

In Her Own Voice:  
A Narrative Inquiry into How Three Women Recently Diagnosed with Breast Cancer  
Utilized the Artist's Fold Book

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A Research Paper

in

The Department

Of

Creative Arts Therapies

Presented in Partial Fulfillment of the Requirements  
for the Degree of Master of Arts  
Concordia University  
Montréal, Québec, Canada

April, 2009

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*Your file* *Votre référence*  
*ISBN:* 978-0-494-63264-2  
*Our file* *Notre référence*  
*ISBN:* 978-0-494-63264-2

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## Abstract

### In Her Own Voice: A Narrative Inquiry into How Three Women Recently Diagnosed with Breast Cancer Utilized the Artist's Fold Book

Katherine Laux

This research investigates how three women with a recent diagnosis of breast cancer approached the multi-faceted artist's fold book within an art therapy group. Literature from a variety of disciplines indicates that a diagnosis of breast cancer is a life-altering event which can have a negative impact on psychological well-being and create psychosocial challenges (Davis, 2004; Tish Knobf, 2007; Turner et al., 2005). A number of authors have noted the benefits of art-making in a supportive environment for women with breast cancer (Collie et al., 2006; Predeger, 1996; Serlin et al., 2000). The literature also reveals a lack of patient-centred knowledge on how these women can benefit from visual artistic expression (Collie et al.). This study provided an opportunity for women with breast cancer to share, in their own voices, their experiences making art together.

For this study, a five-week art therapy group was run at a local cancer wellness centre, followed by narrative-based interviews. Data included the artwork and related discussions arising in group sessions, case notes, and the follow-up interviews; qualitative data analysis was used to identify the major themes that came up in the interviews. The major themes that emerged were *Breaking Down the Isolation*; *Emotional Awakenings*; *Structure and Freedom to Explore*; and *Realizing Capabilities*. It was of utmost importance to include the authentic voices and stories of the women I worked with as they explored both their recent diagnoses and how the art-making assisted them in their daily lives. The 3 women who participated became, in effect, co-researchers. This research describes a unique art-therapeutic intervention to aid in meaning-making and to address the psychosocial and emotional disruptions that may occur following a recent breast cancer diagnosis.

## Acknowledgements

This research project could not have been undertaken without the support of family, friends, colleagues, Hope & Cope Wellness Centre staff, and the faculty of The Creative Arts Therapies Program at Concordia. This study was also supported in part by a Power Corporation Fellowship.

I would like to thank my family, especially my husband and grammar expert Keith and my mother Lauraine, for their unending dedication to my studies and to my well-being as I struggled with the challenges of motherhood and being a graduate student. I thank my children for keeping me in the here and now during my studies and research.

To all my dear friends, I will return to you soon. Thanks for being so patient during my graduate student years.

To my practicum class, especially to Shannon Byrnes and our professor Irene Gericke, thank you for your feedback during supervision.

Thanks to the Hope & Cope Wellness Centre staff who granted me the opportunity to conduct research in a very supportive environment. Thanks to Mona Rutenberg for introducing me to the wellness centre, and for supervising my first art therapy group there. Thanks also to Esther Kalaba who was my co-facilitator.

To the faculty of the Creative Arts Therapies Department at Concordia, I appreciate all of the support and knowledge you have passed on. I owe a great deal to Suzanne Lister for her insight, guidance, feedback, and availability throughout the research process.

Lastly, I want to thank the women of this study who willingly gave their time and energy at a difficult time in their lives to join this project and inform others. You have offered so much, and I have learned more than I ever expected.

*I dedicate this research to my dear Aunt Linda.*

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## In Her Own Voice:

### A Narrative Inquiry into how Three Women Recently Diagnosed with Breast Cancer Utilized the Artist's Fold Book

#### INTRODUCTION

Last semester I had the opportunity to run a five-week, book-arts-based art therapy group for women recently diagnosed with breast cancer, at one of my former practicum placements in a community-based wellness centre for adults living with cancer. I received approval from the ethics board of the local hospital that oversees the cancer wellness centre to conduct a qualitative narrative inquiry into how women with breast cancer used the accordion fold book in an art therapy group. My study follows three women with a first-time diagnosis of breast cancer, ranging in age from 62 to 75. I sought to understand how they approached the multi-faceted accordion book form by understanding the art work they created, the discussions that took place in the group, and narrative-based one-on-one interviews I facilitated following the end of the group. Qualitative data analysis was used to identify the major themes that came up in narrative-based interviews with each of the women, in which they talked about the impact of their recent cancer diagnosis, the group experience, and the artwork they created. It was of utmost importance to include the authentic voices and stories of the women I worked with as they explored, together as a group, both their recent diagnoses and how the art-making assisted them in their daily lives. All three women who participated became in effect co-researchers. The literature notes that there is a great lack of patient-centered knowledge about how women with breast cancer benefit from visual artistic expression (Collie, Bottoroff, &

Long, 2006). This study will provide an opportunity for women with breast cancer to share what their experiences making art together were like.

A review of literature from a variety of disciplines suggests that a diagnosis of breast cancer is a life-altering event which can have a negative impact on the psychological well-being of women survivors of breast cancer, as well as creating psychosocial challenges (Davis, 2004; Tish Knobf, 2007; Turner, Kelly, & Swanson, 2005). Literature also notes the benefits of implementing art-making in a supportive environment for women with breast cancer (Collie et al., 2006; Predeger, 1996; Serlin, Classen, & Frances, 2000). In this research I hope to offer another kind of art-therapeutic intervention to aid in meaning-making and of the psychosocial and emotional disruptions that may occur following a recent breast cancer diagnosis.

## LITERATURE REVIEW

### *Incidence and Prognosis*

According to the Canadian Cancer Society (2008), breast cancer is the most prominent cancer facing Canadian women, with one in nine women expected to get this disease and one in twenty-eight women dying from it. For Canadian women who were diagnosed between 2001 and 2003, the Canadian Cancer Society noted a five-year relative survival rate of 87%. In Quebec, the Canadian Cancer Society notes that close to 6,000 women will be diagnosed with breast cancer and close to 1,400 women will die from this disease this year. While more and more women are becoming long-term survivors of cancer, their needs beyond cancer treatment are not necessarily being met. Bloom, Petersen and Kang (2007) note in their study that reviews seven different types of cancer, including breast cancer, that quality of life (physical, psychological, social, and spiritual well-being) after five years of survivorship is lower than for the general population. These authors write that pain,

fatigue, concerns about appearance, worry and uncertainty about the future, high stress, loss of sexual functioning, and diminished role activity (home, work and leisure) were higher for long-term survivors than in the general population.

### *An Altered Body*

Having breast cancer involves drastic treatment options that can include surgery (mastectomy or lumpectomy), chemotherapy, hormone therapy, and radiation which can take its toll on the physical body. While there are similar issues with all kinds of cancer, the literature notes that most patients with breast cancer face invasive and sometimes disfiguring breast surgery that is very much visible and may challenge the woman's body image, femininity, and sexuality, and can leave them feeling different and isolated (Serlin, et al., 2000). Women who choose breast reconstruction at the time of a mastectomy or months after having breast removal surgery can face feeling abnormal and full of guilt due to societal views that breast reconstruction is solely a cosmetic procedure, and may also reveal an inability to cope with loss according to Hill & White (2008). These authors found that women who waited for breast reconstruction surgery had better body image and self-esteem than women who opted for immediate reconstruction at the time of a mastectomy and they speculate that these women allowed themselves to experience the loss associated with the amputation of a breast before opting for reconstruction. Hill & White write that most women in their study experienced depression following breast removal surgery. Dreifuss-Kattan (1990) also writes that women who lose a breast experience a period of depression, and for some women a period of will to fight or rebel against the loss is followed by a period of active mourning, as the pursuit for the ideal woman is abandoned and new ways of coping and living are strived for.

Another physical altering of the body that can occur during breast cancer treatment is the surgical tattooing of radiation sites on women's breasts. Bell (2006) refers to the artist's book *Tattoo* (1998) by Martha Hall. *Tattoo* was the artist's first book to be displayed publicly, and it shares with outsiders the routine permanent marks that are made on a woman's body during breast cancer treatment. It also speaks of breast cancer survivors who mark themselves with tattoos post-surgery to symbolize their recovery, as well as visible emblems that make connections between them and other women survivors (Bell). In addition to alterations and loss associated with a body undergoing surgery, chemotherapy, and radiation, the impact of breast cancer can also result in physical and emotional depletion. Janz et al. (2007) note in their study of significant post-treatment symptoms for women with breast cancer that fatigue, sleep disturbance, pain, and hot flashes predominated. These authors found that fatigue impacted other quality of life domains such as physical (increased pain) and psychological well-being (increased depression). Hanson Frost et al. (2000) similarly found that women who are recently diagnosed are in significantly more pain than women at other points in the disease phase.

In addition to breast disfigurement and alterations, Helms, O'Hea, & Corso (2008) write that 80% of women with breast cancer gain weight. Helms et al. comment that this weight gain has been attributed to adjuvant therapies (chemotherapy and hormone therapies), a reduction in physical activity, poor coping and whether or not a woman is pre- or post-menopausal. These authors note that weight gain can increase the chance of cancer recurrence and can impact the psychological well-being of women as well as increase the likelihood of being diagnosed with weight-induced disorders such as diabetes.

Hair loss is also prevalent among women under treatment for breast cancer. Lemieux, Maunsell, & Provencher (2008) reviewed 28 studies surrounding the impact

of chemotherapy-induced alopecia (hair loss) on the quality of life of women with breast cancer. Lemieux et al. found that hair loss was one of the most distressing side effects of many chemotherapy treatments; some women found it more difficult to lose hair than a breast, while other women refused chemotherapy because they may risk losing their hair. Some studies that Lemieux et al. reviewed noted a negative impact on body image, sexuality, and engagement in social activity.

Beckjord & Compas (2007) state that sexual quality of life is a broad term, and for their study included interest and involvement in sexual activity, feeling sexually attractive, and ways in which sexual function is experienced. In Beckjord & Compas's study, in a sample of 191 women with breast cancer who were recently diagnosed, they found that a majority of the women had a disruption in their sexual quality of life and this upset was significantly worse than upsets in other major life areas. These authors also noted that sexual quality of life is not routinely assessed by health care providers, and for women with depression surrounding their diagnoses, there was a significantly greater impact on their sexual quality of life. The authors also wrote that women who underwent both lumpectomy and chemotherapy or who had a mastectomy had greater negative impacts on their sexual quality of life than for women who only had a lumpectomy.

The physical changes that occur in women following a diagnosis of breast cancer can impact their psychological well-being. Helms et al. (2008) write that "the breast is one aspect of a woman's overall sense of femininity and body image, disruption of its appearance causes upset in a woman's emotional well-being and self-concept as a whole (319)."

### *Psychological and Social Impacts*

A breast cancer diagnosis involves coming face to face with a life-threatening disease. Landmark & Wahl (2002) write that having a recent breast cancer diagnosis involves a great deal of uncertainty about the spreading of cancer and uncertainty about the amount of pain involved and about death. Women with a breast cancer diagnosis can face a great number of stressors in their lives. Using the four most common stressors facing cancer patients as identified by Dunkel-Schetter et al. (1992)— fear/uncertainty about the future, physical and lifestyle limitations, symptoms and pain associated with cancer and treatment, and relationship problems— Lebel, Rosberger, Edgar, & Devins (2007) found in their study of 72 participants that fear about the future was not only stressful in the beginning following a breast cancer diagnosis, but was moderately stressful for years to come, and should be targeted for psychosocial interventions. In Landmark & Wahl's qualitative study using open-ended interviews and grounded theory analysis, they found that existential concerns, along with the strong will to fight for life, were the most prominent aspects for women recently diagnosed with breast cancer. The authors also noted that women spoke about chaotic emotions, physical suffering, changes in female identity and sexuality, striving for meaningful activities, and issues surrounding social support. Landmark & Wahl found that all the women in their study experienced their initial diagnosis traumatic which led to initial emotional imbalance (strong feelings included loss of control, shock, fear of the future) which greatly impacted their daily lives. Dreifuss-Kattan (1990) and Hill & White (2008) note that following a loss of a breast there is often a period of depression.

Landmark, Strandmark, & Wahl (2002) found in their in-depth interviews with women recently diagnosed with cancer that some women experience lack of support and therefore lack of emotional support and increased isolation from close family and

friends, due to their loved ones not being able to cope with the fear and uncertainty surrounding a cancer diagnosis. Further isolation and insecurity can occur with lack of support from health care professionals according to these authors. Hanson Frost et al. (2000) found that women who have been recently diagnosed or are undergoing adjuvant therapies experience more role difficulties than women who are more stabilized with their cancer which may reflect that women recently diagnosed are trying to fulfill all of their previous roles while also facing physical and emotional depletion. Hanson Frost et al. also found that fatigue was common among women recently diagnosed which can lead to a lack of participation in social activities.

### *Support Groups*

Serlin et al. (2000) note that during the treatment stage, a woman with breast cancer can face excessive exhaustion, both physical and emotional, along with isolation, fear, helplessness and hopelessness, depression, anxiety, and grief. They recommend that patients with the same kind of cancer should meet in a supportive environment to allow them to share their unique yet similar experiences, and to facilitate a higher level of understanding. Support-group work for women with breast cancer is discussed frequently in the literature. Online support groups, peer-led groups, self-help, and professional-run groups are all available. Breast cancer patients are more active with online support groups than other cancer patients, and overall, cancer patients are more likely to seek out support more than any other disease except for alcoholism (Davison, Pennebaker, & Dickerson, 2000). Davison et al. also noted in their large quantitative study that if an illness is life-threatening and the medical costs are high, there is greater tendency for patients to participate in face-to-face support groups.

Hosaka, Sugiyama, Tokuda, & Okuyama (2000) found in their highly structured five-week intervention that patients had more energy and were less depressed, anxious, and emotionally distressed six months after the short-term intervention, except for patients who had a pre-existing adjustment disorder. Vos et al. (2006) studied the extensive literature on psychosocial interventions for women with breast cancer and found that the results were mixed. While many interventions were tested and noted for their ability to reduce emotional suffering and increase the ability to cope, many were also noted for their lack of improvements past the time of intervention. Vos et al. found that patients who were offered a later psychosocial intervention were more distressed six months post-study than women who were offered an intervention close to four months following surgery which indicates a need for women with a diagnosis of early stage breast cancer to receive an intervention soon after surgery.

The literature notes the benefits of Supportive-Expressive Group Therapy (SEGT), which may incorporate other therapeutic aspects such as humor and the arts (Cameron, Booth, & Schlatter, 2007; Kissane, Grabsch, & Clarke, 2004), as well as groups which combine talk and art (Collie et al., 2006; Predeger, 1996; Serlin, et al., 2000). The ability and need for breast cancer survivors to reach out to other women also predominates.

#### *Art Therapy and Art-Based Support*

Collie, et al. (2006) write that breast cancer can cause a broad range of psychosocial difficulties such as a change in lifestyle, interpersonal relationship strains, social isolation, and existential emergencies. Breast cancer, according to Collie et al., can diminish a woman's ability to create meaning and her ability to create life stories that are purposeful. These authors have found that support groups

that involve visual artistic expression allow for psychosocial interventions that are more accessible than predominantly verbal support groups, because they feel less like therapy. Such groups also provide a place for meaning-making through physical acts of creating. Radley & Bell (2007) describe the artworks of two women with breast cancer who chose to address the need for recognition, to share and exchange stories and images with other women sufferers like themselves by making art that would be exhibited in a public space. One of these women was a photographer, the other an artist who created artist's books about her experience with cancer.

Landmark & Wahl (2002) qualitatively studied the wholeness of the women participants' experience of cancer and their deep understanding of that experience. These authors note Rustoen & Begnum's 2000 work. Rustoen & Begnum speak of how the majority of research on participants' experience of cancer has been through standardized questionnaires, rather than the use of in-depth interviews to get a more holistic view of women's experience of having cancer.

Predeger's (1996) qualitative feminist inquiry into a collective supportive arts-based group of women breast cancer survivors included 18 participants or co-researchers who met together to explore the healing aspects of art-making in a group setting. Predeger noted that following a breast cancer diagnosis, women had little time to reflect on or express themselves regarding the diagnosis. Predeger suggests that art allows for expressing experiences and a cooperative supportive group provides a frame to explore and share what it means to live with cancer. Predeger found that the essence of the group was *womanspirit*, consisting of the following themes: a) the women felt a strong need for artistic and emotional expression in spite of overwhelming physical and emotional struggles; b) artistic expression gave control in their chaotic lives; c) art expression, combined with having cancer, allowed them to see their own mortality and focused what was most

important in life; d) self-transcendence pushed women to help other women with a similar diagnosis; e) strong bonding occurred between women; f) the healing art group provided respite; g) art provided connection to each other; and there was a celebration of the feminine, and a seeing and appreciating of women through their art. Womanspirit is multifaceted but can simply be defined as “women, connected in spirit, [who] are finding their own way (p. 57).” This study, according to Predeger, reveals that women living with chronic illness can reach higher consciousness in a supportive arts-based group.

Collie et al. (2006) state that art therapy and art-making provide a number of benefits for women with breast cancer. For example, they found that art-making provided a refuge to women with breast cancer by affirming and protecting their present existence; illuminated their experiences with cancer; processed and released painful emotions; and strengthened the self. The group experience also allowed women to explore their emotions— if not for themselves, then for their loved ones who would be the recipient of their artworks, and who would therefore become witnesses to these women’s needs. Collie et al. also cite the influential work of Driefuss-Kattan (1990), who writes that self-repair through the act of creative expression benefits from being witnessed, as this reduces feelings of isolation. Driefuss-Kattan states

“By writing [or art-making] cancer patients stay in touch with their fantasies and inner objects. They also balance past history with present reality and threatening future. If in this endeavor they also find a companion (doctor, therapist, friend) with whom they can share their ongoing work, they can shield themselves from the terrible isolation and loneliness inherent in the fear of death (p. 170).”

The witness doesn’t necessarily have to be an art therapist, according to Collie and colleagues, because all the women in their study made art for someone else, or they exhibited it; and all benefited from the experience of art-making on their own or with an art therapist.

*Artists with Breast Cancer*

The healing capabilities of art-making for women with breast cancer are noted in the literature. Malchiodi (1999) writes that visual expression can convey the difficulties (loss, pain, confusion) surrounding illness that may not be easy to convey with words. Driefuss-Kattan (1990) also speaks to the power of the cancer book for women with breast cancer. Driefuss-Kattan writes that creating a book about one's experience with breast cancer starts a necessary period of mourning that addresses the incomplete self (breast removal) and the reality that death is inevitable. The author states that the act of creating during this mourning process is an active way to work through depression and repair the damaged self, by metamorphosing a menacing experience of loss into a healing and constructive book form that allows for connections with others (published or shared with loved ones). In one chapter, Driefuss-Kattan focuses on the powerful writing of ten women writers who wrote about their breast cancer experience. In another chapter she focuses on the paintings of artist Richild Holt, who had recently been diagnosed with breast cancer. The self-portrait paintings show Holt confronted with a diagnosis, then a second exam, and follows her through a mastectomy and through a stage of wholeness and acceptance following the surgery. While Driefuss-Kattan's book is predominantly focused on the writings and artworks of artists and writers who used their craft to heal and to make sense of their own cancer experience, some artists depicted were writing or creating works about their loved ones which allowed them a way to work through their loss.

Malchiodi (1997) writes about how women artists and writers have become active in getting their images and voices heard. She notes the works of Nancy Fried, Jo Spence, Hollis Sigler, Matuschka, Audre Lorde, Claire Henze, Deena Metzger, Treya Killam Wiler and Terry Tempest among a long list. Malchiodi has borrowed

images from these artists to work with women with breast cancer as a way to validate their experience, offer some semblance of purpose, and show them the possibility of creating their own autobiographical work.

