

Abstract

Since the 1970s there has been an increase in the number of fine art photographs of women with breast cancer. The objectives of this study were to examine: a) how women who have experienced breast cancer reacted and related to a book of nude photographs of other women with breast cancer, and b) their recommendations concerning the presentation of such photos to other women with breast cancer. This photo-elicitation study involved interviews with 15 women who had experienced breast cancer and the findings revealed that the majority of the women felt that the book of nude photographs gave them a sense of hope for the future. In addition, the findings showed some diversity of opinion about when, how and where to use the book of photos. They disagreed if it should be viewed as soon as women are diagnosed with breast cancer or later in their treatment. Finally, the recommendations included having the photos: a) presented to patients by physicians, b) available in physicians' waiting rooms and chemotherapy rooms, c) available for women's partners/husbands, and d) included as part of therapy. The results suggest that some women who have had breast cancer, perhaps with more of a postmodern versus modern orientation, benefit from viewing fine art photographs of other women with the same disease. Viewing such photographs assists them in identifying with other women with breast cancer who appear elegant, beautiful, in satisfying relationships and accepting for their physical conditions.

Key Words: *Breast cancer, photography, photo-elicitation*

论文摘要

乳腺癌患者：利用同病女性的图片进行的照片引谈调查

自 20 世纪 70 年代以来，以罹患乳腺癌女性为拍摄对象的艺术摄影数量不断增加。这篇论文旨在对两方面进行调查研究：一、乳腺癌患者面对一本其他女性患者裸体人像图册的反应与共鸣；二、她们对此类照片的展示方式有何建议。这项照片引谈研究访问了 15 名乳腺癌患者。绝大部分受访者认为这本图册让她们感觉对未来充满希望。另外，研究还显示受访者对于何时何地以何种方式展示这本图册持有不同见解。有些人认为患者一旦被确诊就应该接触这类图片，另外一些人则认为应该在随后的治疗中使用。受访者对图册使用的建议包括：一、由医生向患者展示；二、放置于候诊区和化疗室；三、向患者的配偶或伴侣展示；四、把图册展示作为治疗的一部分。研究结果表明，那些具有后现代主义而非现代主义倾向的患者更能从这些艺术摄影中汲取正能量。气质优雅、形象美丽，对两性关系满意并接纳自身生理状况，图片主人公所传达的这些积极信息能帮助此类受访者找到身份认同。

关键词：乳腺癌，摄影，照片引谈

Frauen mit Brustkrebs: Photo Elicitation-Interviews unter Verwendung von Fotografien von Frauen mit derselben Krankheit

Seit den 1970er Jahren gibt es eine vermehrte Anzahl an Kunstfotografien zu Frauen mit Brustkrebs. Ziel dieser Studie war es zu untersuchen wie a) Frauen, die an Brustkrebs litten, auf ein Buch mit Nacktbildern von andern Frauen mit Brustkrebs reagierten und b) ihre Empfehlungen für eine Präsentation dieser Fotografien für andere Frauen mit Brustkrebs ausfielen. Diese Photo Elicitation-Untersuchung beinhaltete Interviews mit 15 Frauen, die an Brustkrebs litten und die Ergebnisse zeigten, dass das Betrachten des Bandes einer Mehrheit der Frauen ein Gefühl von Hoffnung verlieh. Weiter zeigten die Ergebnisse eine Diversität von Meinungen darüber, wann, wie und wo der Fotografieband zu verwenden sei. Schliesslich könnten die Fotografien gemäss ihren Meinungen a) vom behandelnden Arzt/der behandelnden Ärztin den Patientinnen gezeigt werden oder b) in Warteräumen und Chemotherapie Räumen aufgelegt werden oder c) den Ehemännern/Partnern der Frauen zur Verfügung gestellt werden oder d) in die Therapie integriert werden. Die Ergebnisse deuten darauf hin, dass einige Frauen, die Brustkrebs hatten und wahrscheinlich eher über eine postmoderne, denn moderne Gesinnung verfügen, von der Ansicht von Kunstfotografien von Frauen mit derselben Krankheit profitieren. Das Betrachten solcher Fotografien hilft ihnen, sich mit andern Frauen mit Brustkrebs, die elegant, schön, in befriedigenden Beziehungen lebend und ihre körperliche Verfassung akzeptierend erscheinen, zu identifizieren

Schlüsselwörter: *Brustkrebs, Fotografie, Photo Elicitation*

Prior to the 1970s, women with breast cancer were not photographed in the nude, often kept their scars hidden, and didn't discuss how their physical appearance had changed. Since the 1970s the landscape of the breast cancer movement has changed from one of medical sovereignty to one of new subjectivities, sensibilities, and solidarities, resulting in how the disease is medically and publicly managed, and socially constructed. This landscape changed, at least in part, because breast cancer research gained corporate and federal support in the U.S. and women with breast cancer gained greater attention through newly formed political and social organizations, many of which sponsored events such as runs and walks in locations across the country (Klawiter 1999; Kaiser 2008). While breast cancer was gaining national attention, an alternative view of women with breast cancer arose in the fine art community. There was an increase in the number of artistic photographs of women with breast cancer. Fine art photographs of women with breast cancer became more revealing, including showing baldness, hospitalizations, treatment procedures, nudity, scars, lumpectomies, unilateral and bilateral mastectomies, and reconstructed breasts. Most of these photos were displayed in exhibits or printed in fine art books and contained multiple photographs of the author and/or other women as they experienced breast cancer, as well as their stories and reflections on their illnesses. This research addresses how women with breast cancer react and relate to artistic photographs of other women with the same disease.

Literature

Photography of Women with Breast Cancer

Two well-known photographers who chose not to conceal the disfiguring effects of their own breast cancer were Jo Spence and Matushka. Their photographs and biographies have been published in major magazines and books, as well as shown in galleries and on web sites. British feminist Jo Spence took self-photographs to document her experiences with breast cancer from the time of her diagnosis in 1982 until the time of her death in 1992. Although her

surgeon suggested a mastectomy, Jo Spence chose a lumpectomy and Chinese herbal medicine. She took hundreds of photographs to document her diagnosis, surgery and alternative treatment methods. She stated that she used the camera to visually come to terms with her disease. She was particularly interested in the political and therapeutic power of autobiography through photography (Spence 1995). She had a reoccurrence 18 months after a lumpectomy and eventually died of leukemia (Radley and Bell, 2007). After undergoing a mastectomy in 1991, Matuschka, a fashion model and artist, photographed her nude body, highlighting the mastectomy scar on her chest and her lack of breast reconstruction. Matushka (1996) stated that if society keeps hidden what cancer does to women's bodies, and if it doesn't accept women's bodies in whatever damaged condition they are in, it is doing a disservice to women.

