincerely,

Dr. Wyona M. Freysteinson  
PhD Student  
Texas Woman's University

<https://owa.twu.edu/owa/?ac=Item&t=IPM.Note&id=RgAAAAA5ftoY9zqWRpuqhLqXA...> 7/11/2011

**RE: Co-author Permission**

Deutsch, Amy [Amy.Deutsch@memorialhermann.org]

**Sent:** Monday, July 11, 2011 12:48 PM

**To:** Freysteinson, Wyona

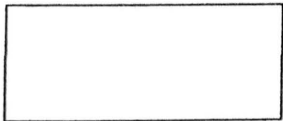
Wyona:

Please permit this e-mail to serve as my permission to deposit the full text of the following article in to your dissertation to meet the graduate requirements at the Texas Woman's University, Denton, Texas.

THE EXPERIENCE OF VIEWING SELF IN THE MIRROR AFTER A MASTECTOMY A paper  
Submitted to Oncology Nursing Forum, June/July, 2011 Wyona M.  
Freysteinson, MN; Amy S. Deutsch, DNP, RN, CNS, AOCNS ; Carol Lewis BSN,  
RN, OCN, CRNII; Angela Sisk, MSN, RN, OCN; Linda Wuest, BSN, RN, OCN and  
Sandra K. Cesario, PhD, RNC, FAAN

My permission extends to any future revisions and editions of your dissertation and to the prospective publication of your dissertation by ProQuest through its UMI(r) Dissertation Publishing business.

Warm Regards!



Amy S. Deutsch, DNP, RN, CNS, AOCNS

Advanced Practice Nurse

System Cancer Services

Memorial Hermann Cancer Services

9401 Southwest Freeway #1148

Houston, Texas 77074

C 281.627.2257

F 713.448.6800

[Amy.Deutsch@memorialhermann.org](mailto:Amy.Deutsch@memorialhermann.org)

**From:** Freysteinson, Wyona [mailto:WFreysteinson@mail.twu.edu]

**Sent:** Mon 7/11/2011 9:16 AM

<https://owa.twu.edu/owa/?ac=Item&t=IPM.Note&id=RgAAAAA5ftoY9zqWRpuqhLqXA...> 7/11/2011



**RE: Co-author Permission**

Sisk, Angela [Angela.Sisk@memorialhermann.org]

**Sent:** Monday, July 11, 2011 9:31 AM

**To:** Freysteinson, Wyona

Wyona,

You have my permission to use the article.

Angela Sisk, MSN, RN, OCN  
Oncology Nurse Navigator  
Memorial Hermann Northwest Hospital  
713-867-2062  
[angela.sisk@memorialhermann.org](mailto:angela.sisk@memorialhermann.org)

**From:** Freysteinson, Wyona [mailto:WFreysteinson@mail.twu.edu]

**Sent:** Mon 7/11/2011 9:15 AM

**To:** Sisk, Angela

**Subject:** Co-author Permission

Dear Angela Sisk,

I would like to deposit the full text of the following article in my dissertation to meet the graduate requirements at the Texas Woman's University, Denton, Texas.

THE EXPERIENCE OF VIEWING SELF IN THE MIRROR AFTER A MASTECTOMY A paper  
Submitted to Oncology Nursing Forum, June/July, 2011 Wyona M.  
Freysteinson, MN; Amy S. Deutsch, DNP, RN, CNS, AOCNS ; Carol Lewis BSN,  
RN, OCN, CRNII; Angela Sisk, MSN, RN, OCN; Linda Wuest, BSN, RN, OCN and  
Sandra K. Cesario, PhD, RNC, FAAN

I am contacting you as a co-author in order to seek your permission to do this. The requested permission extends to any future revisions and editions of my dissertation and to the prospective publication of my dissertation by ProQuest through its UMI(r) Dissertation Publishing business.

I would be grateful if you could return this email to me with your permission to use the article. Thank you for your attention with this and I look forward to hearing from you.

Yours sincerely,

Wyona M. Freysteinson  
PhD Nursing Student  
Texas Woman's University

<https://owa.twu.edu/owa/?ac=Item&t=IPM.Note&id=RgAAAAA5ftoY9zqWRpuqhLqXA...> 7/11/2011

**RE: Co-author Permission**

Lewis, Carol [Carol.Lewis@memorialhermann.org]

Sent: Monday, July 11, 2011 11:49 AM

To: Freysteinson, Wyona

Permission granted

Carol Lewis BSN RN OCN CRNI  
Oncology Nurse Navigator  
713-897-4668  
713-249-0925  
carol.lewis@memorialhermann.org

**Confidentiality Notice**

This electronic mail message (and any attached files) contains information that may be confidential or privileged. The information is intended for the exclusive use of the individual or entity to whom it is addressed. If you are not the intended recipient, you are notified that any use, review, disclosure, copying, or action related to this information is strictly prohibited. Inadvertent communication error shall not compromise or waive any privilege or confidentiality. If you have received this communication in error, please immediately notify the sender by telephone or reply e-mail and delete the original message from your system without making copies.

-----Original Message-----

From: Freysteinson, Wyona [mailto:WFreysteinson@mail.twu.edu]

Sent: Monday, July 11, 2011 9:17 AM

To: Lewis, Carol

Subject: Co-author Permission

Dear Carol Lewis,

I would like to deposit the full text of the following article in my dissertation to meet the graduate requirements at the Texas Woman's University, Denton, Texas.

THE EXPERIENCE OF VIEWING SELF IN THE MIRROR AFTER A MASTECTOMY A paper Submitted to Oncology Nursing Forum, June/July, 2011 Wyona M. Freysteinson, MN; Amy S. Deutsch, DNP, RN, CNS, AOCNS ; Carol Lewis BSN, RN, OCN, CRNII; Angela Sisk, MSN, RN, OCN; Linda Wuest, BSN, RN, OCN and Sandra K. Cesario, PhD, RNC, FAAN

I am contacting you as a co-author in order to seek your permission to do this. The requested permission extends to any future revisions and editions of my dissertation and to the prospective publication of my dissertation by ProQuest through its UMI(r) Dissertation Publishing business.

I would be grateful if you could return this email to me with your permission to use the article. Thank you for your attention with this and I look forward to hearing from you.

Yours sincerely,

Dr. Wyona M. Freysteinson  
PhD Nursing Student  
Texas Woman's University

<https://owa.twu.edu/owa/?ac=Item&t=IPM.Note&id=RgAAAAA5ftoY9zqWRpuqhLqXA...> 7/11/2011

**RE: Co-author Permission**

Wuest, Linda [Linda.Wuest@memorialhermann.org]

Sent: Monday, July 11, 2011 8:44 AM

To: Freysteinson, Wyona

To Wyona M. Freysteinson,

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PhD Nursing Student  
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