Martha Hall's artist's books are another testimony to the power of visual expression, created by a woman who fought hard against breast cancer and who was able to transcend her personal fight and make it into a shared experience with other women (Bell 2006; Radley & Bell 2007). Hall's book *Tattoo* (1998) is a small and square accordion fold book that measures no more than five inches on a side, but expands to close to three feet when expanded. It is small, yet it contains eight short stories marked with visual stamps about her experiences with breast cancer (see Bell 2006). Hall created a number of different kinds of artist's books on her own terms—she didn't use pre-made book objects like journals, diaries, scrapbooks, or photo albums. In her own book based on her artist's books, Hall (2003) reaches out to the public to rethink some of the dominant discourse that surrounds breast cancer. In one book, *Living*, an accordion fold book, the text says "I hate the term cancer survivor. / It implies some people win / Some people lose. / It implies there is a point in time / When there is an answer. / I am living with cancer. / The emphasis is on living (24)." In another book, *Voices: Five Doctors Speak*, she directly quotes the five doctors who are treating her. Some of what the doctors say include their own assumptions about how cancer recurrences of a certain time period aren't that bad or how certain treatments are so experimental that no one knows for sure how they will work or not work, but should be tried anyway because nothing else is working. Hall showed her doctors the book and she felt that this helped change how they viewed her as a patient, improved her relationships with them, and made an impact that would affect how doctors relate with their patients in general. Hall even remade a publication put out by the National Cancer Institute which is titled "What You Don't

Want to Know about Cancer". In 1998, Hall decided to share her artist's book with the public because it allowed her to process the difficult emotions she kept inside, and also because she wanted to share with and inform others. This became the purpose of the rest of her short life.

### *The Book in Art Therapy*

The literature surrounding the use of the handmade or artist's book in art therapy is minimal. The readymade book, especially the journal, is often used in therapy. In art therapy, the journal is used as secondary or complementary to other art therapy techniques. Often, the journal is taken home or used outside of session. The journal may or may not be viewed by the therapist. Anderson (1995) combined clay work as the main medium with journaling in treating adult survivors of incest. Anderson asked her clients to keep a journal to be handed in between sessions and instructed her clients to answer specific questions each week. Keeling and Nielson (2005) document the experience of Asian Indian women who underwent a narrative approach to therapy that combined both art and creative journaling. Keeling and Nielson noted a more in-depth and open response to creative journaling and art-making when it was done as an at-home assignment. Rogers (2001) writes of how expressive arts bring wholeness and awareness by moving from one art form to another in a single session. A client may experience movement, art-making, journaling, sound, and guided imagery.

The journal, like most books in Western culture, is a kind of book form called the codex, with its central binding on one side. Photo albums, comics, diaries, and journals are everyday examples of the codex. Specific attention will be paid to four codex forms that play with the structure of the book form. The four codex forms relevant to this study are illustrated text, comics, lifebooks, and the photo album.

An example of illustrated text can be seen in the work of Flynn & Stirtzinger (2001), who used Winnicott's idea of intermediate space in conjunction with the visual fictional book as a way for a shy, anxious, and socially withdrawn 12-year-old boy to be more in touch with his emotions. The making of the visual/textual book was collaborative. Printing and binding was done by the therapist but the content was the client's own, as was the choice of number and size of pages, cover design, and font.

Mulholland (2004) writes about the power of comics, and has found personal healing creating original comic book figures. He writes that in terms of benefits to mental health, comics (through original or existing cartoon figures) can provide a constructive and creative way to express the self in aspects of body image, verbal language, feelings, and actions. Mulholland mentions the work of multi-media artist Heather McAdams, who created the Autobiographical Comic Strip project for the University of Illinois at Chicago Contemporary Curriculum Initiative that works with junior high and high school children (McAdams, 2000). McAdams' four easy steps for project participants read like narrative therapy mixed with art therapy. McAdams writes that comics are a "youth-oriented medium" and that teenagers "appreciate being given the knowledge and skills to tell stories about their lives in a medium they find exciting" (2000). If appropriate in terms of confidentiality and clients' needs, a multitude of comic artists could photocopy their works and compile them into "zines" or handmade books. Like Mulholland, Seiden (2006) found that comics or graphic novels are just as appropriate for self-discovery as adults as they are for teenagers.

One kind of book that appears to be appropriate for elders and other populations nearing the final stages of life is the lifebook. The lifebook is a technique created to work with the life review process (Magniant, 2004). Ravid-Horesh (2004) followed Erikson's psychosocial theory and found that art therapy enhanced the life

review process. It provides a sense of purpose by sharing memories with a supportive witness. Ravid-Horesh used lifelines, significant memory drawings, and life image drawings as part of the life review process with an 89-year old woman. Magniant facilitated the illustration of life stories with her elderly clients by having them use drawing pads and a variety of art materials. Intermixed with the artwork is handwritten or typed story text with a cover drawing laminated onto the cover of the sketch pad. Magniant uses the lifebook technique to provide structure and order for all of the thoughts that may emerge during the life review process. She also notes that for some elders, the book is a legacy to be handed down to family members.

Another type of book that holds memories is the family photo album. Family snapshots are sequenced together, forming a whole new entity—a visual book. Phototherapists that work with families may use a client's family photo album as a way to confront the self, as discussed in Milford, Frycrear & Swank (1983). These authors write that the family album can be used in assessment of the self-concept of family, as well as providing information on dynamics within the family system. Weiser (2004) writes that whoever created the sequencing has created their own version of the family story. Weiser writes that it can be very beneficial to the client to have them reorder the sequence, to tell their version of the story if they find the original story problematic. In one of Weiser's (2004) example cases, the author attempted to elicit emotion and information from a client by giving an assignment. In noting that her nine-year-old client was having difficulty talking about the relationship she had with her foster mother, Weiser asked the client to photograph people, especially mothers at a local park. The client returned to the session with her photographs, and Weiser noted how easily her client was able to engage in dialogue about mother-child relationships. Weiser (1993) proposes a broad range of active techniques in using the family photo album (or photos taken from a family album).

Photographs can easily be used in conjunction with other art forms (drawing, collage) as well as with text.

Art therapy literature has explored the use of the readymade book in the form of sketch pads (Magniant, 2004), journals (Anderson, 1995; Keeling and Nielson, 2005; Rogers, 2001), and photo albums (Weiser, 1993, 2004) as well as a collaborative graphic "novel" created jointly by therapist and client (Flynn & Stirtzinger, 2001), but there is little mention of the artist's book. Due to the ubiquitous nature of the book form, art therapists may have not used the term "book" when referring to their technique or material, or in the case of the journal; its role is secondary to other media.

#### *Defining the Book and the Artist's Book*

"What is a book? It depends on intention. If that person declares it a book, it *is* a book!" (Smith, 1995, p. 23). Smith details how the book form can be anything from a single image, to a sculpture, to a full-room installation, to a performance.

Drucker (2004) writes that defining the artist's book is very difficult. A simple easy definition may read "an artist's book is a book created as an original work of art (2)." However, many artists' books are made by more than one person and some are made in multiples. Drucker speaks of a multitude of kinds of artist's books and writes that:

"If all the elements or activities which contribute to artist's books as a field are described what emerges is a space made by their intersection, one which is a zone of activity, rather than a category into which to place works by evaluating whether they meet or fail to meet certain rigid criteria (p. 2)."

The activities are numerous and include the following:

"fine printing, independent publishing, the craft tradition of book arts, conceptual art, painting and other traditional arts, politically motivated art activity and activist production, performance of both traditional and

experimental varieties, concrete poetry, experimental music, computer and electronic arts, and the illustrated book, the *livre d'artiste* (p. 2)."

Keith Smith (1995) writes that there are four types of books used in various cultures: codex, fan, fold book, and blind. All four types of books can be readymade or pre-fabricated, or handmade and be considered a kind of artist's book.

### *Readymade, Handmade and Zines*

Readymades refer to any book form that has been pre-fabricated in terms of the page structure and binding. It often refers to a book unit that is industrially manufactured such as the sketch pad, diary, and photo album. A handmade book or an artist's book is made by a person with an awareness of the form of the book and can be made out of a multitude of materials, including but not limited to paper, glass, metal, cloth, and plastic. Zines are a type of inexpensive handmade book which typically consists of computer printouts or photocopied pages that are stapled, taped, or strung together, most often in codex form. They are usually produced in multiple copies for free or paid distribution.

### *The Fold*

Johnson (1993) writes that when parchment replaced papyrus, the ability to use the fold became possible. The codex form developed in the West and is built around a fold that is placed inside the book. It consists of placing one folded sheet inside the other and is typically bound along the fold on one side. "The oriental fold book is created by folding a long sheet of paper alternately back and forth on itself...If an imaged book of this type were not folded, it would be a mural, not a book. However, if that mural is stored by rolling, it is a scroll." (Smith, 1995, p. 23)

### *The Accordion Fold Book*

Johnson (1993) provides a how-to book to create limitless ideas for the handmade fold book from the most simplistic to more complex sculptural dioramas. Sometimes called the Oriental fold book or accordion book, the fold book is simply a long piece of paper folded back and forth onto itself. Johnson writes that the fold book comes from the East; following the advent of paper, the fold book arose in Japan during the Heian Period (794 - 1185). The flexibility of paper allowed for folding the old scroll form back and forth onto itself. Johnson says "there is an organic wholeness about the appearance and feel of Japanese bound books that [he] find[s] absent from those of our own culture" (p. 27). The fold book is simple but it doesn't have to be simplistic, writes Johnson. The fold book can begin and end with one sheet of paper, or it can be far more complex. If you think of the fold book as a building block, you can string or glue fold books together indefinitely. Concepts can be explored and expanded on in depth. When the paper is fully extended, imagery can be viewed on one long plane. A number of images are viewed as one. No matter how long it is, it can always fold down to a codex book form.

The fold book may be used to illustrate the idea that there are *two sides to every story*. One story can be portrayed on one side and a secondary story on the other side. In *Parallax*, an artist book created by Karen Chance, two views are presented on either side of a fold book—a gay man's thoughts of a straight man on one side, and the straight man's thoughts of the gay man on the other (Smith, 1995). Embedded within *Parallax* are cut-out windows so each of the men and each viewer can peer into the other's world. Since the fold book doesn't have to read like a codex, the beginning and end of each story is fluid. One story doesn't precede the other.

Keith Smith (1995), a book artist, writes that the fold book form can be used to hold prints in order of their relationship to each other when being mailed to a gallery. He writes about the fold book *Luminous Perceptions* by David Horton that creates an installation when opened. It has walls, floors, windows, and objects. Johnson (1993) also notes the fold book's various forms of presentation. He describes its panoramic form, three-dimensional sculptural form when placed on a flat surface, and its ability to be read in the conventional way in the hand not unlike a codex. The fold book can be used solely as a means of presentation, to present all the client's art work done over the course of therapy in one long sequence. Schaverien (1993) likens the retrospective review of a client's artwork in combination with their life history to an art-historical biography of an artist, full of photographs of their artwork.

#### *Therapeutic Aspects of the Fold Book*

Johnson (1993) speaks in detail about the educational power of the handmade book and asks teachers of primary and secondary schools to consider the simple accordion fold book form for learning. Johnson asks why it is that a majority of learning comes through books, yet no attention is focused on the book form. Most books "created" in class, Johnson writes, are pre-fabricated. Taking the sketch book as example, Johnson writes that the book that one "creates" by adding sketches was in fact already created. The dimension and feel of the pages and the binding controlled where the markings would go. Johnson notes that "when children plan and design a book of their own, integrate handwriting, lettering, illustration, layout, and binding as a vehicle for the communication of ideas, a superior kind of mental activity comes into play" (p. 13). Rubin (2005) recommends that to invite art-making, art therapists give choices in terms of art materials. From this perspective, a

pre-fabricated book may be less inviting or even intimidating to clients, in that many important choices have already been made for them, thus restricting their creative vision (whether consciously or unconsciously). Malchiodi (2000) also writes about the loss of control of the body that can occur with disease and medical treatments and how art expression can allow for some semblance of control and dignity in freely choosing art materials, dimensions, and subject matter.

Johnson (1993) explores some aspects of the fold book that may be pertinent to art therapy. Johnson writes that the familiar book is simultaneously a public as well as a private object. Not only do we exchange communications to and from the world with the book form, we also ask it to safely hold our most private, intimate, and deep feelings and thoughts. The book is simultaneously revealing and concealing. It's also very containing. Drawing a comic, for example, involves drawing within a frame among a page full of frames, the pages themselves being framed within a book; and if the book is created within a therapeutic context, this represents yet another frame. If one were to add a box structure to the book there could be yet another containing aspect.

Women with a recent breast cancer diagnosis are confronted with treatments that can result in an altered body and can create psychosocial challenges. To facilitate healing and a more integrated self, art-based support groups are recommended. Although it is just one of several options available for women to address the impacts of a breast cancer diagnosis, creating art in a supportive group has certain unique advantages, such as the ability of art to express thoughts and feelings that are not easily put into words, and the fact that an art-based group “feels less like therapy” and may therefore put women more at ease to express themselves and share with each other at a safe distance. In conjunction with a directive yet client-centered approach, use of the artist’s fold book—with its public

and private, revealing and concealing, and containing aspects— may go a long way therapeutically.

#### RATIONALE FOR THE RESEARCH

The focus of this research is to understand how the artist's fold book can facilitate the visual expression of emotions and provide a safe and insightful medium to explore the impact of a recent diagnosis of breast cancer. The literature speaks of the disruption in life for women recently diagnosed, but there appears to be a lack of real-life testimonies of how women can benefit from therapeutic art-making, especially in the domain of artist's books. Use of the codex in art therapy is noted, especially with pre-fabricated journals, albums, and sketch pads; but use of the handmade book that allows the client to have control not only over content, but also structure and form, has been much more limited. I believe that understanding the healing aspects of artist's books for women with breast cancer can provide future therapists with information and the opportunity to explore yet another medium to have at their disposal for clients with cancer and terminal illness.

#### RESEARCH QUESTIONS

How can the artist's fold or accordion book facilitate expression and meaning-making for women recently diagnosed with breast cancer?

What are the therapeutic implications surrounding the book form, specifically the duality of the book, such as its concealing and revealing, containing and ever-expanding, and public and private aspects?

## METHODOLOGY

### *Participants*

The three women who participated in this study were clients registered at a local wellness cancer centre and voluntarily joined my study. I designed a flyer (Appendices A and B) to promote the research group, which was also translated into French and approved by the wellness centre. The flyer was placed at the front reception desk. All interested parties were referred to the coordinator of the wellness centre as referenced by the flyer. Participants were recruited by the centre coordinator, who was also my onsite advisor (or "onsite investigator" in the hospital's official terminology); she was familiar with my proposal and my acceptance by the ethics committee, and coordinated the translation of all consent related materials (Appendices D and E). She made sure each participant met the general criteria for the study, which included women of any age who had been recently diagnosed with breast cancer for the first time; a "recent" diagnosis was defined as one that was made less than a year before the time of starting the group. All participants would have to be able to communicate in English. Initially, the centre coordinator was aiming to recruit eight participants, in the hope that I would eventually have a group of four to five women. The coordinator referred me to eight candidates who were asked to come an hour before the first session to go over the consent information and consent forms and to ask me questions. Participants could consent to all or just part of the requests on the consent form. Participants were aware that they could withdraw their consent at any time before the research paper was completed without any explanation. Each participant was given a copy of their signed consent and consent information forms.

While I had eight possible candidates at the beginning of the group, only four participants arrived for the first session. All four were given details of the study, and

were offered the opportunity to ask questions. All four voluntarily signed the consent forms. Three of these four women became regular participants. The one who didn't return after the first session had found employment and couldn't fit the group into her schedule. A fifth candidate showed a great deal of interest in the project but had to have a last minute medical intervention and wasn't able to attend the group. Finally, a sixth candidate came to the second session and never returned. The centre coordinator was able to contact this woman and found that she needed time to take care of herself as she journeyed through her cancer treatments. The centre coordinator wasn't able to reach the other two candidates so I'm unsure as to why they signed up for the research group and then didn't attend any sessions.

#### *The Regular Participants*

Of the four participants who came to the first group, three became regular attendees. Two of these attended four out of five sessions and one attended three out of five sessions. The fourth participant left the project after the first session, citing her need to return to work. Of the three regular participants, two of them were currently undergoing chemotherapy treatments. One of them had started her treatments the same week she began coming to the book-making group; the other was in the middle of her treatments, and once chemotherapy was completed, she was to start a round of radiation treatments. The third participant had undergone three surgeries in the last ten months and was on adjuvant therapy. Sherman et al. (2008) found in their study of cancer patients which included breast cancer patients that the severity or stress of an illness, and finding fatigue an obstacle, both increased the chance for support group attendance, as did close proximity to the support group and being referred to the group by close friends and family. These authors also noted that the overall attendance was 8 percent and there appeared to

be a preference for professional-run groups over self-help or peer-led groups. Breast cancer patients were more willing to attend groups than most other kinds of cancer patients. All three regular participants were frequently exhausted or didn't feel well enough to attend every session. Sometimes they attended despite their exhaustion and not feeling well. The three participants who attended regularly ranged in age from 62 to 75. The ages of the other two participants who only attended one session each were 50 and 77. All three of the regularly participating women were mothers, two of them single mothers. Two of three women were also grandmothers.

### *Group Setting*

The group ran for five weeks, for weekly two-hour sessions in September and October 2008, and took place in the art room of the local wellness centre. The art room is on the main floor and is a well-lit space with four tables, an art supply closet and a sink. The room can adequately and comfortably accommodate four participants who are working with large sheets of paper to create artist's books. Following the five week book-making group, individual narrative based interviews were conducted in a private office at the local wellness centre, or by phone, from late October through December 2008.

### *Group Structure and Procedure*

Each session revolved around exploring the expressive and therapeutic possibilities of the artist's book, specifically the Japanese-influenced fold book, which is easy to construct and ever-expandable, yet containing. Before the theme was introduced and a guided visualization took place, I would informally call the group to order and remind everyone about the "rules". Confidentiality and being respectful and non-judgemental were the focus of the art therapeutic safe space. I also would

let everyone know that no art skills or art talent were necessary for making art in the group. Following this introduction, I joined the group in doing quick one- to two-minute feeling drawings as a way of introducing each participant of the group, as a way to check in to see how everyone was doing, and also to warm everyone up to the art media. After everyone completed their check-in drawing, each of us took turns saying our name and how we were currently feeling. If no one felt comfortable going first, I would go first to encourage participation and sharing and to make things more comfortable. Following the check-in, a brief introduction was given about the session's directive, and a guided visualization was introduced to help relax the mind (Luzzatto & Gabriel, 2000) and introduce the exercise. In my experience as a co-facilitator of another art therapy group at the wellness centre, I had found that guided visualizations allowed members to enter into the therapeutic space and offered them a way to focus on themselves. For my study, I introduced the theme of the session by using guided visualizations in all sessions except the last one. Because I was adding the box as an extension of the book form in that final session, I wanted to maximize the art-making portion of the session, so I decided to not do the visualization. Also, since it was our last session together, I wanted to provide all participants with the opportunity to share about their experiences in the group and how they were processing the end of the group.

During the guided visualizations, participants were encouraged to sit comfortably, close their eyes if they wished, and to be aware of their breath as I guided them. Once the visualizations ended, I would invite participants to hold the images that they saw in their minds and use them for the session's exercise and to slowly return to the art room. The visualizations took approximately ten minutes. I then ensured that all participants felt comfortable with the exercise and checked whether they had any questions or needed any assistance. Art-making followed.

Paper of various colours and sizes were laid out on one of the art tables every session with some art supplies laid out as well. The art supply closet was left open for any participant who needed further supplies. The art-making lasted one hour. Every fifteen minutes I would check-in with each participant to see if anyone needed anything. Fifteen minutes before the hour of art-making was up, I would let everyone know that the art-making was coming to a close, and clean-up and a short tea/coffee break would follow. After clean-up and break, I would assist participants with hanging the artwork on the presentation wall or mount on a window or display their artwork on a table. I encouraged participants to walk around the room and view each piece. I always left time for the group to discuss their work if they wanted to. When I introduced the opportunity for discussion, I reminded everyone to refer to their own art-making and creative process when they spoke about their work and if they wanted feedback from the group, they could ask for it.

For all sessions, I had prepared a few guiding/tentative questions for the participants to use as a starting point to discuss their work, if they so chose. For example, for session two, *Feeling the body, Finding Feelings*, I presented the following questions at the beginning of the discussion period: 1) Please share with the group what parts of the body you are feeling strong sensations in. 2) What sensations are you feeling in these body parts? 3) What feelings or emotions do you attach to these sensations? Following the discussion portion of the session, I did a quick check-out to assess how each participant was doing, and to make sure everyone was grounded as they left the group. The check-out simply involved asking everyone to share how the exercise went today and how they were feeling as the session came to a close. If anyone was teary or seemed down or not at ease during any part of the session, I would inquire how they were doing one-on-one. A

psychosocial worker was on hand following the group if anyone needed further counselling.