The following articles all discussed photographs of and/or by Jo Spence and Matushka. Bell (2002, 2006) and Radley and Bell (2007) described Jo Spence's photographs as narratives of living with cancer that incorporate visual and textual elements. They also suggested that words do not fully capture the meaning of illness and that extending the study of illness narratives beyond oral and textual accounts can enlarge and enrich social science understandings of people's experiences of illness. How patients construct meaning in the production and display of their art builds an argument for the benefits of developing a visual imagination around illness.

Amaya (2004) and Rosolowski (2001) discussed the role that photography played in the process of self-formation for Matuschka. On August 15, 1993, Matuschka's self-portrait called *Beauty Out of Damage* appeared on the cover of the New York Times Magazine as the signature image for Susan Ferraro's (1993) article, "You Can't Look Away Anymore: The Anguished Politics of Breast Cancer." According to Rosolowski (2001), the New York Times received 125 calls on that Sunday alone and 200 letters in

the days following, an unprecedented response. In 1996, Matushka published a biographical essay in which she described how her art had been impacted by her mastectomy. Matuschka came to be known as “breast cancer’s pin-up girl,” a symbol for other women with breast cancer. Readers have clearly been moved by Matuschka’s image, both positively and negatively. *Beauty Out of Damage* is one of the most recognizable images of breast cancer today, and still evokes heated discussion. Cartwright (1998) argued that the self-portrait photography of Matuschka and other women with breast cancer helps us to think about the ways in which issues such as race, age, and beauty are key aspects in the experience of breast cancer and not tangential cultural issues or appearance-related side effects.

In addition to the increase in the number of photographs of women with breast cancer taken by professional artists, another approach emerged. It involved asking women, who are not professional photographers, to produce visual narratives by taking, discussing and writing about photographs that represent their breast cancer experiences. In four studies, patients were asked to take photographs of their experiences: a) during chemotherapy (Frith and Harcourt 2007); b) related to caring behaviors and demands during their breast cancer experiences (Gates, Lackey and Brown, 2001); c) related to their quality of life as breast cancer survivors (Lopez, Eng, Randall-Davis, and Robinson 2005); and d) during certain aspects of living the breast cancer experience (Predeger 1996). The authors of the four studies cited above all concluded that patient-produced photographs and text served as powerful stimuli for discussion beyond the medical aspects of their diseases. Frith and Harcourt (2007) concluded that this method: a) produced elaborate accounts of illness experiences through representing experiences and discussing the photographs themselves; b) allowed women an opportunity to capture illness experiences over time; c) allowed women a way of capturing the past, which can then be re-explored from the present; d) enabled patients to retain control

over their images and how they choose to represent and describe their experiences; and e) provided a window into the private, everyday experiences of patients away from health care settings.

Nelson (1996) attempted to gain insight about women who were struggling with the uncertainty of breast cancer re-occurrence through photographic hermeneutics, which is based on the belief that experiences are symbolic and can be contemplated, not merely lived. The participant can capture symbols on film that are representative of personal experiences. The photographic symbol is then used by the participant to interpret the meaning or experience. Photographic hermeneutics were used to describe and interpret uncertainty for nine women between two and six years post-treatment for breast cancer. Data were collected using interviews and written interpretations of photographs. For instance, one woman in this study interpreted her uncertainty of cancer recurrence through a photograph of dandelions in her yard and stated: "No matter how well you take care of your yard, the weeds and disease just come in. I am always out pulling, pulling....It's real symbolic to keep the weeds out of my garden. After a few days of rain, they just encroach right in, just like my cancer (p. 4)." This symbolic metaphor provided a unique visual perspective on the uncertainty experience for women living with breast cancer.

And finally, an additional methodology involves using one abstract photograph as an integral part of the therapeutic process to assist breast cancer patients. The approach is primarily nondirective, appropriate to insight-oriented individuals, and may be applied more generally to terminally ill patients. The photograph serves as a trigger or tool for the patient to let his/her imagination go. The stream of thought brought forth by the photograph provides ongoing feedback and contributes to the patient’s creation of new mental images, which translate into increased self-awareness. In this study, Walker (1991) used one photograph to help a terminally ill breast cancer patient confront the significant issues

of her life, including her own mortality. Walker (1991) stated that it is this recognition of the final growth experience that gives new meaning to life itself. The 13" x 19" color photograph (light colors and hues of dark purples and brown interwoven and swirling) that was used was part of a set of ambiguous, abstract images, evocative of primal themes (death, sexuality, and power). Their dreamlike quality was described as a powerful force in their effectiveness. In describing reactions to the photo, the patient became aware that she was describing aspects of herself. The image also encouraged free association and helped the patient realize salient underlying themes in her life. This case history provided a model for the use of photographs in the therapeutic process to deal with issues of mortality with terminally ill breast cancer patients.

In this study we used photo-elicitation interviews to examine how 15 women who had experienced breast cancer reacted to and related to a book of photographs of other women with breast cancer. In addition, their interview transcripts were analyzed for modern and/or postmodern perspectives, in light of the cultural norms that dictate that they appear as they did prior to breast cancer by undergoing additional reconstructive surgeries and wearing adaptive clothing and prostheses. We also asked for their recommendations concerning having women with breast cancer view these or similar photos.

Theory

Gray (1998) outlined four perspectives that he considers relevant to unconventional medical therapies and used cancer as the exemplar for each perspective: biomedical, alternative, progressive, and postmodern. He described each as potentially helpful depending on the individual, the stage of the illness, and how often the patients modify their perspectives depending on the illness context. The biomedical perspective is based on the dominant health care view that medicine is intended to cure disease or if not possible, to relieve pain. The alternative model

proposes that there should be acceptance of domains other than the purely physical for health care, and acknowledges the limitations of the biomedical model. The progressive view supports either biomedical and/or alternative approaches depending on the strength of the scientific evidence. And finally, the postmodern view is critical of the socially constructed views of the privileged authority of physicians.