The format of this group resembles Luzzatto & Gabriel (2000) who found that their highly structured ten-week art therapy model for post-treatment cancer patients generated positive results for patients struggling with their self-identity. Luzzatto & Gabriel's framework involves ten pre-set workshops, each of which is conducted in the same manner: A guided visualization opens each workshop, followed first by the introduction of an art technique and art-making, then by the hanging of the art and the option for participants to share their work— or the process or meaning of the artwork— with the group, and to ask for feedback from the group if they so choose. I found with my previous art therapy group experience at the wellness centre that participants appreciated and frequently requested a directive approach to the art interventions and benefitted significantly from check-ins and check-outs and guided visualizations. In a five-session study that was based on the work of Fawzy et al. (1990), which revolved around a highly structured intervention consisting of guided imagery, relaxation exercises, psycho-education, problem-solving, and psychological support, Hosaka et al. (2000) found that patients were less depressed, anxious, and emotionally distressed and they had more energy six months after the short-term intervention.

#### *The Five Directive-Based Sessions*

Each session was directive-based and focused on a theme that reflected the needs of the women who participated. The directive for the each session was based on what had been expressed by the group as a whole in the previous session. In session one, a variation on Betensky's (1995) Adolescent Window Triptych was introduced to the group as a way for each participant to represent her past, present,

and future, with the objective of visualizing both her current outlook and her perceptions of her future, and how that may or may not contrast with her past. The *Past, Present, and Future Triptych* was also an introduction to the idea of breaking up one sheet of paper into multiple sections and to begin exploring the idea of the fold. This exercise was also intended as a way for each participant to share what some of her current issues were and what they would like to focus on, so that in a sense, session one was a way for each participant to introduce themselves and to share what they were going through at the moment, with the possibility of offering a direction to follow for the rest of the sessions.

The directive for the following session was based on what had been expressed by the group as a whole. In session one, there was a lot of sharing between the participants about body image and how their bodies had changed or been surgically altered since they were diagnosed with breast cancer. The discussion revolved around surgery, radiation, hair loss, weight gain, and some of the negative side effects of medication which included swollen joints and painful burning sensations in the abdomen. A body- and feelings-based exercise was planned for the next session to assist with exploring the ever-changing body and mind connection.

The second session revolved around the theme *Feeling the Body, Finding Feelings*, based on Capacchione's (2006) exercise which assists clients with unlocking their emotions by dialoguing with their bodies through first identifying current physical sensations. Capacchione structures the activity by outlining a body meditation or using relaxation breathing exercises and guided imagery to travel along the body slowly from head to toe and discovering physical sensations (both pleasurable and painful). Clients are then asked to draw their body and use colour and line to represent these physical sensations. When I presented Capacchione's exercise, I also encouraged participants to be aware of their breath as they mentally

travelled through their body and to notice any emotions they may be experiencing as they become aware of their physical sensations. Participants could draw their entire body or focus on one or two parts. Participants were encouraged to experiment with colour, shapes, and words to address their sensations and feelings. During the discussion period, I asked participants to identify both bodily sensations and their emotions. Lightness in mind and bodily heaviness dominated the discussion. This brought to mind Kundera's *The Unbearable Lightness of Being*. Kundera writes that the

"heaviest of burdens crushes us, we sink beneath it... conversely, the absolute absence of a burden causes man to be lighter than air, to soar into the heights, take leave of the earth and his earthly being, and become only half real, his movements as free as they are significant (5)."

The theme for session three was *An Albatross Around One's Neck*. The exercise encouraged participants to explore the idea of weight or concern or worry about their support system (family and friends), the future, the physical and emotional drain of cancer treatment. Weight could refer to mind or body or difficult emotions. Once the weight, burden or difficult emotion was identified, its opposite could be explored on the backside of the accordion book. May (1975) proposes that creativity involves the dialectical notions of abandon or the Dionysian, and the order and form of the Apollonian. Utter freedom and total order could relate to the dialectical notions of lightness and weight. Too much of either can bring disorientation and imbalance. By exploring weight and its opposite through the fold book, participants may work towards integrating or bringing awareness to some of the difficulties they are experiencing, while also seeing the positives and striking a balance somewhere in between. In this session, Rachel was the only participant. Rachel had missed last week's session and preferred to focus on *Feeling the Body, Finding Feelings* exercise rather than exploring the weight or burden she may be carrying while living with cancer.

In session four, the focus was on exploring personal strengths (and vulnerabilities) by *Choosing an Animal* that was of personal significance. Participants were encouraged to create an animal in two or three dimensions, using the book form to draw the animal directly onto or to use as an environment for their animal. The objective for this intervention was to facilitate the identification of their own sources of strength by finding sources of nourishment in the creation of an environment for their animal. The aim was to also reveal areas of self-care that are already occurring in their life or could occur in the future. The chosen animal could also serve as a symbolic representation of the way each participant is currently moving around in the world. I had hoped that a metaphorical self-portrait would be more accessible and comfortable than drawing a realistic or straightforward self-portrait. Henderson (1998) writes of her work with adolescents using images of wild animals as self-representation and has found that for adolescents who are having difficulty expressing themselves in talk therapy, the metaphorical animal image can allow clients to access their inner creativity and imagination in a fun and inviting way. She concludes that using metaphorical animal imagery can be used with clients of all ages. She writes

“By relating to an image of an animal, we relate to its significant characteristics, such as power, ferocity, gentleness, or sagacity. These characteristics reflect aspects of ourselves that we're proud of, hope for, or for the loss of which we mourn. On the other hand, an animal image might resonate with parts of ourselves that we seek to disavow, yet which continue to haunt us.”

The fifth and final session, which terminated the research art therapy group, revolved around finding and creating sources of personal protection through the creation of talismans. The theme for this session was titled *Working with Talismans and Amulets; Finding and Creating Protection*. Stevenson (1994) refers to the amulet object that is either worn or put in one's home as a source of protection against

harm and danger. Participants were encouraged to explore the idea of protection through the use of amulets and talismans. They were given a few guiding questions to facilitate the exercise, e.g. *What object or thoughts or person or beliefs protect you and make you feel safe? Use the book form to explore your source of protection.* In this exercise, the book form was introduced with small boxes to symbolically contain the book and to offer an object to take away that could symbolically contain talisman objects as well as aspects of the book-making or group experience. The book could also be used to identify vulnerabilities or difficult thoughts that may be placed in the box for protection; or the book may represent sources of protection that have a sacred place in the box. In addition to the boxes being introduced, metallic paints and stones were also offered as new media to potentially explore. By focusing on the positive strengths and sources of protection of each participant, I hoped that this short-lived art-based group would have lingering positive effects that could be referred to later, especially with the more permanent containing structure of the box and its possibility of multiple uses. Landgarten (1991) writes that successful closure of therapy has "spill-over benefits into the numerous separations and losses that will be encountered, both by the client and the therapist throughout their lives (p. 176)."

### *Media*

Three types of paper were offered every session. They included white, black, and vellum heavyweight fine art papers. The black and vellum papers were offered in a range heights from 5 centimeters to 100 centimeters for the black and 122 centimeters for the vellum. The white paper was from a roll that was 150 centimeters wide, so a wide array of heights and widths could be cut out to accommodate the needs of the participants. In addition, glue, tape, and thread were

offered so that multiple sheets of paper could be extended in width or height.

Magazines were also offered every session so that participants could cut out images as necessary. In the final session, a variety of small, unfinished wooden boxes with lids were offered to participants.

The wellness centre generously opened their art supply closet to the group. The supplies included a range of papers (wide variety of white drawing papers, coloured construction paper, and tissue paper) and brushes, pastels (dry and oil), tempera and acrylic paints, markers, coloured pencils, watercolour pencils, India ink, and beading supplies, as well as miscellaneous supplies (mirror sections, faux flowers and foliage, yarn, ribbon, and string).

#### *Data Collection*

With the informed consent of participants, I took photographs of artwork, and I wrote case notes written from observations during art-making and any discussions that took place during the group. All artwork made in the group was given to the participants. Following the end of the group, I did one-hour narrative-based interviews (Josselson & Lieblich, 2003) with each of the women individually, in order to hear their own personal experience of creating books in a group. With informed consent from participants, I tape-recorded our conversations. A list of questions was created to refer to during the interview process (see Appendix A). The interview was semi-structured in nature with the questions guiding the inquiry but I remained open to the unique experience of each woman. Qualitative analysis of the interviews followed, using Neuman's (2006) step-by-step approach to coding data to seek out and understand the major themes and types of meaning-making that the participants address in their art-making, and in their narratives about their journey with cancer as a whole. The coding process began by using open coding, in which the

transcribed interviews were reviewed and labeled with codes that summarize key concepts in each interview. After all the codes were noted and no new codes emerged, axial coding began.

Axial coding involved organizing the codes into thematic categories that make sense and which reflect the research questions. Once the themes were derived, selective coding took place. The thick description or rich quotes were compared to the themes to see if they made sense. Negative examples were noted as outlined by Guba & Lincoln (1985). To enhance credibility of the study as outlined by Guba & Lincoln, member checks were done over the phone with two of the three participants. The third participant who wasn't able to attend as many sessions as the other two participants wasn't included in the member check.

One of them added a few additional thoughts and both asked that I remove all "ums" and "uhs" in their quotes which reflected their difficulty with finding the correct English word as both were non-native speakers of English.

### *Study Design*

Narrative inquiry guided this study, in particular for the interviews that followed the end of the book-making group. Polkinghorne (1988) writes that to best understand humans, the human sciences have to realize the primacy of narrative in the lives of people, in their experiences and existence. According to Polkinghorne, narrative inquiry provides the tools to understand people's storied lives. Josselson & Lieblich (2003) write that the goal in narrative is to "create interpreted description of the rich and multi-layered meanings of historical and personal events... the search is for truths unique in their particularity" (p. 259), so as to create and expand on concepts, and to inform others. These authors speak to how the researcher has to remain open to discovery by involving themselves in a process of capturing the lived

experiences of others, and their meaning-making. Neuman (2006) describes the narrative inquiry as one that captures peoples' ordinary lives; the researcher is self-reflective and gets involved in the plot as a co-participant in the study. Marshall & Rossman (2006) speak of the openness and trust involved between the researcher and participant in narrative inquiry. Marshall & Rossman write that the relationship between researcher and participant is mutually collaborative and takes significant time to develop so as to fully understand the participant's experiences.

I recognized that there is power at play in any research— participants are not on equal footing with the researcher. There is some degree of vulnerability inherent in the relationship. I lessened the power differential as much as possible by striving for mutual respect, and by viewing participants as collaborators or co-researchers in the research inquiry. Ethical considerations were imperative to the research inquiry. Confidentiality and consent specific to research purposes were top priorities. Please refer to the sample consent and letter of information forms for participants (Appendices D and E).

Considering the lack of client-centered knowledge in understanding how visual expression may be beneficial for women with breast cancer, and also a lack of data on the artist's book in art therapy, I believe a qualitative narrative inquiry into the use of the book form in therapy was the most appropriate method for this study. The goal of this research was to work with the study participants or co-researchers and to find how they used and benefitted from the artist's fold book. I hoped that the artist's fold book can be used as an arts-based therapeutic intervention to aid in the repair of meaning-making, and of psychosocial and emotional disruptions that may occur following a breast cancer diagnosis.

### *Reflexivity*

Being reflexive means understanding how a researcher's biases can affect the outcome of their study. The reflexive journal, according to Guba & Lincoln (1985), is somewhat like a diary which records information about self and method. The reflexive journal is useful in establishing trustworthiness by helping to identify bias, and is applicable to all four of Guba & Lincoln's criteria (credibility, transferability, dependability, and confirmability) for keeping qualitative research valid and reliable. As I considered this study, I made several assumptions that needed to be brought to awareness. I assume that the artist's book, especially the handmade book, will have some therapeutic value in art therapy. I have experience using the artist's book in my own personal art-making and have taken book arts classes as an undergraduate. My definition of the artist's book is broad. Ready-made journals or family photo albums, loosely organized portfolios of client artwork, or just a paper with two folds that opens up to a triptych— for me, all of these count as artist's books. In the literature I may draw from, an art therapist might not necessarily use the term "book" when referring to her technique or material. My search for exploring the book form in art therapy is wide. I have not found enough literature in any one area, e.g. literature on a particular population or from a particular discipline, to create a highly focused study. Therefore, my literature search is broad and interdisciplinary.

I also assumed that my participants would be unfamiliar with the artist's book, especially the accordion or fold type of artist's book. I didn't expect the creative response to the use of the fold book that the participants had. I found they used and described the fold book in ways I had never thought of. Léa, for example, used the fold in a book about her body to describe feelings of falling. She also found it necessary to present this same book in front of a window, to allow light to illuminate her book.

I also found myself having assumptions about the benefits of the group art-based experience for participants who exhibited a great deal of pain and exhaustion. I couldn't imagine that they could get much out of the experience. I had also assumed that irregular attendance or not being able to attend all sessions was a reflection of the impact of the treatments for cancer. It was only after I interviewed the regular participants, read the literature (Sherman et al. 2008) and heard feedback from my "onsite investigator" about the one-time participants that I understood that the impact of the book-making group was broader than I had anticipated, and that participation didn't necessarily reflect feeling well enough to attend, but could be due to conflicts with medical or other appointments, for example.

I have never had a cancer diagnosis. My personal experience with cancer is being a caretaker for a close family member who was in hospice care following a late cancer diagnosis. This family member never had support outside of family and I believe she would have immensely benefited from a support group with like women, especially one that was arts-based, for she found it difficult to share in words her experience with cancer. I also have volunteer experience working with adults who are living with terminal illness in a hospice house. One of my main motivations for this study is to give voice to women who have been recently diagnosed with a cancer diagnosis and to understand how they can benefit from art-making in a supportive environment, especially using the fold book.

### *Reflexive Journal*

Throughout the research process, a journal was used to note personal feelings and thoughts, in order to keep personal biases in check. Following every group session, in-depth process notes were handwritten, then typed, so that they could be referred to at any point. Quick notes were written during the session, during the

interviews, during the data analysis, and during member checks, to help me process personal thoughts. I also made art work during and after sessions, to identify my personal reactions to the group process.

#### *Qualitative Validity and Reliability*

I am aware that my subjectivity has affected the outcome of this study. I intend to be transparent in my biases. I have kept a reflexive journal, to keep a record of my research process and my subjective thoughts, values, and interpretations throughout the inquiry. Validity and reliability have been addressed by prolonged engagement with the research participants, triangulation of data sources (data collection includes the literature, interviews, photographs of artwork and the session process notes), member checks (having participants review and approve transcribed derived themes), peer debriefing, use of thick description and contextual details (setting, population) and the use of a reflexive journal to track personal biases and expectations.

#### *Prolonged Engagement*

I facilitated five two-hour sessions with my participants and was available for them before and after session to answer questions and talk over any concerns they may have. In addition, I interviewed two participants in person and one participant over the phone for 1-2 hours each. I believe that a trusting relationship was built between me as facilitator/researcher and the three main participants.

#### *Triangulation of Data Sources*

My data collection includes a range of literature in creative arts therapies, breast cancer research, artist's books, narrative inquiry and qualitative research

methods, and in the meaning-making literature. The rest of my data comes from the work I did with the participants of the study, and includes interviews, photographs of the participant's artwork, and my process notes and reflections from each of the sessions, interviews, and member checks. Other data sources include my own quick "feeling drawings" I did with the participants in session, plus a few drawings I did following certain sessions that helped me to process some of my own feelings towards the group and research in general, and which could be considered part of my reflexive journal.

#### *Member Checks*

Member checks were made over the phone with two participants, each lasting 30 minutes to an hour. The third participant was a negative case because a lot of what she said was different than what the other two participants said. My understanding of her different feedback was that she wasn't able to participate as actively as the other two participants, nor was she able to attend as many sessions, because of the side effects of her cancer treatments. She also appeared to have a different understanding of the purpose of the group. She thought the group was supposed to have been more of an open studio where the focus wasn't on the self but on art instruction. Thus, her experience and feedback in light of the purpose of the study could be construed as a negative case.

The member checks involved checking in with participants to see if the four major themes that arose from the coding analysis still made sense or resonated with what their ideas and thoughts were of the book-making group experience. I also shared with the two participants the content of the thick descriptions that reflected the themes, so that they would have some idea what quotes I would be using in my final research paper. Both approved the themes and the content and quotes I would

be sharing from their original dialogue. Both asked that I clean up the dialogue so that it wouldn't include hesitation words like "um" or "uh", or the repetition of dialogue when they were at a loss for words in English when their native language was French. Because they were not native English speakers they were at times self-conscious about how they worded things in English. Special attention was made to keep the original French dialogue intact with translation in brackets afterward. One participant asked that I keep her real first name and the other created her own pseudonym which was of great importance to her. All changes requested by the participants were implemented.

#### *Peer Debriefing*

Guba & Lincoln (1985) write that qualitative based inquiries can be a lonely process and using peer debriefing can assist the researcher with releasing emotions or thoughts that may be affecting their understanding of the research. I worked with the staff of the wellness centre to develop a research proposal. With the feedback from several of the staff researchers and with the help of my research advisor, I developed a proposal that was approved by the ethics committee of the hospital that operates the wellness centre, and that was then implemented with the assistance of the coordinator of the centre and other staff members who offered onsite supervision and feedback and frequent check-ins. Throughout this process and during the writing of my research, my research advisor, practicum advisor and practicum classmates have offered feedback, support, and advice; they have been my guides throughout the bookmaking group sessions, interviews, data analysis, and research writing.

### *Thick Description and Contextual Details*

In the findings section of this paper, the major themes of the qualitative data analysis are linked with the original transcribed dialogue to verify the findings. Themes are linked with quotes taken directly from the original interview and are compared and contrasted with other data sources. It should be noted that two participants requested the removal of “ums” and “uhs” as related to difficulty finding the appropriate word in English as English was not their native language. Some quotes were modified to reflect this type of participant request. Contextual details of the three participants and of the setting are included in the beginning of the methodology section, under the Participant subheading.

## FINDINGS

The goal of this study was to investigate how the artist’s book format can facilitate expression and meaning-making for women recently diagnosed with breast cancer, and the qualitative data analysis described above provided answers to this question by bringing into focus certain recurring themes in the participants’ experience of the group. After analyzing the interviews in light of the sessions, my case notes, and the artwork created, the analysis of the narrative-based interviews yielded four major themes: (a) Breaking Down the Isolation; (b) Emotional Awakenings; (c) Structure and Freedom to Explore; and (d) Realizing Capabilities. The narratives overlapped many aspects of the participants’ lives, including their living with cancer and how they coped, and the impact of the group and art-making. The group, including the facilitation of the group, art-making, and the artwork itself all *reduced isolation*. Becoming more self-aware or *awakening* occurred through the art-making and during group discussions. The structure of the directive approach by which the sessions were run, combined with the fold book form and a broad range of

media of various dimensions, allowed for a combination of *containment* with an opportunity for free expression and consequently, *self-exploration*. *Identifying and reinforcing strengths and capabilities* in light of a recent cancer diagnosis, subsequent treatments, and a great deal of uncertainty became possible during art-making and group discussions, and is reflected in the content of the art itself. The following describes in more detail each of the themes with quotes to support the themes.

### *Breaking Down the Isolation*

In the narratives about the group itself and also its facilitation, it became apparent that the art therapy group with its bookmaking focus was perceived as a safe, warm, and engaging space to be oneself and make connections. Codes that referred to the group and to the art space included *congenial, building relationships, mirror, hearing others, pleasure, comfortable, easy participation, stimulating, precious, and new encounter*. All participants were appreciative of the opportunity to participate in this supportive, arts-based environment, and oftentimes participants made the effort to come to the group even though they were in great deal of discomfort and fatigued. Many sessions began with the participants sharing about their hair loss and how they were coping by wearing wigs and scarves and cutting their hair. The sharing of treatment stories was also predominant. Rachel and another participant shared with Léa how the chemotherapy treatments would happen as Léa began her own chemotherapy course of treatment. The participants also checked in with each other to see how each of them was coping with the impacts of cancer treatment. For Rachel, the sharing of her cancer treatment stories was one of the few occasions that she felt comfortable enough to talk about her current state. Rachel, who was in the ending stages of her chemotherapy treatment with radiation

treatments soon to follow and was in a great deal of pain. Rachel couldn't actually be present for the whole session and would often just sit and listen and be with the group with only minimal participation in the art-making and discussions. Rachel said in her interview that "it was nice meeting the other girls. It was very nice. The room was very comfortable. And you [group facilitator/art therapist] also very much wanted to help and I appreciate it very much." Another participant, Léa, said that she observed that she would arrive not feeling well but after the art-based directive she would feel better. She stated "it's the same for Rachel who feels very bad and sometimes with the activity she smiles and feels good and it's the same for me. I feel more good after the activity." Léa said the following during her interview:

Yes. It's a good experience for me. The group is small but it's very sympathique. It's... Je vais dire un petit peu en français... c'est un groupe qui était chaleureux, où on se sentait tout de suite bien avec le groupe et euh et bien avec vous aussi... Ce n'était pas difficile. (I'm going to say a little bit in French... It's a group that was warm, where people felt comfortable right away with the group and comfortable with you as well... It wasn't difficult.) Même les matins où j'étais moins en énergie... (Even the mornings where I had less energy...) ... more tired... When I arrive it's good for me, it's very agreeable.