Modernism

Hall's (1998) theoretical model, an extension of Frank's (1995) work with illness narratives, was selected and applied in the present study, because she based her theory specifically on the sentiments of breast cancer patients. Hall (1998) summarized two views concerning breast cancer patients' illness narratives or stories: modern and postmodern. The two views are described separately below but in reality are not mutually exclusive. A single illness narrative may contain elements of both views depending on the context. The modern view is based on the biomedical model in which the patient submits the self wholly to the physician and medical establishment. Frank (1995) labeled narratives of patients with modernist views as restitutive and described them as believing that they will get over their diseases or be cured and life will continue as it was pre-illness. Illness narratives in this realm include statements that reveal that: a) the disease is transitory, b) more attention is on the remedy than on the self, c) medicine can triumph over illness, and d) the patient can return to normal.

For example, Kaiser (2008) described efforts such as the Susan G. Komen Race for the Cure, which is a 5 km run/walk held in over 100 locations annually to raise funds and awareness of breast cancer, as illustrating the modernist view. Mastectomy scars and disfigured bodies are hidden at this and other events. Prostheses makers, fashion magazines, and cosmetic companies encourage women with breast cancer to project a particular definition of wholeness and femininity. They are taught to wear pink and cover up the reality of

what their bodies look like after treatment by way of clothing, breast reconstruction, and prostheses (Kaiser 2008).

Postmodernism

In contrast to the modern view, Hall (1998) described the goals of the postmodern view as uncovering the meaning of breast cancer and its implications. Frank (1995) labeled patients who espouse the postmodern view of illness as on a quest. In quest narratives, the patient recognizes that his or her illness has resulted in life changes and seeks to embrace a new life or rebirth. A new “body-self” is the product (Frank 1995, 172). Illness narratives in this realm include statements that reveal that the patient a) learned valuable life lessons, b) became more involved in social change and advocacy, and c) gained valuable insights that need to be passed on to others. Frank (1995:259) described postmodern narratives as “resembling life in that both move forward unpredictably and in an ever-changing manner.”

Postmodern Artistic Photograph

Dungan (2003:8) described the end of the 20th century as a time when there was a “veritable explosion of artistic representations of the body and when the body became the common theme in the work of artists, critics, curators, and art theorists.” Several art historians and curators described the 1980s and 1990s as a time when exposure of the body was used to make a postmodern statement about the politics of gender and identity (Dungan 2003; Posner 1998; Sussman 1993). Shildrick and Price (1998) stated that after decades of being kept hidden, the body came to the forefront of discourse in the social sciences and humanities, as well as in medicine. This paradigm shift corresponded with the rapid growth of the feminist movement.

Photography became one of the tools for promoting the postmodern approaches used by many researchers and artists in attempting to understand women’s experiences with breast cancer. For example, well-known photographer Hannah Wilke

conducted a project between 1978 and 1994 that chronicled her mother’s experience with cancer and her own experience with lymphoma. She photographed her mother’s emaciation, hair loss and black and blue marks. She photographed her own body bloated from chemotherapy and marked by radiation scars. She shot hundreds of photographs of each of them and described the process as therapeutic. She believed that photography is a vehicle that promotes healing because the individual being captured on film becomes immortal, important, the center of attention, and a star (Buszek 2006). We asked a question in this study that has not been addressed previously. How do women who have had breast cancer react to and relate to a set of fine art photographs and text about other women with the same disease using modern and/or post-modern perspectives?

Method

After obtaining approval from the first author’s university ethics review board, two local breast cancer support organizations in a Midwestern city recruited participants for this study via e-mail requesting research volunteers. If they were interested in participating, they responded directly to the first author by telephone or e-mail. The women needed to have been diagnosed at least one year prior to the study. Fifteen responded and all completed the interviews. Four months after the study was completed, the women were invited to attend a university medical humanities seminar in Indianapolis where the first author and Art Meyer presented and discussed some of the findings. Five of the 15 participants attended.

The research team for this study was made up of the first author and three female graduate students. The students were enrolled in a 3-credit course pertaining to this project. They practiced applying Hall’s (1998) and Frank’s (1995) views about modernity theory to an independent set of illness narratives and photos written by breast cancer survivors (see Fisher, 2006). The goal was to reach group consensus in order to achieve high inter-coder

understanding and agreement. In addition, with the participant's permission, each student attended at least one of the interviews conducted by the first author as a silent observer and later wrote detailed field notes about the context. Students made observations of participants at different times during the interview, and when the participants were viewing and discussing different photos. Their field notes also included data on the themes of interest here: reacting and relating to the photographs.

Photo-Elicitation

Collier (1957, 1967) defined photo-elicitation as involving using photographs to guide and stimulate discussion and memory during verbal interviews. He stated that the use of photographs in interviews provides the researcher with additional data that would otherwise not be communicated by the participant. Photographs inserted into interviews elicit longer and more comprehensive interviews and at the same time help participants avoid the fatigue and boredom that can be felt with strictly verbal interviews. This methodology evokes information, feelings, and memories that are due to the photo's particular form of visual representation (Harper 2002). In addition to inserting photographs into verbal interviews, photo-elicitation allows for creativity on the part of the researcher to meet identified research goals. For example, Heisley and Levy (1991) investigated a technique called auto-driving, similar to photo-elicitation, in which multiple iterations were involved. They were conducting a methodological study to determine if an iterative auto-driving process would work as a projective technique. The participants met with the researcher for three separate sessions: a) photo shooting, b) photo-elicitation interviews that were audio-recorded, and c) a later session in which the tapes and photos from the photo-elicitation interview were reviewed and commented on by the participant. Harrison (2002) elaborated on the advantages and disadvantages of including visual methodologies in qualitative research and suggested that a combination of visual and traditional methods may be

recommended, including the visual genre of painting, drawing, video, and still photography.

Rose (2007) divided photographs used in visual or social science research as serving either supportive or supplemental roles. She places photo-elicitation studies in the first category and justifies this by stating that the images are subordinated to the researcher's interpretations and are examined to determine what they can contribute to answering a research question as opposed to being a visual supplement to the written text created by the researcher.

The photographs that are used in photo-elicitation can be secured in a variety of ways. For example, they can be taken by: the participant in preparation for the interview; the participant, or others earlier in his or her life; the researcher for the present or previous studies; and/ or others and labeled found or existing images (Blinn and Eyring, 1989; Blinn and Harrist, 1991; Blinn-Pike, Phillips and Reeves, 2006). Blinn and colleagues (1991, 2006) conducted photo-elicitation interviews with various audiences and concluded that, when combined with participant-produced photos, the photo elicitation process aided in understanding individuals facing life transitions. It appeared to be particularly useful when attempting to understand people who are faced with living in the middle between a familiar lifestyle and an unknown future. According to Radley and Taylor (2003:131), photographs act as "triggers for memory" that depend on whether the photographs were taken by the person being interviewed or by other(s). However, in both cases, drawing meaning from the photograph is critical for understanding what the image is about, and is often articulated in the verbal narrative that surrounds the photograph.