For Léa the art-making within a small group of women was a pleasurable activity where she appreciated what the other participants said about their own books and the creative process. Léa said "It's more open, the consciousness, for me because it's another point of view, another *explication* [explanation], another feeling another. It's a new consciousness for me. Yes, the artwork. The work of the others. It's like a mirror. Another point of view." In session three, Rachel was the only participant who could make it in. Léa had a chemo treatment and Danielle had called in to say she was too ill to come. Rachel mentioned that she missed having the other participants there with her and wanted to know how each of them was doing especially Léa because she had just started her chemotherapy treatments.

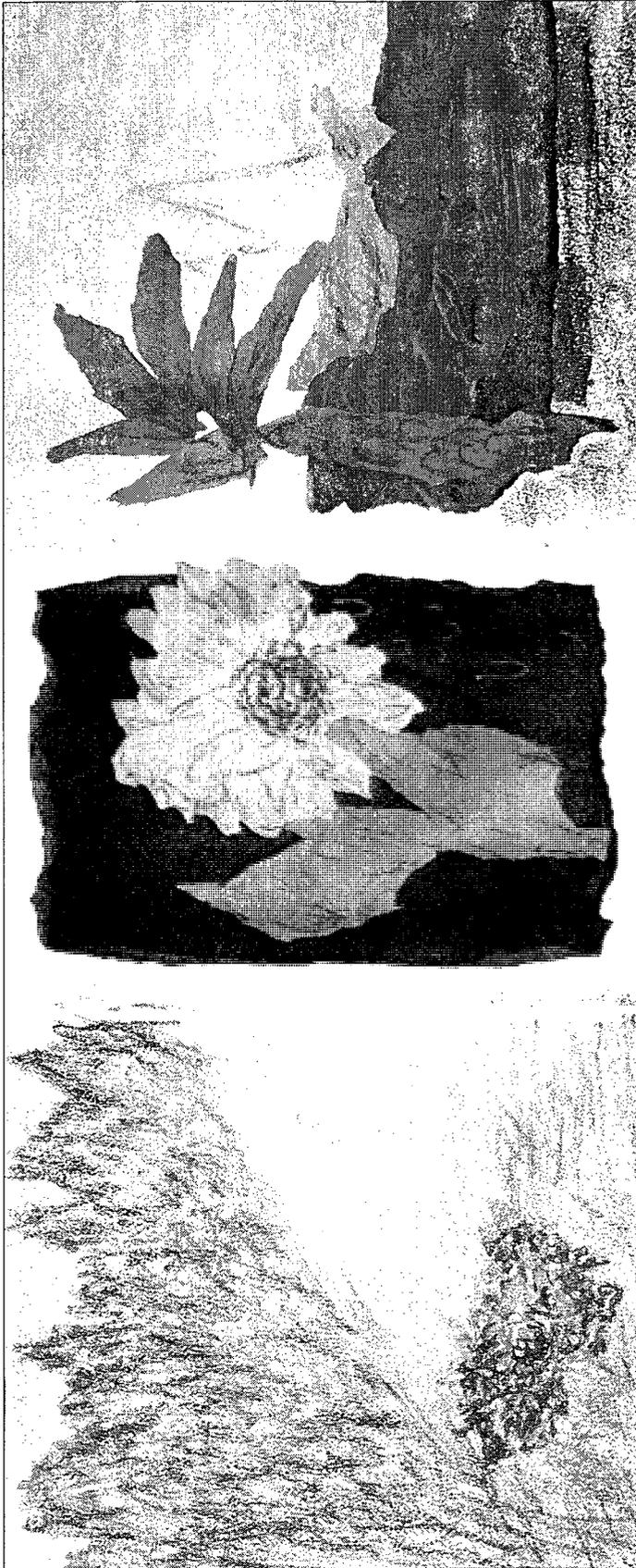
Léa and Danielle met in the group and made a connection that led to a friendship outside of the group. Danielle shared in her interview that Léa "...is a nice

girl. We are going to see each other. We are a lot alike.” Both Léa and Danielle have grown-up children and are single mothers, and found a way to break their isolation with friendship. Danielle shared a great deal about her “unhappy solitude” during the group sessions, her artwork and in interview. She remarked in her post-study interview that “it helps to be with other people. I was used to working alone in my workshop” but as of late, she has been unable to create artwork at home like she used to; yet she was able to create a great deal of spontaneous artwork in this group and also in an open studio painting class that she attended weekly.

### *Emotional Awakenings*

*Awakenings* refer to enhanced self-awareness and the ability to move forward with new insights through art-making and discussing the creative process in the group. Codes referred to increased awareness of the impact of a recent cancer diagnosis and moving forward with new perceptions include *discovery, challenge, life reflection, life shortcomings, ups and downs, loss of self, lonely diagnosis, talking about emotions, violent expression, anger, desperation, destruction, ashamed, death, different standards for women, healing expression, stopping and starting, not knowing, simultaneous lightness and heaviness, loss of loved ones, anxiety, tiredness, and crying.*

The accordion book form became a medium where participants explored their recent cancer diagnosis, especially the emotional side. One directed activity in particular, the *Past, Present, and Future Triptych*, brought some semblance of self-awareness for all participants. For Léa, the triptych (Figure 1) allowed her to see how



*Figure 1. Untitled. Past, Present, and Future Triptych done by Léa*

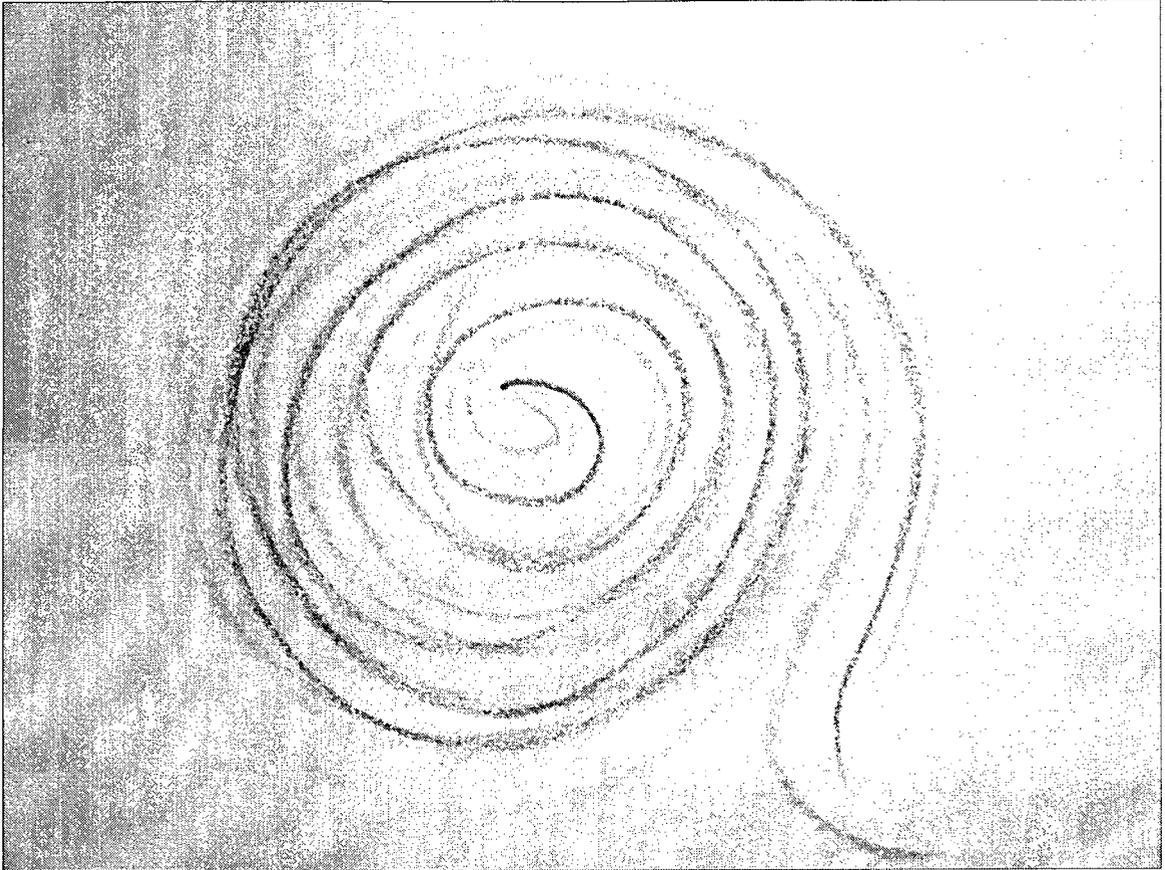
alone she was with her diagnosis. Léa said that the triptych spoke to her the most out of all the books she created. She said when referring to her triptych that “my interior is very alone with this cancer because I don’t draw the person in the now time, just in the future. The other [participants] draw many people and family. I realized just for this part that I don’t have people because in my interior I feel alone.”

In the ‘present’ portion of Léa’s triptych (see Figure 1) as seen in the middle is represented by a large yellow flower which is shedding tears. During the discussion that followed the art-making in this session, Léa said that she deliberately placed the heavy crying flower on black paper because she had a lot of fear of her first chemotherapy treatment that week and that she had cut her hair in anticipation of losing all of it. She cried as she spoke of her fear and the cutting of her hair. It was only later during the post study interview that Léa shared how alone she felt in the present with her new diagnosis. She said “my feeling is very alone at this time” despite also sharing that “I have three children and friends”. When Léa came to the group she brought her son with her for support and still she felt very much alone. She also carried a lot of fear. Léa said

“the first chemo ... Je vais le dire en français. Parce que j’appréhendait... on a toujours peur de l’inconnu (I am going to say this in French. Because I was worried... You’re always afraid of the unknown...). Avant la 1ère chimio – il y a la peur de l’inconnu et cela crée de l’anxiété (Before the 1st chemo – there’s a fear of the unknown and that creates anxiety.)

In my process notes of this session, I noted how the future is depicted as a tropical waterscape with two sails above a yellow boat, which is the same yellow as the flower with the same brown pastel marks throughout. On the beach front there are two empty reclining red beach chairs. From my own observations of the artwork, Léa’s future looks empty and devoid of actual people. This feeling may resonate with Léa’s perceptions of her unknown future as she just begins her chemotherapy

treatment with surgery to follow. Léa is becoming aware of being alone and of the unknowns with having a new cancer diagnosis. In the following session, the group focused on identifying what bodily sensations they were feeling through a guided visualization, and also on identifying emotions that may be attached or hidden within their physical self, especially surrounding the physical sensations they were experiencing. This intervention, *Feeling the Body, Finding Feelings*, was modified from Capacchione's (2006) book, *The Art of Emotional Healing*. Following the visualization, participants were asked to create imagery that reflected the bodily sensations they noted in the visualization and to explore any emotions or feelings that arose while becoming aware of their physical sensations. During the check-in quick drawings for this session, Léa drew a pale pink and blue spiral (Figure 2). Léa said that the pink represented lightness and weakness and the blue represented darkness and strength. Léa shared that these contrasts of colour as well as lightness and darkness were like the ups and downs of her first chemo treatment. She said her head feels scattered, while in her belly the chemotherapy has caused a great deal of burning. In the fold book Léa created for this session, she chose a wide piece of vellum and she oriented the book vertically to represent her body (Figures 3 and 3a-c). She folded the vellum in two large sections for the head and torso, and for her legs and feet she made four folds. She used oil pastel to create the three parts of her body – head, torso, and legs. She drew her face with clouds covering most of her eyes. Léa says that sometimes she can still see the sun. Her partially covered right eye looks similar to the golden sun. Her hair is long and cherries dangle from her lips. When discussing her book in group, Léa said that her hair used to be long but is now short to help her cope with chemotherapy-induced hair loss. The cherries, according to Léa, represent her over-eating; she says that she has lost her sense of

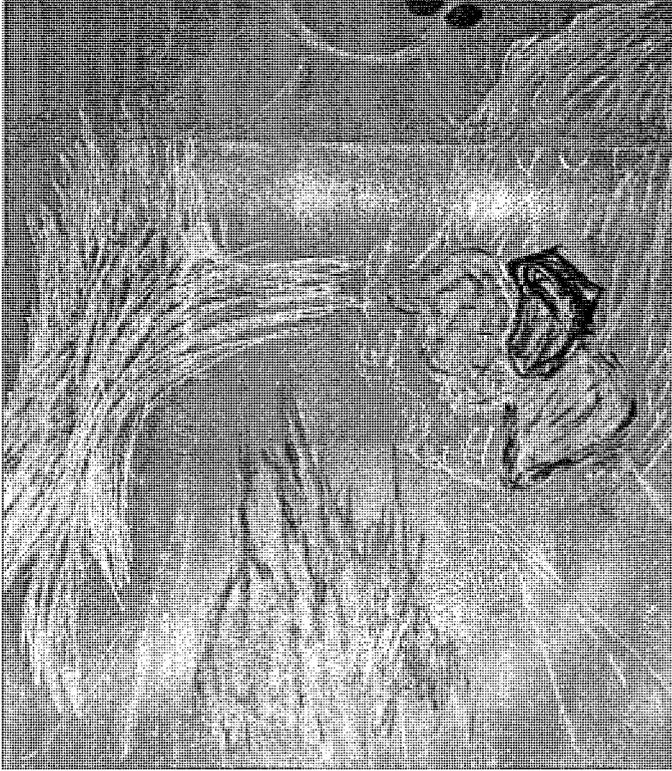


*Figure 2. Untitled. Quick check-in drawing done by Léa*



*Figure 3. Untitled. Feeling the Body, Finding Feelings done by Léa (left)*

*Figure 3a. Untitled. Feeling the Body done by Léa. Head Detail (above)*



*Figure 3b. Untitled.*  
Feeling the Body  
done by Léa.  
Torso Detail.



*Figure 3c. Untitled.*  
Feeling the Body  
done by Léa.  
Legs Detail.

taste with the chemo. Léa didn't represent her breasts in the section depicting her torso. Léa drew her shoulders with rocks (left shoulder) and wings (right shoulder). She said that her shoulders feel alternatively too light or too heavy. When Léa spoke of her family during the session discussion, she referred to the weight of family. Family for Léa right now is a source of support, but at the same time she worries about them. In Léa's drawing of her belly, she put an orange fire which reflects the burning sensations she feels in her abdomen as the result of her cancer treatments. Léa drew her legs as light wings. She shared in group that the three folds in her legs represent the shakiness of her legs and how recently she feels she may fall. In the post study interview Léa shared the following, "sometimes it is very hard and sometimes it is more light and sometimes I feel light but my body is not responding. I hate this feeling because it's too tired." Léa was very surprised at finding out she had cancer because she felt fine at the time of her diagnosis. She said the following in interview:

I'm surprised because it creates a duality because I am in a good form and I have a diagnostic [diagnosis] and the treatment and it's difficult sometimes. The breast cancer is a time of life that we stop more things because and je dois [I have to]... je dois être patiente [I have to be (a) patient], patient for more months and weeks. For me the project, one year to report and I think this situation created this duality [of lightness and weight]."

It appeared that the directive about the body and mind connection allowed Léa to explore and become more aware of the duality of her diagnosis and treatment, and of how that has impacted every aspect of her life from family, to having to be patient and not knowing what the future holds, to being exhausted and eating too much and feeling heavy while also feeling scattered emotionally. Other participants noted the predominance of either weight or lightness of their being or situation. Danielle referred to the burden of weight and of aging. She felt too heavy and less mobile due to her increased weight and her older age.

Rachel was unable to come to the session that revolved around the body and emotional connections, but she was the only participant to come the following week, and she decided she would rather focus on the body-based activity from the previous week rather than the directive I had planned revolving around the weight of a cancer diagnosis. I followed Rachel's lead and introduced the visualization from the previous week's *Feeling the Body, Finding Feelings* intervention. After the guided visualization, Rachel used black marker to draw a simple body (Figure 4) with no head. She drew her spinal column, her arms and hands, a line for her hips, her legs and feet. Pain is marked in all of her joints and throughout her spine with the markings of red or orange pastel. It was a very quick drawing. Rachel was visibly uncomfortable and was often squirming in her chair during this quick exercise. She said that she is nervous all the time and is constantly worried. She feels like she is a burden to her children and her husband. She mentioned that she always has to ask her husband to bring her things. It was apparent that Rachel was very uncomfortable physically and wasn't engaged for very long in the *Feeling the body* directive. Rachel didn't want to talk or draw anything that revolved around her cancer diagnosis and treatment. She began to talk about what a pleasure it is to go to galleries and museums. She spoke of her admiration of Vincent Van Gogh's paintings and said she had never painted before. I invited her to paint for the first time. She created a colourful landscape with red sky and earth with acrylic paints (Figure 5). Rachel appeared to go or not go where she needed in this session. She was aware of her pain that resulted from her chemotherapy treatments and focusing on her pain was too much. She chose to stay with the image of her body for only a short while. She made the decision to visit the work of Van Gogh and decided to try painting for the first time in her life. She made a landscape rather than imagery of herself directly. She was proud of her painting.

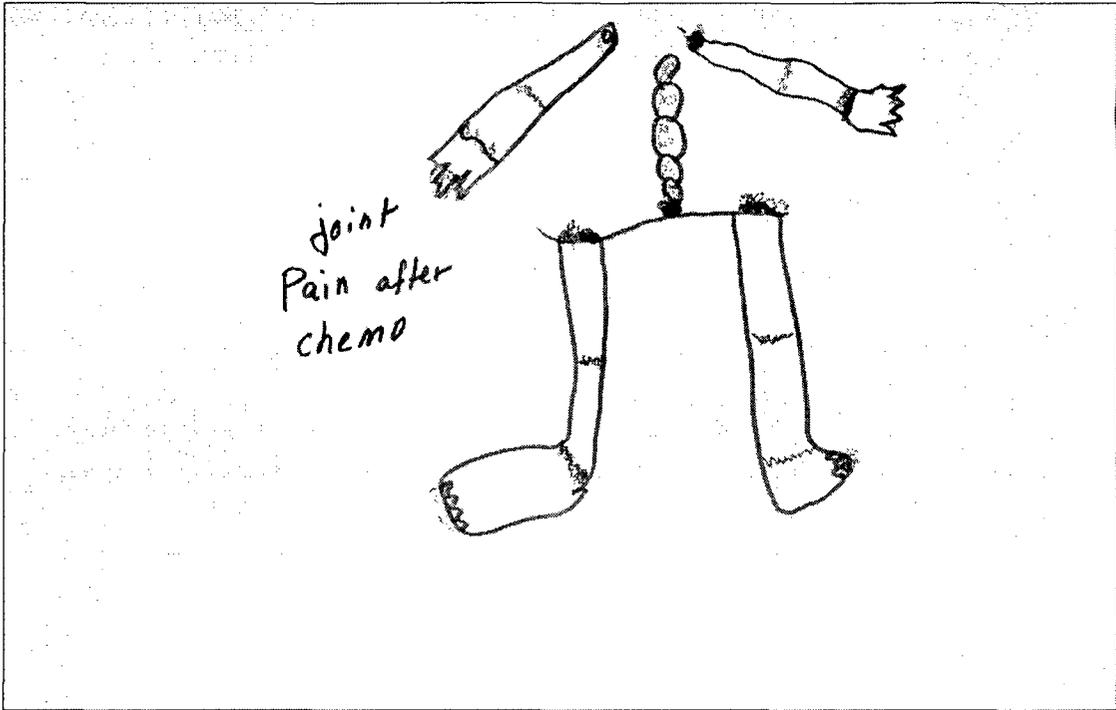
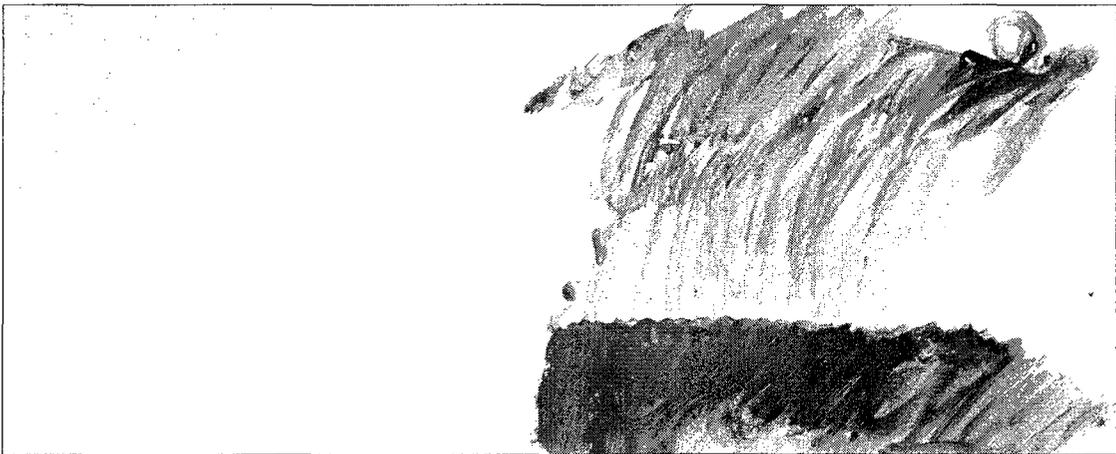


Figure 4. Untitled. Feeling the Body done by Rachel  
Figure 5. Untitled. Rachel's first painting.



In the first session, Rachel also found it difficult to speak of her current journey with cancer. When Rachel made her *Past, Present, and Future triptych* (Figure 6), she had folded a long sheet of paper in three parts but was dissatisfied. She asked in session if she had to depict the present and was told that she could do the triptych any way she chose, there was no right way. While Rachel felt that her cancer was very much present she didn't want to speak of the cancer. She folded her second long sheet of paper in half and depicted her past full of images of children (her grandchildren) on the left. She also included an image of a red heart with a heart monitor line beeping through it. On the right, in the future, Rachel wrote down all the cities and countries she hopes to visit one day. Rachel said she is frustrated by health insurance companies who are reluctant to give longer term coverage for travelling to people with cancer. She found it very difficult to visit her grandchildren for only two weeks at a time as they live so far away.

The book-making also gave Danielle the space to share and realize all of her recent losses, including the loss of her long-time companion, her beloved cat. For Danielle, the fold book that revolved around choosing an animal that she could identify with, and then providing this animal with nourishment and an environment, assisted her with identifying her strengths as well as revealing some of her soft spots or vulnerabilities (Figures 7, 7a). Danielle said this book in particular was the one that helped her the most, because it allowed her to express her feelings. In the directive, *Choose an Animal*, a strength-identifying intervention, Danielle chose the cat as the animal she felt most connected to. She created a four-page accordion book that detailed the life of her cat from when he was a kitten until his death. The first page shows her cat as a playful kitten who bats at yarn. The next page shows where her cat liked to spend most of his time; his environment was inside the bathroom where he felt very safe. In the next panel, Danielle fondly recalls how her

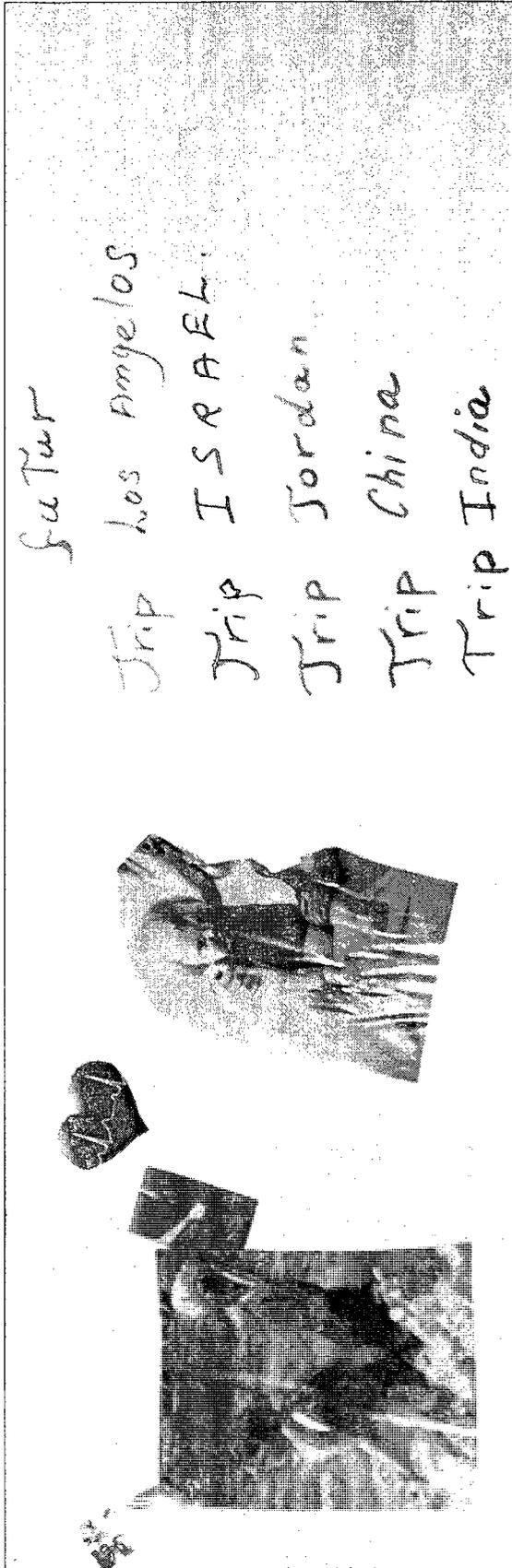


Figure 6. Untitled. Past, Present, and Future Triptych done by Rachel.

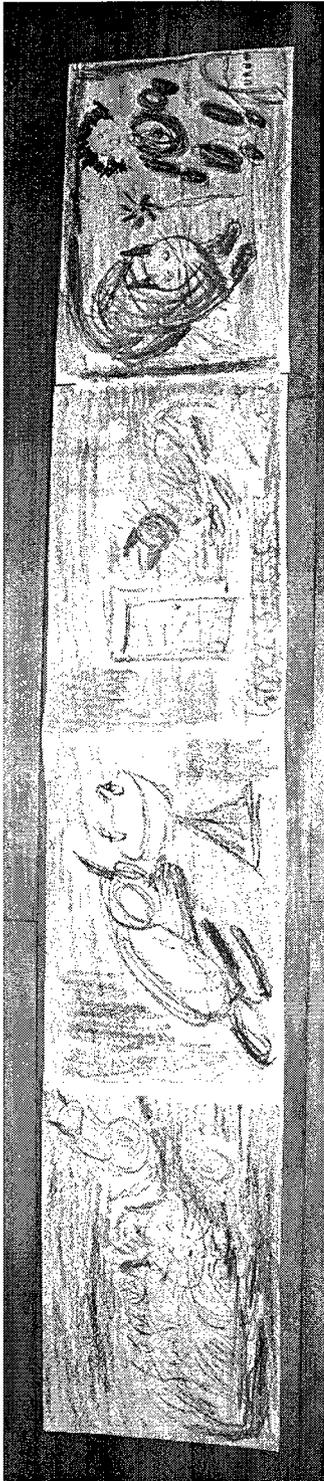


Figure 7. Loss of the People I Loved, done by Danielle. (left)

Figure 7a. Loss of the People I Loved. Detail of final panel. (above)

cat greeted her with much excitement every time she came in the door. The last page shows Danielle crying after her cat died. She is standing next the urn where her beloved cat's ashes lie. Danielle said the following in interview when talking about this book:

"I think you get a clearer idea as fast as you go on with the different parts. Your ideas are clearer especially the one with the cat. When you start you don't know what you are going to draw. At first it's not very defined, the cat. It's just a very fast draft, you know. The end is very... the ashes. At the end I was getting close to how he really felt."

Danielle brought in a recent drawing she made of her cat at home during our interview together. She spoke of wanting to keep his memory alive by drawing him. She found it extremely difficult to make the drawing. She said "I shouldn't have done this because it's too hard. But anyway I did this." Danielle appeared to be processing the death of her beloved companion while also becoming aware of being alone, and while realizing some of her current limitations in terms of taking in a new companion cat. This metaphorical animal-portrait exercise allowed Danielle to identify with an animal that appeared to reflect her current journey with cancer. She was able to explore her personal strengths and sources of healing, as well as some of her current vulnerabilities and difficulties.

During the member check, when I asked Danielle if the themes still resonated with her, she said that the animal-based exercise "helped me express my feelings" and it also made her realize that "I won't get a new cat; it would be too hard to take care of anybody else right now". Danielle shared a great deal about her "unhappy solitude" during the group. The death of her companion cat was very difficult, she said, because she felt so alone and for the first time felt unhappy in her solitude. She also spoke of feeling abandoned following her cancer diagnosis. She said that "a friend, after she learned I had cancer, she didn't call me anymore. For some people, it's too hard." During the member check over the phone, she also spoke about the

death of her brother. She said the book allowed her to begin processing the deaths of people close to her. She also shared that she doesn't know what will happen to her artwork when she dies. She knows that her son will be "stuck" with all of it, and this made her think of how her brother's children had an auction to sell all of his sculptures. The group, the artwork and the interview itself have given her a place to recount her memories, the struggles and joys of her life. She has in many ways begun a kind of life review process.

In addition to becoming aware of all the unknowns that come with a cancer diagnosis, Danielle also frequently spoke of the unknowns and her frustrations at becoming older. In her rendition of the *Past, Present, and Future Triptych* (Figure 8), she drew the "past" on the left, which consists of her happy childhood with a smiling face in the green trees and a blue sky surrounding a house with golden window, golden door, and a chimney. The "present", in the middle, is full of colourful arcs. Danielle spoke of the present as moving. The "future", on the right, consists of a large green mountain next to a yellow sky that turns red and blue. The foreground is the rocky earth in brown. When Danielle shared about her image of the steep mountain, she said she's getting older and the future is unknown and will be difficult because of how old she feels. She notes her changing body. In this same session, she shared how she had been in denial when she attended an art therapy group six months ago. She couldn't come to terms with having a cancer diagnosis soon after she found out. She felt that today she is more aware of her diagnosis and of getting older, and more able to express how she's feeling. In her interview in late October 2008, Danielle had expressed that "lately, since last year, I was only able to work at home a little bit, just a little bit of drawing in my black book, but apart from that the solitude was too big. But now I want to do something at home. I've moved on." She expressed at several points how she's going to build a small art studio space for



*Figure 8. Past, Present, and Future Triptych done by Danielle*

herself in her apartment so that she can work again on her art at home. During the member check a few months later, Danielle shared that she is experiencing a lot of painful and crippling side effects from a cancer medication she's taking, and the above thoughts of creating a studio space and making art at home are less of a reality right now because she cannot walk. Her thoughts of making art at home are future desires rather than current realities.

### *Structure and Freedom to Explore*

The accordion book appeared to be an inviting medium that allowed participants to reveal or constrain thoughts and ideas depending on presentation and when and how they decided to use the fold during the art-making. Some participants preferred to present their book closed to be read on a table top, while others hung their books fully open on the presentation board or on the window pane. One participant worked fold by fold rather than using the paper as a whole sheet. It's a medium with endless possibilities, which can help accommodate a range of feelings and experiences when a variety of materials and sizes are offered in conjunction with a directive-based approach. Codes that referred to the structure and freedom of the book form, as well as to the directive yet client-centered approach, included *inventive, different spaces, expose, constrain, manageable, segments, experiment, beautiful, radiant, keeper of ideas, multiples, spontaneous, focused, not knowing, clarity, familiar, precious, letting go, appreciation, new technique, witness, push, exploration, comfortable, colour, and texture*. Colours such as gold, yellow, and "wonderful blue" (as named by Danielle) and the powerful influence of the natural world (sea, sky, flowers, animals, mountains) predominated during the interview.

Two of the participants expressed that the book form was easier than drawing or painting on a plain sheet of paper. Rachel expressed that the book directives were

"a start of something because I discover painting but I didn't know how to start, but the book was easier. It gave you more ideas. The book was very good. You left with something you did." Danielle found that being able to fold the paper into pages or segments was a less intimidating way to work. She said in interview that "sometimes if you have too big of a surface, if your sheet of paper is too big it's more difficult to draw something. If it's something small, you can constrain your ideas. It's easier because it's smaller." Danielle found that working on individual pages allowed her to "keep your ideas, you anticipate the next one and the next one rather than if you have a big sheet which is more difficult especially if you don't have much time." She said that by breaking down the paper into smaller sections or pages, it allowed her to work in a fast yet focused way because "you don't get lost and the colour has to work... it gets narrow." Danielle also appreciated the range of presentations of the book form. She said in interview that "I like the experience. It's very nice because you can put it on the wall like this or like this [she shows me how she can hang one of her books both vertically and horizontally on the wall]." Danielle experimented later on with drawing on both sides of the book and playing with what end of the fold book is the first page in *Feeling the Body*.

Léa also found that having choices about both size as well as a variety of papers and textures and objects would permit participants to explore whatever they needed to explore. In interview, Léa said "*Différents états d'âme et besoins, les formats et les textures permettent des espaces variés – une petite boîte peut contenir un précieux trésor*" (Different states of mind/soul and needs, the sizes and textures allow for different spaces – a small box can contain a precious treasure). In particular, Léa shared a great deal in the interview about choosing the vellum for exploring her body (Figure 3) and choosing the box form (Figure 9) to hold things that are precious to her.

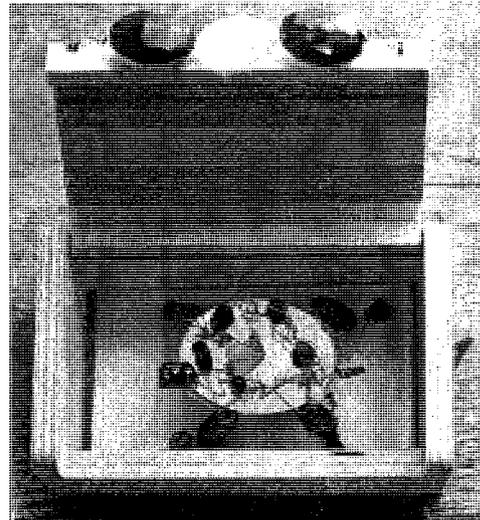
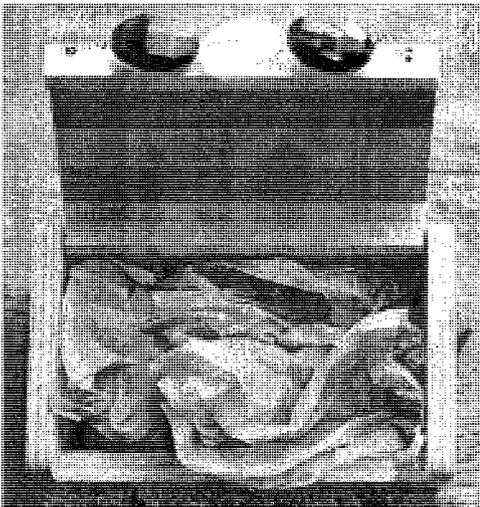
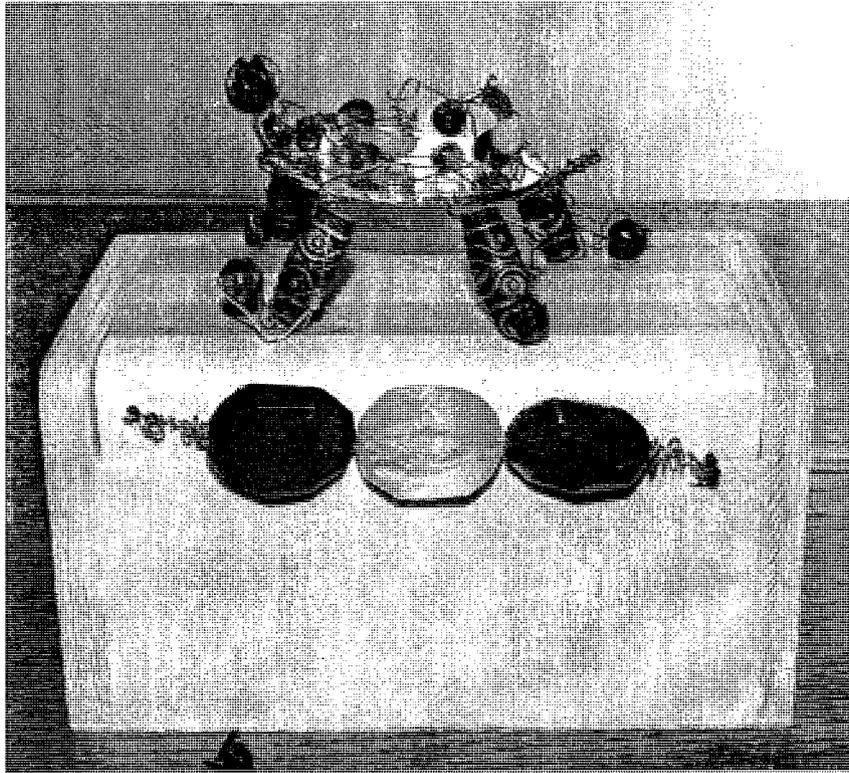


Figure 9. Ami Box done by Léa.

Figure 9a,b. Ami Box details. (below)

Vellum was a new material for Léa. She found the transparency interesting "because it's the interior of the body and it's just like a radiography [X-ray] of the body. It reflects what is moving in the interior and it's radiant. It's very interesting to use the material." She said the vellum allowed her to expose what is hidden, especially when she taped her vellum book to the art studio window. She explored a great deal about the impact of her diagnosis and how that has caused a number of dualities for her. For example, Léa spoke about how she felt physically well and content in her life at the time of her diagnosis. She now feels worse having started her chemotherapy treatments. She spoke about the lightness in her mind combined with a body that was heavy and not moving or that was burning. She depicted her eyes as being partially covered by clouds while simultaneously looking out at the viewer. These dualities have left Léa feeling scattered emotionally.

In interview, Léa was able to see the prominence of yellow and blue in many of her books and in her box, and discussing the role of these colours in her work became a jumping-off point for deeper insight into the emotions and experiences she was trying to express. While Léa didn't seem sure why she chose these colours, the contrasting yellow and blue appeared to be motifs or symbols that were present in every session, and could refer to the dualities Léa frequently spoke of. The post-study interview became a place for an image review, not unlike that which occurs during the termination phase of group and individual art therapy. Léa spoke more about the artwork in the interview than during art-making sessions. She appeared to be making more personal connections to the art and gaining some insight into her experience with cancer. The turtle in *Ami box* has a yellow heart. On the outside of the box are three large beads, a yellow stone sits between two blue stones. Léa referred to the yellow stone as being joy while the blue stones on either side represent the sea and sky. I wondered if her contentedness lay somewhere between

the sea and the sky or that for her true happiness, she needed to be surrounded by nature. The vertical opposition between sky and sea/earth seems to also reflect her feelings of extremes or dualities of feeling too light (sky) or too heavy (earth). Léa described her turtle as having its legs connected to the ground while the mirrored torso reflects the sky. The turtle, it seemed, was between or connecting the earth and sky. The turtle has a yellow heart. I wondered if the yellow stone on the outside of box represents the turtle or herself between earth and sky or between life and death or between feeling grounded and feeling light high above in the sky. The right eye in Léa's body piece (Figure 3a) is also yellow like the sun. The crying flower and the boat in Léa's past, present, and future triptych (Figure 1) are also yellow. In the triptych, blue waters are on the left and right. A blue sky is also present in the future with the yellow flower in the middle, in the present. In addition, Léa created a yellow butterfly to represent herself when she explored her metaphorical self-portrait through identifying with an animal (Figure 10). Although Léa did not seem consciously aware of any special symbolism in her choice of colours, the predominance of the contrasting colours yellow and blue and their role in her artwork point to a deeper level of meaning that would have been interesting to explore further if the length of the study had allowed it.