An examination of the "methodological foundations of photo-elicitation interviews in the social sciences must address the varied and dynamic interrelationships between pictorial images,

interview transcripts and theoretical foundations, through which meaning is constructed rather than simply found “ (Felstead, Jewson and Walters, 2004:105). Felstead, Jewson and Walters (2004) illustrated the interaction of still images, transcripts, and theory through post hoc descriptions of several of their visual studies after the studies were completed. They reviewed these studies and concluded they were different in being driven by: a) the researcher’s photos and sociological theories, with little contribution from the participants’ comments; b) the interview transcripts with visual images playing a minor role; c) the equal contributions of images, and interviews with less interest in theoretical interpretations; and d) the equal contributions of images, interviews, and theory.

Participants

Overall, the 15 volunteers were a middle class, middle aged, White group with college degrees, and long term marriages. Ten reported incomes between \$45,000 and \$75,000. The average age was 55 years. In terms of race, 13 were White, one was African American, and one was Hispanic. In terms of education, nine had 4-year college degrees or graduate degrees. Five women reported they worked full time, seven worked part time and the remainders were unemployed or retired. Their occupations ranged from retail sales clerk to certified public accountant (2). Ten reported being married an average of 27 years and being married an average of 20 years when they were diagnosed with breast cancer. The number of years since their first diagnosis with breast cancer averaged 6.33 years.

The sample was approximately evenly divided into four groups concerning their decisions regarding reconstructive surgery. Three had lumpectomies and no additional surgery. Of the 12 who had mastectomies, five chose to have no reconstruction, three had immediate reconstruction, and four waited from several months to a year to have reconstruction.

Procedure

Each participant was mailed a copy of a book titled *Winged Victory: Altered Images Transcending Breast Cancer* (Myers and Marrocchino 1996) at least two weeks before an individual interview. She was given the book to keep and asked to review the photographs and text in the book and think about a series of questions prior to the interview. Are there any photographs/text that “speak” to you or “move” you? Are there photographs/text that show women you can or can not relate to because of your own situation? Are photo books like these helpful to breast cancer patients? Why or why not?

Winged Victory: Altered Images Transcending Breast Cancer (Myers and Marrocchino 1996) contains 22 black and white photographs of women who have had breast cancer. It was selected for this study after a careful review of similar books because of the: a) diversity in the physical appearances of the women who had different breast cancer procedures, b) presence of partners/husbands in some of the photos, and c) quotations accompanying each photograph which briefly describe each breast cancer story.

Rose (2007) suggested that to understand the richness and complexity of an image, three sets of questions need to be asked about: a) the production of the image, b) the image itself, and c) the viewer. The questions are dependent of the context and purpose of the making of the image but might include when and by whom the image was made, as well as the social identities of the maker, the owner, the viewer, and the subject of the image. Following Rose’s line of thinking, we made contact with the photographer of the images being used in the study. At the beginning of this project, to understand the photographer’s view of his work, the research team conducted a tape recorded telephone interview with Art Myers, the photographer for *Winged Victory: Altered Images Transcending Breast Cancer*. He subsequently came to the first author’s university, at her

invitation, and attended a conference on illness narratives. He is both a physician and award-winning photographer. The phone interview lasted one hour and was transcribed for review. In the interview he described a) why he took each photo; b) what he was attempting to show in each photo; and c) non-identifying information about each woman and her breast cancer story, including her age, marital status and type of surgery. This information facilitated the first author in answering participants' questions about the women in the photographs during the interviews.

He stated that he undertook this photographic project hoping to show a postmodern view that a woman's fundamental nature is not dependent on anything external; that the loss of part or all of her breast is not a threat to her essential being. He hoped that these pictures revealed the persistence of a woman's beauty, strength, and femaleness in all of its complexity, even after the transforming experience of breast cancer. In all of the photographs the women are naked from the waist up. In addition, they show: the women alone or with partners/husbands (5), bilateral mastectomies with no reconstruction of the breast (8), mastectomies of one breast with no reconstruction (11), reconstructed breasts (3), and scars from lumpectomies (3). Some photographs are in more than one category. Thirteen of the women in the photographs are White, one is Asian, and one is African American.

Interviews

The photo-elicitation interviews were conducted by the first author, lasted approximately 1.5 hours each, and were tape recorded and transcribed. They took place at locations that were convenient for the participants, including medical clinics, a church, their homes, and a university. The interview session was divided into two parts. First, the participant told her breast cancer story and then, second, she discussed each of the photographs in *Winged Victory: Altered Images Transcending Breast Cancer*.

Telling her story first "broke the ice" and provided a context with which to relate to the photographs.

All of the participants had reviewed the book and came to the interviews prepared to discuss the photographs. Three brought notes they had taken of their thoughts and recommendations. The participant selected the order in which to view the photographs. She was asked if there were some that she most wanted to talk about and those were discussed first, followed by each of the remaining photographs.

Data Analysis

Reflexivity refers to the process of self-conscious reflection on the part of the researcher that can be expected to have an impact on the data due to differences of race, class, gender, and experience (Murphy and Dingwall 2003). In this study, none of the team members had had breast cancer or had a close relative or friend who had the disease, although they were encouraged to think about and clarify their own attitudes and beliefs about women and breast cancer throughout the project. This was done to support the belief that subjectivity is a central aspect of visual knowledge, interpretation and representation (Pink 2007). In the first step of the data analysis, each interview transcript (parts one and two) and the corresponding set of post-interview field notes were read in their entirety to gain a sense of the participant's experience as a whole. A content analysis was conducted based on the two pre-identified themes: reaction and relatedness, as well as modernity, the theoretical foundation for the study. Reactions were coded as modern, postmodern or a combination. Relatedness quickly emerged from the data due in part to the fact that they had been asked to consider the following question prior to the interview: Are there photographs/text that show women you can or can not relate to because of your own situation? Dominant subthemes of relatedness were identified and then further analyzed for modern, postmodern, or combined sentiments. Independent coding and group process with high intercoder agreement were used to arrive at both the

subthemes under relatedness and reaction, and modernity classifications.