#### *A Book Inside a Box*

Introducing the book in a box form was a way to close the group in our last session together on a positive note. The box was offered as container for a fold book as part of a directive to create a talisman or amulet, as a way to help identify and create sources of protection as the women continued along on their journey with cancer. All three participants created and enjoyed the box form for a variety of reasons. Léa said that she plans to "use the box for the precious things,

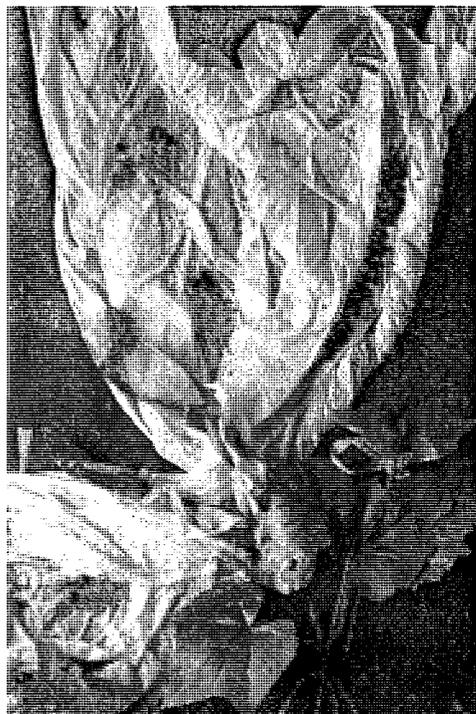
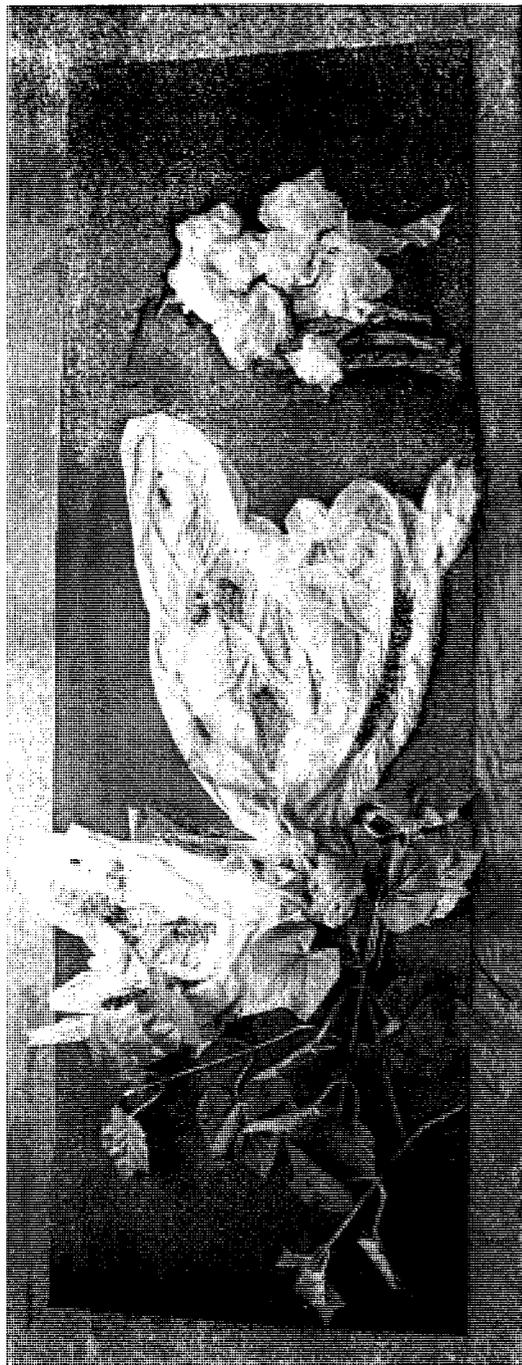


Figure 10. *Untitled*.  
Choosing an Animal done by  
Léa. (left)

Figure 10a. *Untitled*.  
Choosing an Animal done by  
Léa detail. (above)

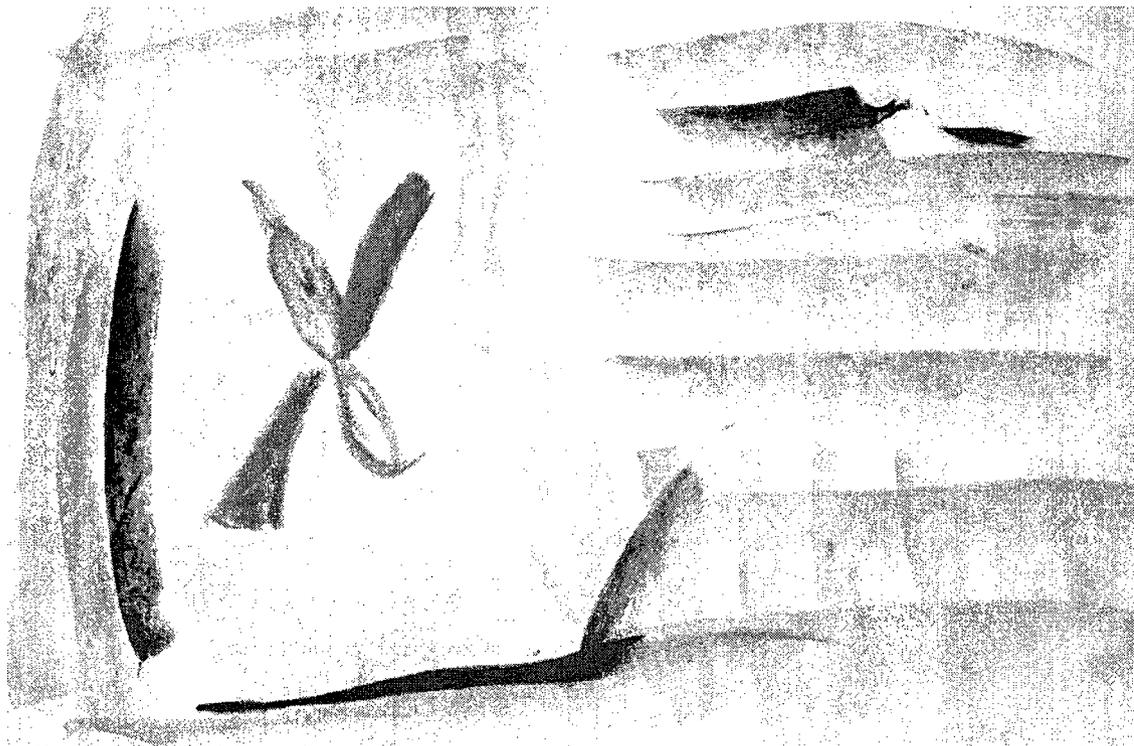
for proverbs and a place to put photos or pictures of people who are very important for me. I just put it in my box and I am a good guardian for my box, my *Ami box* (Figure 9)." Léa wrote the following about her *Ami Box* during the interview: "*Des pensées et des phrases motivantes pour moi (proverbs, dictons) ex: Le temps d'une vie est le même qu'on le passe en riant ou en pleurant.* " (Thoughts and phrases I find motivating [proverbs, sayings] e.g. The length of our lives is the same, whether we spend it laughing or crying.) Léa thought that she would use the fold book to add meaningful proverbs. She created a turtle talisman out of many beads, wire, and an oval mirror for the torso. For Léa, the turtle was very powerful because turtles live long lives and are very strong. She described her turtle as having its legs below the ground and above the mirror-torso is the sky. Léa said the turtle can live on top of the box and also inside. When she was done making the turtle, she placed it on top of an incomplete fold book and wrapped it gently in a piece of pink tissue, similar to the pink tissue she had used for her butterfly scroll (Figure 10) a few weeks earlier. The outside of the box is simply adorned with three large beads that Léa strung on wire and glued to the front of the lid. Léa shared that the two blue beads on either side of the yellow represent the sea and sky. The yellow bead represents joy. Joy sits between the sea and sky. Léa also shared that she had lived in Africa for some time and felt connected to their use of the talisman. For Léa, the box had more longevity or permanence than the books. In interview, Léa said "I like [the box] because the book is a thing and after we arrange it in the place when here is the past, but with the box it's all the time with me. It's not just for this time, it's for a long time."

Rachel referred to the box as something to keep, a souvenir to take home with her that she is proud of and can share with loved ones. In interview Rachel said the box was a

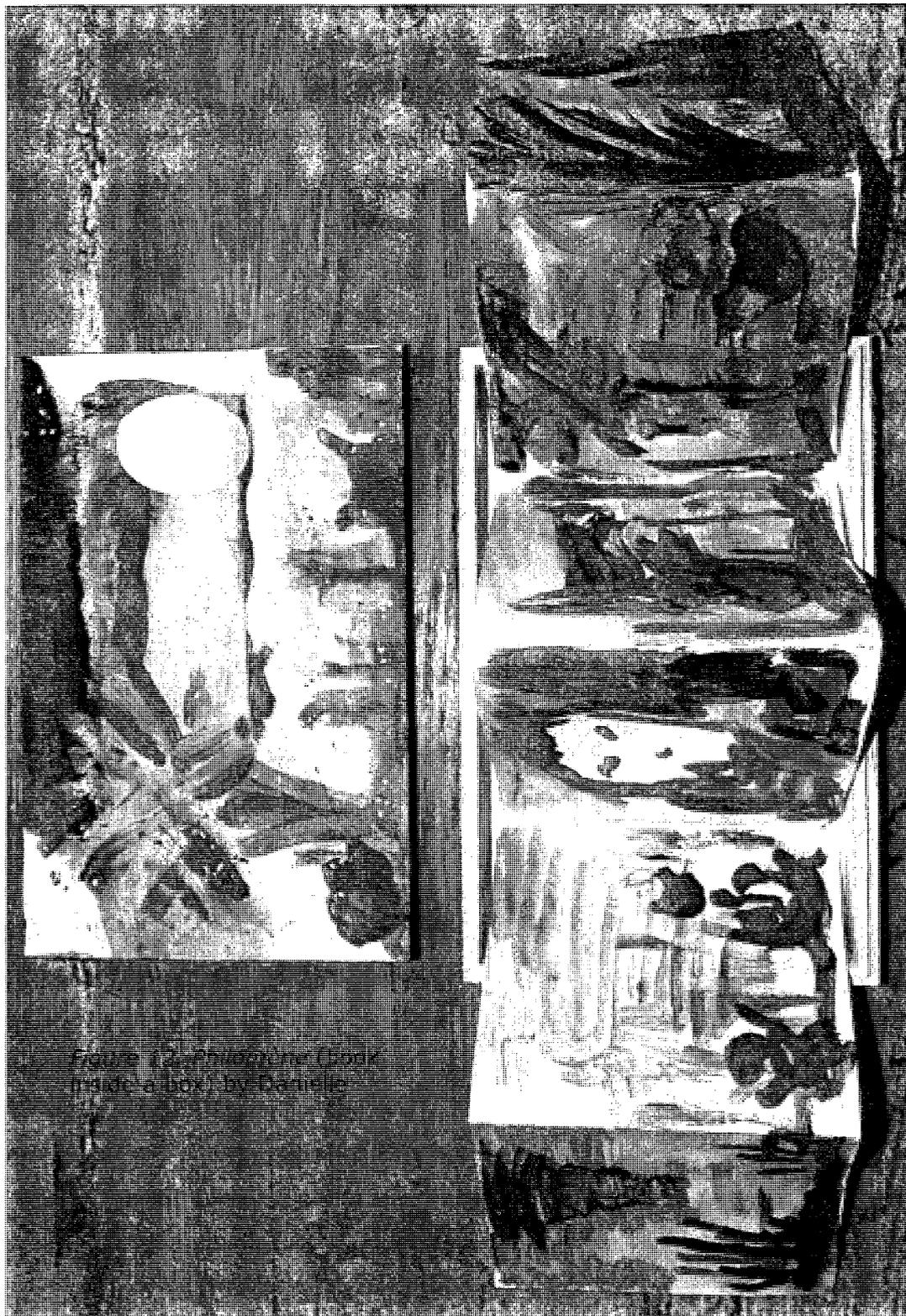
"...nice small thing, a small souvenir to bring home because I did this and it's all the time good when you do new things. You are proud of yourself and you want to have a small souvenir at home. Each time I put my jewelry in there and I show the children I did it, so that was good."

Danielle referred to the box as a gift. Danielle was immediately excited when she came into the art room in our final group session together. She said in interview that "the box was such an idea. The box was a gift of life, you know." She saw the boxes laid out and was enthusiastic to begin working. For the quick feeling check-in drawing before she began to work on her wooden box, she drew a box (Figure 11). She said that life is a gift, full of surprises, but at the same time she is very angry at all the losses in her life. Her losses include the recent death of her companion cat, her brother and the death or loss of neighbours and friends. She was experiencing "unhappy solitude" which was something new. She said that she has been living alone content for a long time and only recently has felt unhappy with being alone.

Danielle connected to the symbol of the box. She spoke of the box as a container, just like houses, drawers, nests, and purses are containers, and that there is a connection between women and containers. She said in interview that "there's something about the container because we contain life. Especially us women, we can have children. We have that inside of us." Danielle created a box and a fold book to be placed inside and she titled it *Philomène* (Figure 12). In group, Danielle said she chose a nature scene for the box because she felt very close to and secure with nature. She talked about the power of objects to bring groundedness and safety during difficult moments in life. She shared a story of when she held a pebble close to her during a very trying time and found it very effective. She also shared why she added a mirror to her box; she said that the mirror is our reflection. When she was



*Figure 11. Untitled. Quick check-in feeling drawing done by Danielle in last session.*



From *Le Livre de la Vie* (book made a box) by Danielle



*Figure 12a. Philomène accordion book by Danielle. (left)*

*Figure 12b. Philomène accordion book detail by Danielle. (above)*

very young and trying to figure out her identity by looking in the mirror, her mother made fun of her. Danielle shared that the mirror is very important as is projection. "Everything we project is about ourselves, be it our anger, or other feelings." Philomène, according to Danielle is her "little girl" who has been with her since she was a child. Danielle spoke about how Philomène grew up too fast but that she can keep her young in the box. Having a child and identifying with her inner child was a prominent story line for Danielle. She spoke a great deal about the beauty and struggles of raising a child as a single mother. She said in interview that:

"You know when you have a child you start to work, you start to paint and then your child needs you and your husband and your house and then you are at work. You have to [reconcile] everything, it's difficult. But it's life and that's what gives you... When you have a child like that it gives you ideas too. It's life and the child is teaching you how to live."

Using the structure of the box form gave Danielle the opportunity to discover what was precious to her. For Danielle, the child represents all that is spontaneous and precious in life. She wrote that her grown-up self would never draw in the way that Philomène allows her to. She said in interview that "my adult, my adult part would never draw like that. It's not right, it's not beautiful, it's not exact." She also said, "you know how kids draw. They draw fast and they don't think about what the other people are going to think about it. They just do it." The box allowed Danielle to keep connected to her inner child and keep her spontaneity sacred.

### *The Directive Approach*

The structure of the session layout and the directives themselves appeared to provide a guiding force that allowed for a great deal of safety to explore emotions, difficult thoughts, strengths and vulnerabilities, and appeared to provide the space to become more self-aware. Danielle and Léa both offered feedback on the quick check-in feeling drawings that became a beginning ritual for all sessions. Danielle said

these initial quick drawings were an “opening” that allowed for expression. She said the following in interview:

“You know this first exercise we do...this one here [the warm-up/check-in quick feeling drawings], this is like the TMC [Technique de mobilisation de créativité or Creativity mobilization technique by Wolfgang Luthe] because there is something when you do the TMC, it’s the way you do it, it’s very... and after that you express so much. It’s a no-thought mess painting but I have some like that, I have a whole bunch of them that, whoosh!, something comes up but the exercise you were giving us at first, it’s very, it’s an opening.”

Léa expressed that when I, as facilitator, joined the group in drawing the quick feelings, it brought us all together as a group of women and it wasn’t just an activity for those with cancer. Léa said in interview “I appreciate your approach and I appreciate you draw a feeling now *avec nous* [with us] because it’s not just I am sick [but it’s] just a feeling now for you and us.... It’s just a human action and I appreciated it.” While I was directive in my approach, I was also client-centered and therefore followed the needs of the participants. To make the group an inviting and comfortable experience, I drew with the participants to help put them at ease and to encourage trust-building through a therapeutic alliance. This also seemed to directly reflect my emphasis on working together with the participants on the research as collaborators.

Both Léa and Danielle found the visualizations that guided the group into the directive of the session very helpful in focusing the images and ideas they have in their minds. Léa said in interview that “the visualization is very good. For me, I have many images, many pictures in my head because when I understand the visualization, it’s easy after to fix it in the paper.” Danielle said in interview that “I like that part when we visualize and then you open your eyes and then you have an idea which you don’t have if you don’t close your eyes, you know. Because your mind goes everywhere, everywhere.” Léa also found that she preferred that I come up with the themes for the group. She said in interview that “I appreciate when you

drive the theme because it's most difficult when I choice [choose] the theme because I prefer you [choose] the theme and then I explore." Rachel found that making books with a directive was a lot easier than when she did a free painting. She said in interview when referring to the past, present, and future triptych that "I started with something, so that gave me a push..." It appears that the structure and facilitation of the sessions, and the structure and containment of the book and the box, permitted all three participants to safely explore and find meaning as they cope and live with a recent diagnosis of cancer.

### *Realizing Capabilities*

During group discussions and conversations and in the interviews, the impacts of a recent diagnosis on the daily lives and the psychological well-being of each participant were pronounced. Losing one's hair, along with a changing body, exhaustion, pain, mixed feelings toward the support of loved ones, having increased fears of the unknown, and feeling alone and isolated were just some of a long list of psychosocial impacts. Among the stories of psychosocial impacts were narratives of how they were coping with this new illness and how they were living and moving forward while having cancer. Codes that reflected capabilities included ability to create, participation despite maladies, taking part, stimulating, moving forward, sharing, new ways of working, and realization. Danielle shared in interview that "art saved my life. I can say that to you because it's always there, you know. You can always take a pencil..." Despite the loss of her companion cat, Danielle realized that she still has her inner girl. "I speak with Philomène, you know... I'm in touch with my little girl all the time, although I am in my 70s." During the member check, Danielle expressed that art therapy allowed her to be spontaneous again and "to work on the unknown".

Despite all of her current pain, Danielle still sees building an art space of her own in her apartment as a future goal. She also shared in member check that she is making art at home despite her current limitations. She spoke of drawing portraits for loved ones. In the post-study interview, Danielle showed me an intricate pastel drawing she made of her cat after the group ended. She had also taken on a painting for her hairdresser friend.

Léa expressed that despite having many friends and family around her, she still felt alone with her diagnosis. While Léa felt alone, she still booked her social calendar with outings with friends to help her cope with chemotherapy treatments. She said in interview that she would be having eight chemotherapy treatments in total, and the third one is that week. "All the time is Thursday. I take appointments with my friends just before I go." Léa appeared to be trying to lessen her isolation by involving her friends into her cancer treatment schedule. Léa also expressed that if she is not feeling well, she is aware that coming to group allows her to feel better afterwards. All participants who made it to the group for one or more sessions braved feelings of exhaustion and pain to come to group and be with other women with a similar diagnosis.

## DISCUSSION

This study sought to examine how three women with a recent cancer diagnosis used the artist's fold book in an art therapy group. Particular attention was paid to the therapeutic aspects of art-making in general, and to the use of a directive approach to the artist's fold book in particular. Qualitative data analysis of narrative-based interviews that followed the group uncovered four major themes. The themes were *Breaking Down the Isolation*, *Emotional Awakenings*, *Structure and Freedom to Explore*, and *Realizing Capabilities*. The themes revealed that an arts-based

supportive group can provide a safe place for women to connect, share, and assist each other, and can reduce the isolation that can be brought on by a cancer diagnosis and subsequent treatments. Other themes revolved around enhanced self-awareness of strengths, finding sources of protection, and adjusting to living with cancer. Art-making using the fold book and the box, in conjunction with a directive-based approach to art therapy, provided the guidance and safety for participants to explore the psychosocial impacts of their recent cancer diagnosis, and to find meaning in their current life through the use of tangible art materials and finished art works.