Likewise, the majority of participants had opinions about how the photo book should be used with other women with breast cancer because they had been asked to consider this question when they received the book, prior to the interview. Their recommendations were categorized according to when, how and where they believed the photo book should be used. Data describing opinions about the book being shown to other women with breast cancer were as coded as modern, postmodern or sentiments of the two combined in the same response.

Results

The first aim was to determine how women who have had breast cancer react to and relate to a book of artistic photographs of other women with the same disease, from modern and/or post-modern perspectives.

Reactions

The dominant reaction to the book is represented in the following quotation. The majority of the women stated that the photographs and accompanying text gave them a sense of hope for the future, which was Art Myers' main goal. One woman represented the dominant opinion by stating:

I think it is a great book. I think it gives you hope...When you see pictures from the surgeon, it is the clinical cold pictures with the florescent light and door for a background... So the clinical pictures I think are scary because you don't have all the answers, and it is just the bust, you don't see if this person is happy, you don't see if they are sad, you don't know anything about them, but this is what their boobs

look like...This book it shows women who have moved on; their scars have faded, so it gives you hope that your scars will fade. For some women who think that no man is ever going to love me if I only have one breast or no breasts, then this sort of thing shows them that no, there is hope.

There were three women who had diverse reactions that were more extreme than the majority: a) not wanting to view the photos at all, b) using it as a book in her home to open up discussions about women's breasts with her sons, and c) using it as a coffee table book in her home to open up discussions about breast cancer with visitors. The three views are shown in the quotations below, in order. The first quotation shows a modernist perspective in which the viewer prefers to keep the physical realities of breast cancer hidden from view, while the other two show a postmodern view when they openly display the book of photographs in their homes.

My general feel for the book was I don't see any purpose for this book, because I feel it is sort of exploiting. I would not pick up a book and look at it of women that didn't have breast cancer showing their breasts, so it is not something that I would...I don't see a purpose to look at them when I am not learning about reconstruction, it is kind of like, here is my body and I almost feel like if these women probably would have done this sort of thing before they had cancer, they are probably women that would do it after cancer. That is my kind of feel for it...I don't think the pictures do anything. I would almost prefer to pick up the book and read about people's stories of breast cancer. I don't think the pictures are doing the story any good... I would get more out of reading some peoples stories than I would out of any of this stuff; and when you put it in the context of a book

like this, I don't even read it, because I don't care for the way this is presented.

It has been sitting out at my house. It isn't hiding anywhere, my boys have looked at it, but they have also seen their mom. That is one thing I have never been afraid...even when it first happened. They have seen it all. They have seen every stage of it, all the bulbs hanging out of me and everything else...They will respect them a little more, and respect the women that carry them around, not the breasts. They are not what makes you a woman, they are not what makes you a mother ...I have taught them those things by sharing with them. I don't want them objectifying, because they are not going to make you who you are.

There was somebody at our house and I had the book on the coffee table, and they go, oh. It was a man. I will tell you what, it opened up a conversation. He started asking, he goes now how do they do this? What do they do? You never know, he may run across some woman, or his wife or something that ends up with breast cancer, and he started to feel a little more comfortable with it. He goes you know I have always wondered, how do they do this? It really got him talking.

Relatedness

This aim involved examining how the women related to the photos in the book. Did the photos serve as triggers for telling their own modern, postmodern, or mixed stories? Through independent coding and then discussion, the research team arrived at consensus that the participants related to the photos by talking about the following subthemes in their own lives: a) mortality, b) breast reconstruction, c) surgical procedures, d)

marital relationships, and e) body image. Each of these subthemes is illustrated below along with the photo and text that were the triggers for the focus of the particular discussion. Included in this section is information about subthemes that include evidence of modernity views.

Mortality

The following quotation shows how viewing a photograph of a couple (Dora and Cy) in their 70s, who had been married 42 years since her diagnosis with breast cancer and double mastectomy, resulted in a 38-year-old participant discussing her own mortality from a combined perspective. She fully accepts that many women who have had breast cancer will not be "cured" and she reluctantly accepts that when she will die is not in her control (postmodern). The photograph that she was reacting to and the text accompanying the photo follow her quotation.

That is probably one of the hardest things, you meet a lot of women in your journey ... knowing and understanding beneath it all that some of us aren't going to be here, and some of us sooner than others...it's what you leave behind that has to be dealt with...that bothers me more than anything. I wish my children were grown, because I don't want to leave them... making friends along the way and then losing them, that is even harder...there are a lot of women even younger than me ...I don't wish cancer upon anybody. I don't want anybody to have to deal with it, but it is a part of life...I just wish I would have been a lot older...couldn't you have waited about another thirty or forty years? It doesn't work that way.

Photo 1: Dora and Cy



In the text accompanying her photo, Dora described how she and Cy rejected the prevailing modernistic view at the time that women should keep their scars hidden, even from their husbands.

While I was in the hospital shortly after surgery, my husband's aunt was sitting by my bedside. I remember her saying: Whatever you do, never let anyone see your scar, especially never let him see it. I was devastated but being a super husband, he frowned on that comment. He has shared my problem with me for the past fifty-two years.

Breast Reconstruction

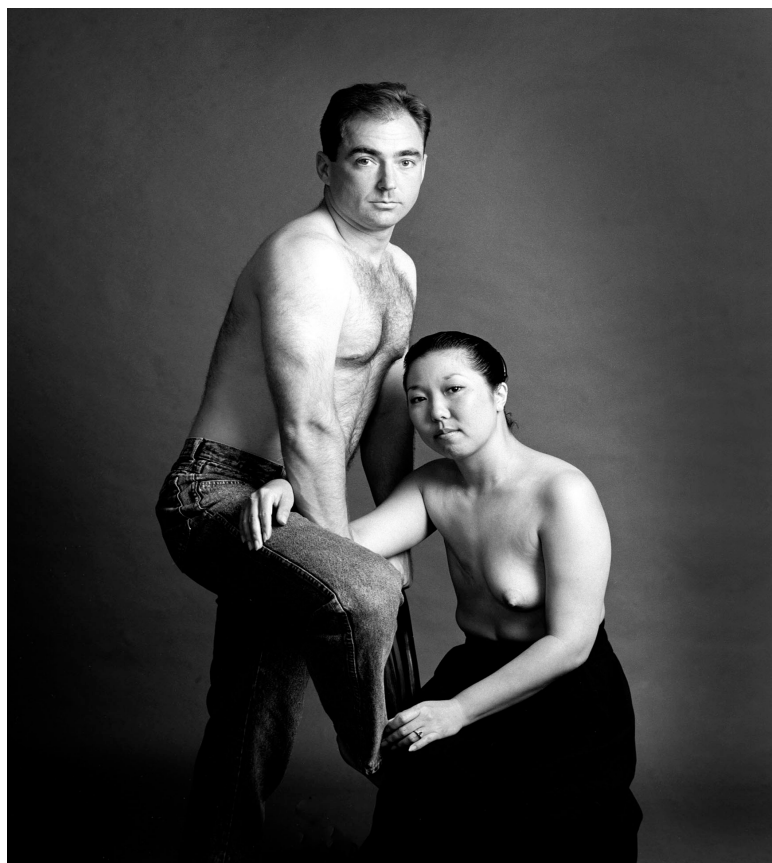
Viewing the photos resulted in some participants feeling regret about the post-operative breast reconstruction decisions that they had made. The next quotation came from a woman who had breast reconstruction and is feeling some regret after viewing the photographs of women who chose not to have reconstruction. She appears to be caught between modern (reconstruction) and postmodern (no reconstruction) views.

I was really kind of pleased to see all these women that had had mastectomies that didn't even go for reconstruction, just kept the mastectomy...I don't know if I would have gotten reconstruction again...because of the type that I had and how quickly I got it. I did not see a lot of pictures of women who had a mastectomy. So it is really interesting for me to see the women who didn't have reconstructive surgery.

The following text accompanied the photo of Blair and Susan in the book. Blair stated:

I used to look at her and see all beauty, to long to be with her, to enjoy just touching her, to seek her comfort and warmth...Nothing had changed; I still do all of these.

Photo 2: Blair and Susan



Surgical Procedures

In addition to the indecision or regret some participants expressed about breast reconstruction, some also viewed the photos and expressed indecision or regret about having a lumpectomy versus a mastectomy. The following woman related to a photograph of a woman with a large scar on her chest (Ulla). It resulted in her talking about the pros and cons of having a

lumpectomy versus a mastectomy as a personal choice that caused her some uncertainty.

That one bothered me. I wrote down the word choice because of her scar, because of the indentation. That's how mine is...I don't know if she had a mastectomy or a choice between lumpectomy, lumpectomy, and radiation and she made that choice... I don't know how seeing this picture would have affected my choice. Sometimes I think the lines are cleaner with a mastectomy rather than having a lumpectomy... would access be better than seeing the scar? You know you have a scar. I mean...I think it's almost less noticeable with a mastectomy than it is with a lumpectomy. You still have a deformed breast rather than the absence of a breast. I'm not sure ...but I really think maybe the scars are worse on the lumpectomy just because you're looking at a deformed, not deformed, but you're looking at a different breast where I think with the mastectomy it's just cleaner. Now, I don't know about reconstruction. I think maybe if I did the mastectomy I don't know if I would have reconstruction. I don't know. I think that's a difficult one.

The following text accompanied photo 3. Ulla wrote:

If you look at my photograph I want you to see that breast cancer need not disfigure you or end your life- only as much as you allow it to happen. Cancer is a rough disease to handle! However, you have the choice to enjoy every moment of your life now or let cancer take over.

Photo 3: Ulla



Physical and Emotional Relationships

Seeing the photographs and reading the stories of couples who were viewed as connecting emotionally and sexually in spite of the physical deformities that can accompany breast cancer surgery (i.e., Dani and Ralph), prompted the following four women to discuss their own marriages and husbands from somewhat different postmodern perspectives. Their marriages changed as a result of their illnesses and those changes are

accepted and embraced (postmodern) but the path to this view was unique for each couple. The first two quotations are from women who met their partners after their breast surgery. The last two were in long term marriages when diagnosed.

These are my warrior marks, I look like WWII from my neck to my thighs, and you know, I love them; I love my scars; my husband loves my scars. Actually that is probably...I always tell him you are a freak. But he even when we first started dating, it was...that was one of the first things that I showed him, were my scars. Nothing sexual, nothing...it was just...and we had been friends growing up when we were younger, so to me it was no big deal. But he wanted to share that part of me because he hadn't been around during my two or three year battle. He appreciates them, and I do too.

That is how it was with my current husband; we started dating after my surgery. It bothered him. It really bothered him about the surgery, about what I went through and for a long time he wouldn't look at it, because he said it hurt his feelings, because he said, you are such a nice person to have to go through that. I said, well it is not a big deal. We all go through something, and this has made me a different person. Not that I was a bad person to begin with, but it has made me much stronger in my faith, in my walk, and everything. I mean, this just shows life after cancer to me.

Oh my. I had a real tough time. So those of us that have husbands that stick by our side, we're very fortunate. But it definitely caused some issues from a sexual standpoint with my husband and I. We don't. It's absent. Because I mean, although my husband

and I are not close that way, I mean we still enjoy doing things together. We are glad we have the days we have.

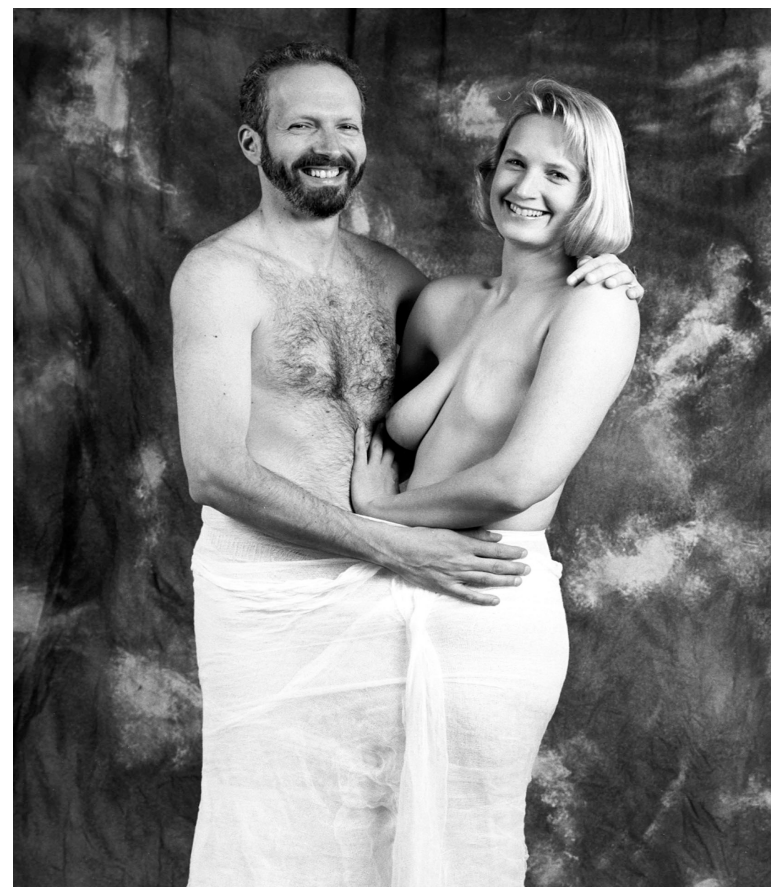
It took him [husband] a long time to go to any of what they call caretaker groups... I bought him this book, Breast Cancer Husband and did all these things. It took awhile, but actually he has started a group called Men Against Breast Cancer. It is a national group, and we are the first organization, charter member. Like he has become a real advocate too. He was with 800 women in Florida in February for the Young Survivor Coalition National Conference. He went to the executive leadership conference for them. He went knocking on doors in Washington DC with me as we worked with senators and representatives for the National Breast Cancer Coalition. There were two thousand women and thirty men.