In Collie & Long's (2005) article on evaluating meaning and meaning-making for women with breast cancer, they found that clinicians should offer women the opportunity to develop their own approach to meaning-making, by providing the necessary circumstances that women with breast cancer themselves have shown to be useful in creating meaning. Collie & Long conclude from their analysis of other qualitative studies that incorporated the voices of women living with breast cancer that the following circumstances have allowed women with breast cancer to derive meaning: the space for reflection, the space for expression especially in front of a witness, the space to talk or express difficult emotions, the space to identify strengths and purpose, as well as the opportunity to assist other women in dealing with a breast cancer diagnosis. Collie & Long's list of meaning-making conditions is similar to how the book-making group was facilitated, by the supportive and safe group space and through the art-making. I found that the structured directive approach combined with the containing book form as used by a group of three women allowed for meaning-making and resonated with the circumstances that Collie & Long speak of.

Collie et al. (2006) found, in their narrative analysis of 17 women with breast cancer who used art or art therapy, that art-making allowed these women to identify and process emotions, including difficult ones, and “affirmed their existence as strong psyches within threatened bodies and to counteract the potential annihilation of their former selves (p. 770).” The permanence of fold books, especially in conjunction with the box, appeared to all three participants to be a way of self-preservation. Words like precious, treasure, and gift were associated with the box. Danielle used the box to contain a fold book of her inner child who allows her to remain spontaneous and free, despite her limited abilities as the result of cancer treatments and aging. Léa used the box to contain a turtle she made, which for her is a powerful symbol of strength and longevity. Léa didn’t finish the fold book that was to be stored in her box but she had shared that the book was to contain inspirational proverbs and photos of loved ones to give her strength. Rachel was proud of her box which she shared with her children and grandchildren. She placed her jewelry in the box and called it a souvenir of the group which she would never forget. Farrell-Kirk (2001) writes that the box can be used in art therapy to highlight the importance of objects placed inside because of the symbolic significance of the box (coffin, treasure chest, secret space). The author goes on to write that the box allows for the coexistence of opposites; a small simple box can be large enough to hold complex issues.

This coexistence of opposites can also apply to the accordion book, with its ability to have different meanings when opened or closed, or choosing where the fold should go, or not to fold at all. Danielle found that it was much easier to work page by page rather than using one large sheet of paper. At the end she enjoyed the ability to present the work on the wall vertically or horizontally, or to close the book and have the viewer open the book like a codex page by page to be explored from

the table top. Danielle also experimented with drawing on both sides of her *Finding Feelings* book, so that the book became fluid with no end and no beginning. Léa found that sometimes she needed her paper to remain open like a scroll. Other times she folded different portions of a book to convey different feelings. When she drew her body she added extra folds or pages for her legs because she had been feeling the urge to fall. Léa also experimented with different kinds of papers and found that vellum was a good medium to explore the body because of its transparency, especially when it was hung in front of a window pane. Having a wide variety of materials, textures, and dimensions goes a long way in allowing for an array of personal exploration for each participant.

Having structured interventions in conjunction with a wide variety of materials encourages self-exploration. Luzzatto & Gabriel (2000) outline a short-term, ten-week group art therapy program for cancer patients that is directive-based and focuses on trust-building and repairing self-identity. Each session has a pre-planned workshop and begins with a visualization to relax the mind and build trust in the group; following the art-making, there is a voluntary discussion in which patients view their art from a distance. Luzzatto & Gabriel have found that this short-term program enhances self-confidence and improves self-identity for people who have cancer who have started at least one course of treatment. In the current study, all three participants found the directive approach and structure of the session to be extremely helpful in allowing them to explore with ease. One aspect of Luzzatto & Gabriel's program that was not congruent with the experience of the book-making group was that they stressed that the ten-week program was not intended for patients to share cancer stories or advice and was not a support group. For the three women I worked with, the group was not only a supportive space to make art and access the creative parts of themselves, but also a place to exchange stories and a

place to offer advice and consolation. The group often began with how everyone was feeling that week, and support was given to women who needed it. Collie & Long (2005) write that one way to encourage meaning-making for women with breast cancer is to offer the opportunity to assist other women with a breast cancer diagnosis. The book-making group provided a safe space that allowed the women to help each other. Most of the assistance given was in the form of advice or consolation or the sharing of stories. Two participants began a friendship outside of group that involved calling each other and going out together and offering support. At least two of the participants only attend art-based groups. If that is the case, then having an art-based support group may go a long way in reaching out to women who wouldn't feel comfortable in a talk-based support group. Collie et al. (2006) found that support groups that utilize art interventions may be more accessible than strictly verbal ones because they feel less like therapy. Malchiodi (1999) writes that visual expression can convey the difficulties (loss, pain, confusion) surrounding illness that may not be easy to convey with words. Danielle also shares this same thought. In interview she said that "sometimes you express things that you cannot put words on it, but there's a feeling of the moment". Danielle also said when referring to drawing that showed her anger and how she finds it violent, "sometimes you don't draw what you would like".

One of the storylines that came through in all three interviews was how the group reduced feelings of isolation that can come from a cancer diagnosis. All three felt like a burden on their family, despite having the support of their families. The group provided the space to make connections and share their diagnosis and treatment with each other. While two of the participants asked for paper to take home to work on books on their own during the five weeks we worked together, neither one made art at home. Art-making became a possibility in the group setting.

Danielle, who had been making art for over forty years, has had difficulty making art in her home lately but is able to create with a great deal of spontaneity in both the book-making group and in an open studio class she attends weekly.

Collie & Long (2005) write that another way to encourage meaning-making for women with breast cancer is to offer a place to identify strengths. Two of the directives, identifying strengths through the use of metaphorical self-portraits and finding sources of protection through identifying with a talisman or amulet, allowed for all three participants to realize their capabilities and coping strategies. In the talisman directive, the use of the book in conjunction with the box allowed for all three participants to see their strengths. Léa and Danielle, who worked with an animal that they connected with, both created environments that nourished their animal. Both identified with the strengths of their animals. Léa found that her butterfly was strong because it could survive through many transformations from pupae to butterfly. Danielle chose the cat because it related to her bond with her companion cat who had recently died. In selecting the cat as her animal, she also made a connection to her son, because they are both lovers of cats and her son is a source of support for her. Creating art objects reinforces the meanings that the participants build for themselves because they are tangible objects that they can take home with them and refer to at a later time, which can reinforce the group support and their accomplishments as artists. It can become a souvenir, as Rachel said. Collie et al. (2005) write that the term meaning-making is made literal when they noted how the women they interviewed actually created meaning by making.

Another way to build meaning-making is for women to identify and process emotions, especially difficult ones, according to Collie & Long (2005). One directive in particular focused on finding sources of pain and discomfort in the body and then identifying emotions that were connected with the physical sensations. All three

participants were present for this intervention, and all three were able to express some of the difficult feelings they were trying to process. For Danielle, the difficult emotion was her anger at not being as physically able as she used to be, and anger for all of her recent losses of people close to her, which resulted in what she called “unhappy solitude”. For Léa, her cancer diagnosis was difficult to come to terms with because she had felt fine and was shocked to find that she had cancer, and now that she was doing chemo she felt extremely tired, scattered, and anxious, and these emotions and sensations caused her to feel a duality of being both too light and too heavy. She described her head as being in the clouds, her shoulders as simultaneously too heavy and too light and her legs as feeling like they would collapse. For Rachel, who was in a great deal of pain throughout her body as the result of chemo, the emotion of frustration and having had enough predominated. She also found that she was impatient. Collie & Long write that emotional distress in terms of the dominant medical discourses can be seen as pathological but in their analysis of women with breast cancer, the ability to express and share negative emotions is a healthy way to create meaning. Art-based support groups can facilitate the expression of emotions, especially difficult ones, which could be empowering for a woman who is not being supported by her doctors and surgeons or her caretakers and loved ones.

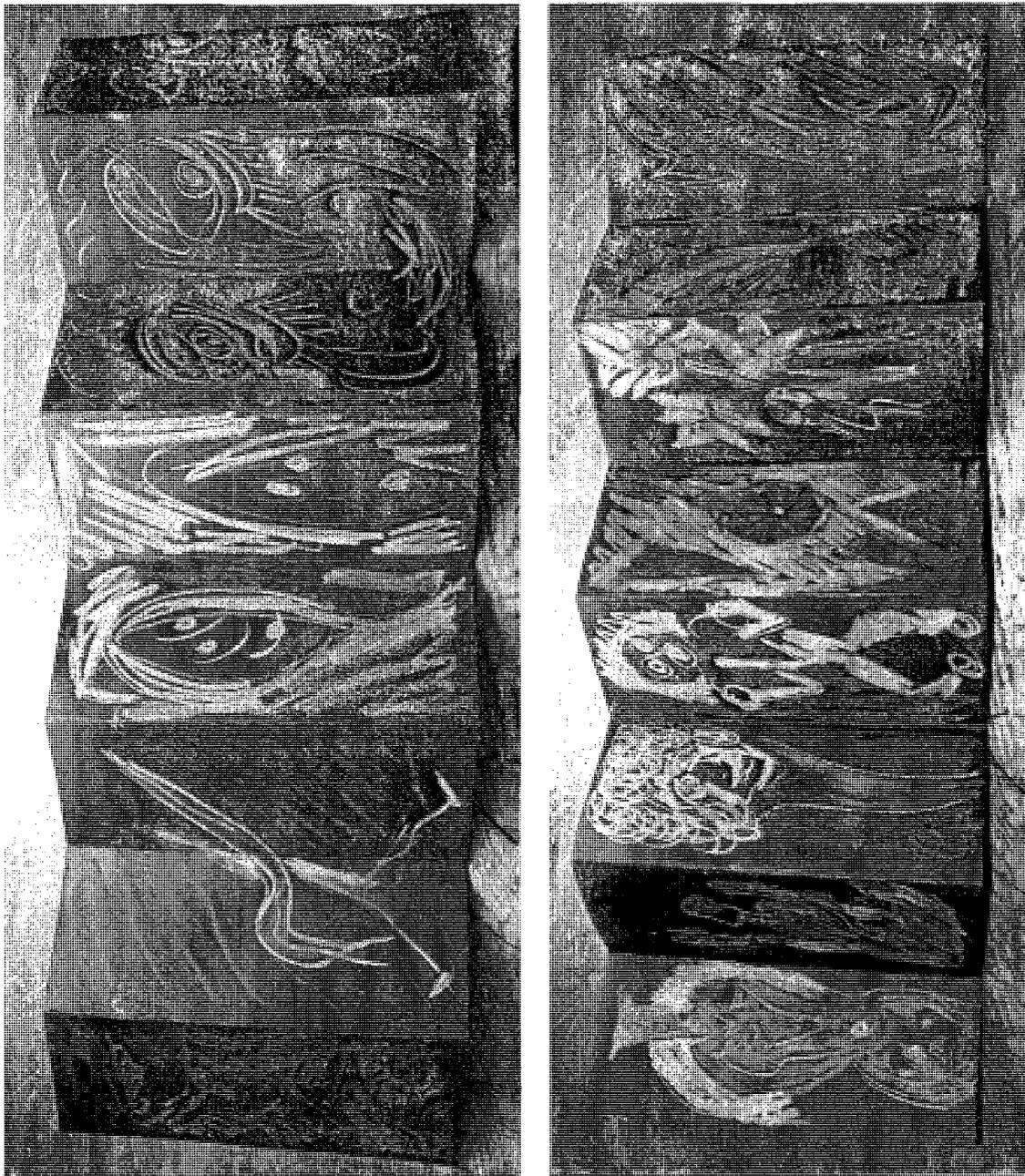
One of the benefits of incorporating the voices of research participants is that it has challenged some of the assumptions I had before and during the research process. One of these assumptions was my thought that participants in a great deal of discomfort, who were unable to participate in the art-making or discussion at all or in part, didn't derive as much benefit as participants who were more physically and emotionally engaged in art-making and talking with other participants. Rachel, who didn't participate in as many sessions, and who sometimes needed my assistance

making books and the box, was surprised at how much she had accomplished in session when she referred to all of her artworks. She said in interview that “it was a very nice experience and I never thought I would do all this...I will finish all my treatments and I’m going to start again.” She spoke in the interview of getting back into art-making after she recovers from her upcoming radiation treatments. Her interview, as well as the other two interviews, provided me with a lot of important feedback about some of the assumptions I had.

I perceived that Rachel didn’t get much out of the group because of her visible pain and discomfort and inability to participate fully in any one exercise. I was struck during the interview at what she did get out of it, even when it appeared that she couldn’t participate much and was in such visible pain and discomfort I couldn’t imagine that she could get much out the group. Hall (2003), a book artist who had breast cancer, created a book of stories that revolved around a group of women she knew who all had breast cancer. One of the stories was called *Cathy* about a woman who was so ravaged by breast cancer that she was skeletal, couldn’t speak and was wheelchair bound. This woman attended an arts-based workshop for women with cancer and her only interaction with the group was to signal with her head that she needed more morphine. What Hall’s story and Rachel’s lack of engagement shows is that as therapists we cannot make assumptions on what we think a participant or client has benefited from in a supportive group setting, we can only ask the women we work with to tell us or share with us their stories of how they do or don’t benefit. Another element that came through in the interviews that wasn’t as apparent in the group itself was how all three participants were extremely appreciative of the experience to be with each other and to make art with each other, and of my presence and my way of working with them.

By focusing exclusively on one technique for this research, namely the fold book, the group was able to discover and explore the unique benefits of this technique in greater depth. Two participants found that working in segments, or in one small section at a time, was more manageable than using a plain sheet of paper or canvas. Perhaps the familiar book form is in itself less intimidating than using more traditional fine art materials. It may feel less like “art” than other kinds of media – clay, pre-cut fine arts papers, and canvas. The fold book’s ability to open and close may also offer benefits. When the fold book is closed, it is very much like a traditional codex book. One kind of codex that may be pertinent to women is the diary which holds private thoughts. The book form has the ability to close and to contain private thoughts. The fold book in particular can expand to reveal all thoughts, or it can close to contain them. The fold book may be a place to safely explore very intimate thoughts. While the fold book has the ability to be small and intimate, it also has the ability to expand vertically or horizontally; it can become quite large to accommodate a range of explorations, and then reduce (by rolling the scroll or folding pages back onto themselves). The fold book also has the ability to present two different ideas at once when both sides of the paper are used; for example, in her *Feeling the Body* book (figure 13), Danielle was able to use one side to identify her changing body and the other side to explore her associated emotions. When used in this way, the fold book no longer has a clearly defined beginning and end— another way in which it differs from the traditional codex book.

Like other book forms, the fold book naturally allows for a sequenced structure in which words and/or images are presented in a specific order. The fold book is unique in that it can be opened completely to reveal all its pages at once. It can hold a series of images or thoughts on one or multiple planes. Danielle explored both of these aspects in her *Choose an Animal* book, which she drew one page at a



*Figure 13. Untitled. Feeling the Body, Finding Feelings done by Danielle.*



Figure 13a. Untitled. Feeling the Body, Finding Feelings detail done by Danielle.

time and whose structure she only truly “discovered” when she opened the book completely at the end.

Another aspect of the book form that is different from other art forms is its ability to be touched. While many fine art works are meant to be viewed only, the book can be held and explored on a very intimate level— as when Danielle specifically chose to present her *Feeling the Body* book on the table, where it could be opened, closed, and handled, rather than hanging it on the wall. The artist’s fold book can also be easily reproduced and shared among many people at one time. It therefore has far-reaching potential in terms of exhibition and mass mailings.

One other interesting point that arose in this research was the recurrence of certain types of symbolic imagery in the participants’ artwork. In her discussion of art therapy’s usefulness in exploring both the hurting and healing aspects of living with cancer, Minar (1999) identifies symbolic imagery that may indicate more of the hurt and more of the healing (although she notes that sometimes a symbol can both represent the hurter and the healer). Minar identifies the following kinds of images that may represent the hurter (cancer itself, grief, life changes): “dark clouds, volcanos, shifting sand, barriers, jagged rocks, explosions, weeds, whirlwinds, whirlpools, chains, seaweed, burning candles, sunsets, serpents, and forests (p. 229). Minar also identifies symbolic imagery that may represent aspects of healing the hurter or identifying personal strengths. These images include images of the self as represented by animals and trees and could also include metaphorical images of God, loved ones, other supports, light, water, growth, and mystical characters. Minar writes that “many cancer patients show God as light; sometimes as the sun, sometimes as a distant glow, and sometimes just by the strong use of the colors yellow or gold (p. 231).”

Some of the symbols noted by Minar (1999) came up in the artwork of all three participants. I note the sunset landscape that Rachel made spontaneously during the one session in which she was the sole participant, and in a great deal of pain and discomfort— not only because of her cancer treatments, but because she was the only member to be present, and she had hoped to be able to converse with the other participants. This sunset could reflect the hurt that Rachel may have been experiencing which was also directly noted in the body drawing she also drew that session. Danielle and Léa both used yellows and golds in their artwork, which could be representative of both the painful aspects of their cancer experience as well as the strengths they had to cope with the cancer. Léa used yellow to show herself crying at how alone she felt with her diagnosis in the past, present, and future triptych. She also used yellow to represent her contentedness in the faux stones that adorned her box and her positive outlook as represented in her *Feeling the body* book in which one of her eyes is seen in part as a glowing sun. These seemingly contradictory uses of the same colour could be an example of the same symbol representing both hurter and healer, as noted by Minar. Danielle was excited to use gold paint when she created her Philomene book box. For Danielle, the gold was a special color to adorn her inner girl. Danielle and Lea also spoke to the power of blue in their artwork. Danielle spoke of “wonderful blue” quite a bit, and the color blue can be seen in almost all of her books. Lea often incorporated blue with yellow as seen in her *Feeling the body* book, the Ami box with turtle, and the past, present, and future triptych. While the symbols present in the artwork weren’t extensively explored in session, this could be an interesting issue to explore in future research with longer-term groups.

## RECOMMENDATIONS FOR FUTURE RESEARCH

This study is small and limited and should be considered more of a pilot study for further research with larger samples. More research is needed to understand how women with breast cancer at different stages of the disease phase use art-making to create meaning when their lives and emotional wellbeing become disrupted with a illness diagnosis. Different approaches to art-therapy-based group research would be recommended. Different approaches could include art-as-therapy groups as well as open studio groups. A range of interventions and non-directive based art therapy groups could be explored and contrasted with art-as-therapy groups. Interviewing women with breast cancer who make art on their own would also be an interesting area to explore. Using an exhibition as the starting point of research to explore the benefit of women sharing with other women in the public's view might be interesting. There is a strong need to add authentic real-life voices into research studies that revolve around meaning-making. Narrative, feminist and social action research inquiries would be recommended so as to include the voices of the women involved in the research process.

Further research into creating exhibits of client artwork, to allow clients to share with others and to have a purpose, may go a long way towards building meaning for these clients. Such research could also challenge some of the dominant discourse that can be disempowering to women who don't fit the mold of what is the ideal woman with breast cancer. Collie & Long (2005) write that representations of women with cancer in the media often revolve around young women who are sexualized and maternal, and don't take into consideration that the majority of women with a breast cancer diagnosis are past menopause and don't consider the loss of their breasts as the largest impact on their personal identity. Books may be an art form that could link the personal with the public because they are a familiar

medium for most people, and may be a more comfortable way for some women to access their creative side and their voices; another advantage is that books can be reproduced and easily exhibited.

The book is a kind of art form that compels the viewer to engage with it through physical handling. Hall (2003) writes that "people may not want to 'touch' the topics I explore in my books; yet the books invite handling, touching, interaction (p. 14)." The fold book, alone or in conjunction with the box form, appears to be a medium that can assist with meaning-making for women with breast cancer, especially when used with an art therapy approach that is client-centered and directive-based. The three participants in this study used the book form to process difficult emotions; identify sources of strength and protection; identify their fears of what lies ahead when you have a cancer diagnosis, including thoughts on death and of the unknown; and create objects of expression that they can share with others and refer back to for their own needs. Further research is needed on the use of the symbolic and containing book, in conjunction with the box, as a medium for women with breast cancer. It may be interesting to research how the box form could be used to contain all the books made in session.

Another avenue of exploration would be the incorporation of natural materials such as tree branches, bark, wool, sand, clay, and leaves into the book art-making, considering the predominance in this pilot study of imagery from the natural world. Gaylord's (2005) *Spirit Books*, which incorporate the use of vines, roots and twigs in the artist's book form, may be a good reference as to what is possible here. Nature was a place of solace for two of the participants in my study, and working with non-synthetic materials, especially if they are found by the participants themselves, could be empowering. In warmer weather, incorporating the outdoors by involving short walks to gather art materials, or by creating artwork outside, might be another way

to get closer to nature. In an in-class discussion of the research presented here, a fellow student wondered whether having a weekend book-making intervention might be another way to work with cancer patients, especially if they are interested in exploring the book form in more depth. Retreats or day-long sessions could allow for the creation of handmade papers utilizing natural materials and woven materials, as well as more complicated bindings and theme explorations. Such sessions would also require less of a long-term time commitment than a typical group which extends multiple meetings over many weeks, and this might be easier for women who are undergoing cancer treatments.