Dani stated the following sentiment to accompany photo 4:

One day, long before I met my sweet heart, I stood naked in front of the mirror and made peace with my smooth mastectomy scar...I decided to truly feel beautiful. Later, after a romantic weekend in Mexico, he called and told me that he loved the asymmetry of my chest. I smiled and laughed to myself.

Body Image. Maintaining a positive body image while undergoing treatment for breast cancer was not easy for any of the participants, although it was achieved by several women. The following quotation embodies the postmodern acceptance of changes in body image and loss of hair after breast cancer treatment. When she looked at photo #5, Carol, she stated:

Photo 4: Dani and Ralph



I gained about sixty-five pounds...I weighed almost 200 pounds during treatment due to the steroids, and just the type of treatments I was receiving. So it was an eye-opener for me. I was very comfortable with myself. I was really surprised. I thought losing my hair and gaining the weight I would just want to crawl in a hole and just hide and I didn't. I still went

to work, wore my flamboyant makeup, I wear big earrings, didn't wear a wig, and part of that reason was because I wanted people to ask me. It happened a lot. I would walk at lunch that was my exercise, I would come, and walk for an hour and a half, then walk back to work. I wanted people to ask me. They would look and say, you are so young, why are you bald? Well let me tell ya'. They were like, how can that happen you are only? I was like, it does happen, and it happens more than people think. Now, I am probably happier with my body more so now than I was before I was diagnosed, scars, and all.

Carol described her early feelings about her breast cancer in the text accompanying her image:

...I returned to my daily swimming at the gym. Timidly. At first, I went over late at night, when I knew the locker room would be empty...But I couldn't help wondering, where were all of the women with mastectomies? Why had I never seen one in the locker room? My fear was born of theirs, as was my sense of disfigurement and embarrassment.

Recommendations for the Use of Fine Art Photographs of Other Women with Breast Cancer

The second aim was to determine what recommendations the participants had for the use of fine art books with photographs showing other women with breast cancer. Each woman was asked to make recommendations concerning when, how and where books like the one they viewed would best be used to help other women with breast cancer. The discussion about when to introduce this book to women centered on how soon it should be viewed after an initial diagnosis of breast cancer. One woman said that it should not be used at all.

Photo 5: Carol



Five stated that the timing would depend on the woman and her anticipated reaction. Two said it should be presented to women immediately after their initial diagnosis. Four thought it should be presented later, such as while discussing surgery options or after surgery is completed. Three had no opinions. The following three

quotations reflect the diverse opinions about when to present women with breast cancer with similar photographs. The first is a modern sentiment that the results of cancer are ugly and should be covered and not represented artistically. However, this is also a mixed narrative because she expresses a positive view when she goes on to talk about the plastic surgery that resulted in improving her appearance.

I think for the most part women will just take the book and throw it aside for the same reason I did; I am like what are they trying to...be it beautiful? I don't think there is a beauty to cancer. It is like saying let's take a whole bunch of war veterans that have had their legs amputated or arms amputated and we are going to try to show it is an artistic form to make it look beautiful...There is an ugly side to cancer; it doesn't mean that you are ugly when you are going through cancer ...we are very blessed because you can have reconstruction, and in some ways, other than the scars, I actually look a lot better than I did before, because I went to a very good plastic surgeon and there is a perk to it. I ended up getting a butt lift, and a tummy tuck, and...and that is all just part of it.

The second quotation shows more of a postmodern perspective in that she has discovered that viewing photographs of this type can help you get in touch with your soul.

I think it depends on the woman. There are some women out there that really are curious and they really want to know and then there are some that ...want to deal with it on their own. To give that to everybody, I don't know. I think it depends on the woman ... are they really curious? Do they really want to know? You can be beautiful even if you don't have breasts or you only have one breast. .. I would rather

see a book like that than just a bunch of random patient pictures...That's just too medical and too cold and - - I think it's a beautiful book because it is more about souls than it is about body. But I also think breast cancer gets you more in touch with your soul, and for some people it takes longer to get there than others. And I think at the beginning of the breast cancer journey, I don't know that people are that in touch with their souls, but I think it causes you to get in touch with your soul.

The third quotation, below, shows that she compared the clinical photographs of breast cancer given to her in the hospital (modern) with those in *Winged Victory Altered Images Transcending Breast Cancer* (postmodern).

I think it is a great book. I don't think women should get it immediately, I think if they start talking about surgery...I think it gives you hope... when you see pictures from the surgeon, it is the clinical cold pictures with the florescent light, and door for a background...one mistake is bringing me the pictures. I was given a giant three-ring binder full of pictures, and left alone with them. It is horrifying to be left alone with these things, because you don't know how far out these women are, you don't know what stage of it they are in, and there are these big red scars, and all these frankenboobs, and it is scary. Then the nurse came in and she sat down, and she was like oh, blah, blah, blah, and she had this...and then it just all seemed so much better. So the clinical pictures I think are scary because you don't have all the answers, and it is just the bust, you don't see if this person is happy, you don't see if they are sad, you don't know anything about them, but this is what

their boobs look like. So that part I think is a little hard.

Several suggestions were given about how and where the book should be presented to breast cancer patients. The suggestions included: a) with husband/partner present, b) in physicians' waiting rooms, c) by oncology nurses in chemotherapy rooms, d) by physicians, and e) by trained counselors in therapy sessions. In addition, all of the women agreed that seeing fine art photographs such as these was preferable to seeing medical photographs or drawings that can be "cold" and "scary." The following quotations give more details about their recommendations, all three of which are postmodern sentiments.

You know what, if it is in the waiting room then someone has the option, the choice whether or not they are going to pick it up and look at it. I think it should be made available. Even back in the chemo areas, they have got all the magazines, books, and you are in there for three or four hours, sometimes longer than that. Make it a choice. Like you said, there are some women, if they hand this to them are they going to get emotionally damaged...Me, it wouldn't have bothered me, but I don't know. I just think there are a lot more women out there that don't...we all handle it differently, but a lot of the women that I have met, it is so negative at first...I don't know that this would scare the bejesus out of them. That is what I am going to look like? I don't know. Some women look at it like that, you know? I see beauty, but that is me.

I would like for physicians to be able to see this book because maybe it will remind them that the physician-patient relationship is incredibly important and having a bad physician might end somebody's

life, and I'm just talking again about the physical damage that it can do and so forth.

I think it should be a part of any counseling. I really think the visualness of it because I am a tactile person, I would think that someone in therapy - a therapist working with this could really get insights into where a woman was in her journey.

Limitations

There are several limitations to this research that need to be acknowledged. First, caution needs to be used when generalizing from these results because the sample was primarily White, middle class, married and professional. Second, there may have been a self-selection bias in that these particular 15 women may have volunteered for a study of this type because they were more likely to espouse postmodern, rather than modern, sentiments regarding their breast cancer. Perhaps volunteering for such a study is post-modern in nature. Volunteering in a study like this may be considered a post-modern action.

Discussion

It may be impossible to represent bodily experiences adequately with only words. Disease, pain, death, and sensory experiences often do not easily lend themselves to language (Dungan 2003). The genre of feminist artistic books about breast cancer began as a statement against the world of fine art that is perceived as secret, elitist, and inaccessible to the masses. Instead, the books were mass-produced, inexpensive, and widely available. Bell (2006) lists the purposes of such books as: a) making meaning for the photographer; b) educating a wider public; c) strengthening ties with the patient and other patients, family, friends and caregivers; d) helping create support networks; and e) improving social life. All of these purposes were achieved with *Winged Victory: Altered Images Transcending Breast Cancer*. First, Art

Myers had a meaningful connection to the photographs he took because he is both a physician and a photographer and his sister and wife had breast cancer. His wife is photographed in the book. Through her, he became an active volunteer in the breast cancer support movement and became friends with the many of the women he photographed for the book. Second, it contributed to public education through its wide distribution, including being available on several Internet sites. Third, some of the women in the study described how when they talked about and showed the book it strengthened ties with other patients, as well as with their children, families, friends, and caregivers. There is anecdotal evidence that as a result of being a part of this study, some of the women used the books for informal discussions at their various cancer support groups, as well as in their homes, thereby improving their social networks and social outreach.

According to Bell (2006:39), Jo Spence believed that photographs are never complete and that they “should always provoke debate, encourage action and direct viewers toward situations that exist outside the photographic frame.” However, until this study, no visual researcher had shown photographs such as these to women who have had breast cancer and systematically recorded their reactions, feelings of relatedness and recommendations. This study explored how 15 women who have been exposed to the dominant modern paradigm of femininity and appearance-making as ways of coping with breast cancer would view a set of realistic photographs and text. Many of them revealed that they had both modern and postmodern views, depending on the context. They had an overwhelmingly positive response to the book with only a few negative reactions to individual photographs. On one hand, all but one of the women said that she would agree to pose bare-chested for a book similar to this one, a postmodern view. On the other hand, all of them were active in the breast cancer support community and participated in numerous walks and races wearing pink t-shirts and hats, thereby supporting the institutionalized view that their bodies needed to appear like they did before

breast cancer and that disfigurement needed to be dealt with surgically or kept hidden, a modern view.

Careful thought should be given to how these photos are distributed and used with women who have had breast cancer because a larger sample may have revealed even more diversity in reactions, feelings of relatedness, and recommendations concerning their use in the medical setting. Future research needs to determine if the modern, postmodern, and or combination views about the photos were due to differences in the women’s ages, diagnoses, surgeries, types of reconstruction, support systems, physicians’ perspectives, illness states, etc.

Conclusion

In the current study it was considered critically important to meet and have discourse with Art Myers, the photographer. Being both a photographer and physician, as well as friends with the women being photographed, and his own experiences with his sister and wife both having breast cancer, enriched the meaning he expressed in the photos. Having this knowledge and being able to pass some of it on to the participants in the interviews was valuable and influenced the interview transcripts as well as the researcher’s analysis of those transcripts.

Based on the analysis previously delineated by Felstead, Jewson and Walters (2004), in which a series of their visual studies were described after the fact according to the resulting contributions of still images, interviews, and theory, this study placed equal value on all three components and was driven by their interactions. These interactions can improve our understanding of: a) how photo-elicitation can be of value to visual researchers by giving the participants ownership of the images, both literally and figuratively, in advance of the interview; b) women’s experiences living with breast cancer, and c) modernity theory applied to illness narratives and photographs of women with breast cancer. It appears that women who have had breast cancer, and have

more of a postmodern orientation, may benefit from viewing fine art photographs of other women with the same disease. Viewing such photographs can assist them in identifying with other women with breast cancer who appear elegant, beautiful, in satisfying relationships, and accepting for their physical conditions.

Beyond the context of breast cancer, this research is important because of its contributions to the use of photo-elicitation methodology. First, this study was unique in giving the photographs to the participants ahead of time and letting them own them. No photo-elicitation studies were found that did this. It was considered critical in this study to help them prepare for the interview, process key questions ahead of time, or drop out of the study if they preferred. The researchers found no studies that used this methodology or examined if artistic photographs could be used to improve the lives of patients with other diseases. And second, no photo-elicitation studies were found that afforded the researchers and participants direct or indirect contact with the photographer of found images in books. Howells (2003), among others, explored the complex relationship between photography and reality. One view is that the role of authorship of an image needs to be given more attention, as it was here. The photographer's attitude, decisions, and technical skills make objective reality impossible. When participants view photographs they are actually interpreting the photographer's visual representation of reality (Pink 2007).

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