Another possible area for further exploration would involve identifying specific types of symbolic imagery that often recur in the artwork of women with breast cancer, which could help art therapists to identify women who are potentially in need of further interventions. Identifying symbols may also aid in assessments with this population. Recently, I took part in a group meeting with practitioners who were involved with art-based services at the wellness centre. Part of the discussion involved the art therapists informing the open studio teachers of themes and topics that may come up in the artwork that were pertinent to cancer patients, as a way to potentially flag participants in the open studio who might be in need of further interventions. I believe firmly that art therapists need to learn from and utilize the voices of clients and research participants into their work and into publication, if they are to work successfully and ethically.

Most importantly, as noted by Collie & Long (2005), allowing women with breast cancer to identify their own sources of meaning-making without any constraint is paramount to their well-being. I hope to have shown that the artist's book, with its many dualities and expressive possibilities, can be a powerful and flexible tool for these women in their quest for meaning.

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APPENDIX A  
Interview Questions

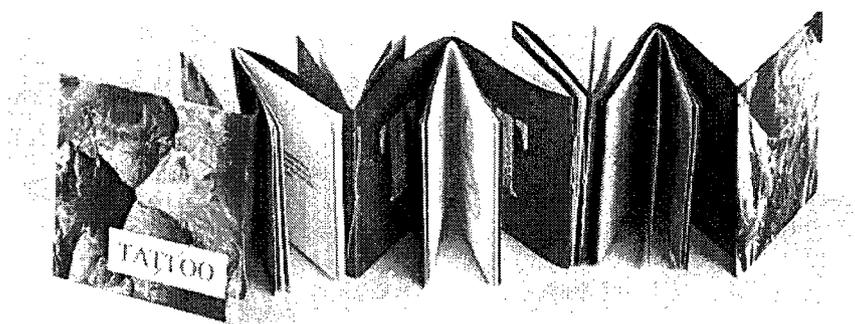
The interview questions are to be used to encourage participants to tell their story of art-making in the book-making group, in their own words, and to understand which themes or books meant the most to each of the participants. Tentative questions:

1. Please share with me your experience of making books in the group. What was it like?
2. What books or themes spoke to you most?
3. Was there a particular book that you found special or more meaningful? If so, can you tell me more about it?
4. Did book making assist you as you journey through your cancer diagnosis and treatment? If so, please elaborate.
5. How did you find working with the book form and also using the box?
6. Is there anything else you would like to share?
7. Do you have suggestions for future book art-based support groups for women with breast cancer?

## APPENDIX B

**An Artist's Book by Women Recently Diagnosed with Breast Cancer**

Inviting women with a recent diagnosis of first-time breast cancer to join a supportive arts-based book-making group to begin September 15<sup>th</sup>. The group will meet every Monday from 10.00 to 12.00 for 5 weeks in the art room of the wellness centre. Each week will revolve around a theme that is important to the group. No art or book-making experience is necessary and all materials will be provided.



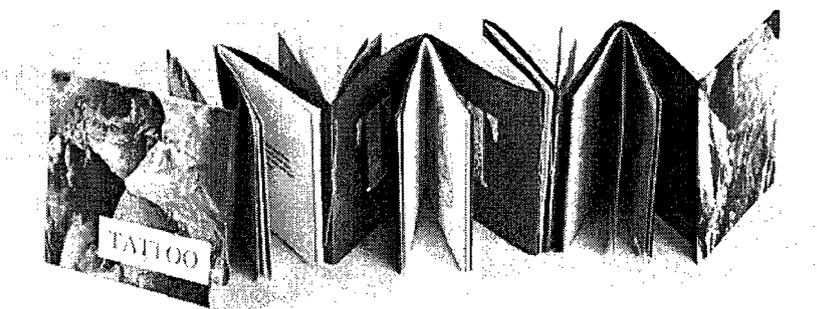
*Tattoo* by Martha Hall

This project is part of Kate Laux's research for her Master's degree in Art Therapy at Concordia University, exploring how book art-making benefits women with breast cancer. Please contact the centre for more information and to sign up for this unique opportunity.

## APPENDIX C

Un Livre-accordéon par et pour les femmes chez qui on vient de diagnostiquer  
le cancer du sein

Nous faisons appel aux femmes chez qui on vient de diagnostiquer pour la première fois le cancer du sein, afin de constituer un groupe qui débutera ses activités le 15 septembre. Ce groupe aura pour objectif de réaliser un livre-accordéon portant sur l'art. Il se réunira tous les lundis de 10h à midi, pendant 5 semaines dans la salle consacrée aux arts, au centre. A chaque séance, le groupe traitera d'un thème particulier qui aura été choisi pour son importance et sa pertinence. Aucune expérience préalable en art ou en rédaction de livre n'est nécessaire et tout le matériel est fourni.



*Tattoo by Martha Hall*

Ce projet fait partie de la recherche de Kate Laux dans le cadre de sa maîtrise en thérapie par l'art à l'Université Concordia. Son objectif est de juger dans quelle mesure une telle activité est profitable aux femmes atteintes de cancer du sein. Veuillez contacter au centre pour plus de renseignements et pour vous inscrire à cette activité unique en son genre.

## APPENDIX D

## RESEARCH PARTICIPANT CONSENT INFORMATION FORM

## Exploring the Artist's Book with Women Recently Diagnosed with Breast Cancer

## Introduction:

You are invited to take part in a research project. This research and subsequent paper is in partial completion of Katherine Laux's Master's degree in the Creative Arts Therapies Program at Concordia University. You have the right to know about the purpose and procedures that are to be used in this research study, and to be informed about the potential benefits and risks of this research.

Before you give your consent to be a participant, it is important that you read the following information and ask as many questions as is necessary in order to understand what you will be asked to do, should you decide to participate. It is also important that you understand that you do not have to take part in this study.

## Purpose of study:

Women with breast cancer who have been recently diagnosed face a range of feelings, a changing body image, and lifestyle changes. Literature has shown that visual artistic expression within a group setting can provide an alternative safe outlet for expressing emotions and gaining insight. The literature speaks of the disruption in life for women recently diagnosed, but there appears to be a lack of real-life testimonies of how women can benefit from therapeutic art-making, especially in the domain of artist's books. This project hopes to add to the body of art therapy literature which explores the use of the artist's book as an expressive and insightful medium for women living with breast cancer.

## Procedures:

I am interested in running a closed group for eight women with breast cancer who are presently in treatment or who have recently had surgery. The group will run for 4 to 5 weeks and will revolve around exploring the expressive capabilities of the artist's book, specifically the Japanese-influenced fold book, which is easy to construct and ever-expandable yet containing. This group will be held in the art room at the centre. Each week will revolve around a theme that pertains to the experience of women living with breast cancer. This group will begin in August or September 2008. Following the end of the group, one-on-one one hour interviews will be conducted in a private location at the centre. If permission is granted, the interviews will be recorded. Interviews will take place within two months following the end of the book-making group.

The information obtained through the creation of artist's books will be added to other information I've gathered for this research project. With your permission, I would like to take photographs of your artwork and include brief descriptions (case notes) of your participation in the book-making group. All artwork you create belongs to you.

**Risks:**

No harm should come to you for participating in this study. However, art and the creative process can be at times quite revealing and may bring up difficult emotions and experiences for participants. In the event that difficult material comes up as a result of any of the book-making sessions, a psychosocial worker will be available. All personal information will be kept private and secure in a locked cabinet; no details through which you could be identified will be used in the paper, presentations, or in publication. A copy of this study will be bound and kept in the Concordia Library as well as in the Creative Arts Therapies Resource Room. You may consent to all or just part of the requests on the accompanying consent form. You may withdraw your consent at any time before the research paper is completed without any explanation. If you have any questions or concerns, you may contact me or my research advisor or the onsite investigator at the phone numbers listed below.

**Benefits:**

You may gain great insight into your cancer journey as you take part in an art-based support group. Literature has shown that group art therapy provides a safe haven to explore difficult emotions and to share experiences with women who have a similar background (Predeger, 1996). Art-making can also provide women with a more comfortable way to communicate the difficulties surrounding a recent cancer diagnosis than words can do alone (Collie et al., 2006).

**Voluntary participation/withdrawal:**

Your participation in this study is voluntary. You may choose to participate now and decide to stop your participation at any time before the research paper is completed without explanation.

**Confidentiality:**

All information obtained about you during this research will be treated confidentially within the limits of the law. The information gathered in photographs, case notes, and interviews will be used primarily for my research paper. Subsequent to completion of my studies, the data may be used for future presentations and publications. No details through which you could be identified will be used in the paper, presentations, or in publication. All personal information will be coded, and kept under lock and key. Decoding can only be performed by Katherine Laux. Case notes will be kept private and secure in a locked cabinet. Digital photographs of your artwork and digital audio recordings of the final interview will be kept on a password protected computer used solely by Katherine Laux. Digital photographs and audio recordings may at some point be burned to disk and stored with the case notes in a locked cabinet. All research material will be kept for seven years after completion of the study and will then be destroyed.

**Costs and compensation:**

There will be no costs or compensation to you for participating in this study. The art materials and research procedures will be provided to you free of charge.

**Contact information or questions:**

If you have any questions or concerns about the research now or later, you should call Katherine Laux at xx. If you have questions about your rights as a research participant, you may call the hospital patient representative xx at xx or Adela Reid, Research Ethics and Compliance Officer, Concordia University, at (514) 848-2424 ext. 7481 or by email at [areid@alcor.concordia.ca](mailto:areid@alcor.concordia.ca).

## RESEARCH PARTICIPANT CONSENT FORM

## Exploring the Artist's Book with Women Recently Diagnosed with Breast Cancer

I have read the information above and the contents of this form, and my questions were answered to my satisfaction. A copy of this signed consent form will be given to me. I may consent to all or just part of the requests on this consent form. I may withdraw my consent at any time before the research paper is completed without any explanation. I understand that if I have any further questions or concerns, I may contact Katherine Laux, or her research advisor or onsite investigator, at the phone numbers listed below. I freely consent and voluntarily agree to participate in this study.

I authorize Katherine Laux to use photographs, case notes, and audio recorded interviews as part of her research project (please circle one and initial). All artwork I create belongs to me.

case notes (written notes of each session) INITIALS	YES	NO
photographs of the artwork I create INITIALS	YES	NO
audio-recorded interviews INITIALS	YES	NO

The information gathered in photographs, case notes, and interviews will be used primarily for the researcher's Research Paper. Subsequent to completion of her studies, the data may be used for future presentations and publications. All personal information will be kept private and secure in a locked cabinet; no details through which I could be identified will be used in the paper, presentations, or in publication. The information will be kept for seven years after completion of the study and will then be destroyed.

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Name of Participant: \_\_\_\_\_

Consent form administered and explained in person by:

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Name of Site Investigator (or its delegate)

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Katherine Laux Concordia University Art Therapy Student and Intern  
Master's in Creative Arts Therapies Program

Suzanne Lister, PhD, ATR, OATR, CACPT (514.848.2424 ext. 4799)  
Research Advisor and Assistant Professor  
Department of Creative Arts Therapies, Concordia University

xx  
Site Investigator and Research Coordinator

## APPENDIX E

## FORMULAIRE D' INFORMATION POUR CONSENTEMENT A UNE RECHERCHE

Un livre d'artiste par et pour les femmes chez qui on vient de diagnostiquer le cancer du sein

## Introduction:

Vous êtes invitée à participer à un projet de recherche. Cette recherche et le mémoire qui en résultera font partie du diplôme de maîtrise que Katherine Laux prépare à l'Université Concordia, dans le programme des Thérapies par les arts créatifs. Vous avez le droit de connaître l'objectif et les procédures de cette étude, ainsi que les avantages et les risques qui pourraient en découler.

Avant de donner votre consentement pour y participer, il est important de lire l'information suivante et de poser toutes les questions nécessaires, afin de bien comprendre ce qu'on vous demandera de faire, au cas où vous accepteriez. Il est également important de comprendre que vous n'êtes nullement obligée de participer à cette étude.

## Objectif de l'étude:

Les femmes chez qui on vient de diagnostiquer un cancer du sein éprouvent toute une gamme de sentiments et font face à des changements dans leur corps et dans leur mode de vie. La littérature médicale a démontré que l'expression par les arts visuels dans le cadre d'un groupe peut fournir un exutoire alternatif très sain pour exprimer les émotions et pour acquérir plus de pénétration. On parle longuement du désordre qu'apporte le diagnostic dans la vie des femmes; par contre, on a peu de témoignages vécus sur la manière dont ces patientes peuvent profiter d'une thérapie par l'art, surtout en ce qui a trait à la création d'un livre d'artiste. Nous espérons que ce projet ajoutera un plus au corpus de la littérature sur l'art- thérapie qui explore l'utilisation du livre d'artiste comme moyen d'expression et de connaissance de soi pour les femmes vivant avec un cancer du sein.

## Procédures:

Il s'agit pour moi de constituer un groupe limité à huit femmes atteintes de cancer du sein, qui sont en ce moment en traitement ou qui viennent d'être opérées. Ce groupe se réunira pendant 4 à 5 semaines et traitera des possibilités de s'exprimer dans le livre d'artiste, en particulier dans le livre-accordéon d'influence japonaise, facile à construire, expansible à volonté tout en demeurant contenu. Les séances se tiendront dans la salle réservée aux arts au centre. Chaque semaine, on explorera un thème en rapport avec l'expérience de femmes atteintes de cancer du sein. Cette activité débutera en août ou septembre 2008. Au terme de cette activité, une entrevue en tête-à-tête, d'une heure aura lieu dans un centre. Si l'autorisation en est donnée, l'entrevue sera enregistrée. Toutes les entrevues seront faites dans les deux mois qui suivront la fin de l'activité.

Les renseignements obtenus grâce à la création des livres d'artiste seront ajoutés à d'autres renseignements que j'ai recueillis pour effectuer ce projet. Avec votre permission, j'aimerais prendre des photos de votre oeuvre d'art et inclure de brèves descriptions (sous forme de notes) de votre participation à ce groupe de création du livre. Tout ce que vous aurez créé vous appartient.

#### Risques:

Aucune conséquence négative ne résultera de votre participation à cette étude. Cependant il faut noter que l'art et le processus de création peuvent être parfois très révélateurs et faire vivre aux participantes des émotions et des expériences pénibles. Au cas où des événements pénibles résulteraient d'une des séances de travail, une travailleuse psycho-sociale sera disponible. Tous les renseignements personnels seront conservés en toute sécurité dans un casier fermé à clé; aucun détail qui permettrait de vous identifier ne sera utilisé dans le mémoire, dans des exposés ni dans des publications. Une copie de cette étude sera reliée et remise à la bibliothèque de Concordia, ainsi que dans la salle de ressources du département des Thérapies par les arts créatifs. Vous pouvez consentir à toutes les demandes du formulaire de consentement ci-joint ou à une partie seulement. Vous pouvez aussi retirer votre consentement à tout moment, sans aucune explication, avant que le mémoire ne soit achevé. Si vous avez des questions ou des inquiétudes, vous pouvez me rejoindre ou contacter mon directeur de thèse ou la responsable sur place, aux numéros de téléphone mentionnés à la fin de ce document .

#### Avantages:

Grâce à votre participation à ce groupe de soutien axé sur l'art, vous pourrez approfondir votre connaissance de vous-même tout au long de ce cheminement créé par la maladie. La littérature médicale a démontré qu'un groupe de soutien par l'art-thérapie procure une espèce de refuge sécurisant qui permet d'explorer des émotions pénibles et de les partager avec des femmes ayant vécu des expériences similaires (Predeger, 1996). La création artistique donne aussi aux femmes un moyen privilégié de communiquer les difficultés qu'elles rencontrent lors d'un diagnostic de cancer, moyen plus efficace que les mots seuls (Collie et al., 2006).

#### Participation volontaire/retrait:

Votre participation à cette étude est volontaire. Vous pouvez aujourd'hui décider de participer puis d'arrêter à tout moment, sans aucune explication, avant que le mémoire ne soit achevé.

#### Confidentialité:

Tous les renseignements vous concernant, obtenus au cours de cette recherche seront traités confidentiellement dans le respect de la loi. Les informations recueillies au moyen de photographies, de descriptions de cas et d'entrevues seront utilisées tout d'abord pour mon mémoire. Par la suite, après la fin de cette étude, les données pourront servir pour de futurs exposés et publications. Aucun détail qui permettrait de vous identifier ne sera utilisé dans le mémoire, dans les exposés ni dans les publications. Tous les renseignements personnels seront codés et conservés sous clé. Le décodage ne sera effectué que par Katherine Laux. Les descriptions de cas seront conservées en toute sécurité dans un casier fermé à clé. Des photos numériques de votre oeuvre et l'enregistrement audio-numérique de l'entrevue finale seront conservés sur un ordinateur, avec un mot de passe convenu, accessible seulement à Katherine Laux. Ils pourront plus tard être gravés sur disque et conservés sous clé avec les descriptions de cas. Tout le matériel de recherche sera gardé sept (7) ans après la fin de l'étude puis détruit.

Coûts et dédommagement:

Votre participation à cette étude n'entraînera ni coût ni dédommagement. On vous fournira le matériel nécessaire gratuitement. Il en sera de même pour la procédure de recherche.

Contact pour plus d'information ou pour questions:

Si vous avez des questions ou des préoccupations à propos de la recherche, maintenant ou plus tard, vous pouvez appeler Katherine Laux au xx. Quant aux questions relatives à vos droits en tant que participante à une recherche, vous pouvez les adresser à la représentante des patients, xx, à l'Hôpital xx, au xx, ou à Adela Reid, *Research Ethics and Compliance Officer*, à l'Université Concordia, au 514-848-2424, poste 7481 ou par courriel [areid@alcor.concordia.ca](mailto:areid@alcor.concordia.ca).

Merci de votre participation!

Katherine Laux

**FORMULAIRE DE CONSENTEMENT COMME PARTICIPANTE A UNE RECHERCHE**  
 Un livre d'artiste par et pour les femmes chez qui on vient de diagnostiquer le cancer du sein

J'ai lu les renseignements ci-dessus et le contenu de ce formulaire; on a répondu à mes questions de façon satisfaisante. Une copie de ce formulaire de consentement signé me sera remise. Je peux accepter toutes les clauses du formulaire ou une partie seulement. Je peux retirer mon consentement à tout moment, sans aucune explication, avant que le mémoire ne soit achevé. Je sais que si j'ai des questions ou des préoccupations, je peux contacter Katherine Laux, ou son directeur de thèse ou la responsable sur place, aux numéros de téléphone ci-dessous. Je consens de mon plein gré à participer à cette étude.

J'autorise Katherine Laux à se servir de photos, de descriptions de cas et d'entrevues comme éléments de son projet de recherche. (SVP, encerclez une mention et apposez vos initiales). Toute l'œuvre que je créerai m'appartient en propre.

Description de cas (notes écrites à chaque séance)	OUI	NON	
INITIALES			
Photos de l'oeuvre que je créerai	OUI	NON	INITIALES
Enregistrement audio des entrevues	OUI	NON	INITIALES

Les informations recueillies au moyen de photos, de descriptions de cas et d'entrevues seront utilisées tout d'abord pour le mémoire de la chercheuse. Par la suite, après la fin de cette étude, les données pourront servir pour de futurs exposés et publications. Tous les renseignements personnels seront gardés secrets et conservés sous clé; aucun détail qui permettrait de m'identifier ne sera utilisé dans le mémoire, dans les exposés ni dans les publications. Les renseignements seront gardés sept (7) ans après la fin de la recherche puis détruits.

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Nom de la participante: \_\_\_\_\_

Formulaire de consentement présenté et expliqué par:

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Nom de la responsable sur place (ou de son délégué)

\_\_\_\_\_

Katherine Laux  
Étudiante et interne en Art-thérapie à l'Université Concordia  
Maîtrise dans le programme de Thérapies par les arts créatifs

Suzanne Lister, PhD, *ATR, OATR, CACPT* (514-848-2424, poste 4799)  
Directrice de thèse et Professeure adjointe  
Département de Thérapies par les arts créatifs, Université Concordia

xx

Responsable sur place et coordonnatrice de recherche