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# Exploration of the Process of an Altered Book Project With Women Cancer Survivors

Jillian E. Luz Loyola Marymount University

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# Exploration of the Process of an Altered Book Project With Women Cancer Survivors

Jillian E. Luz Loyola Marymount University, jillianeluz@gmail.com

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with

**Women Cancer Survivors** 

by Jillian Luz

A research paper presented to the

# FACULTY OF THE DEPARTMENT OF MARITAL AND FAMILY THERAPY LOYOLA MARYMOUNT UNIVERSITY

In partial fulfillment of the requirements for the degree MASTERS OF ART

May 1, 2016

## Signature Page

Author's Signature:



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### Acknowledgements

I would like to acknowledge the faculty of Loyola Marymount University's Clinical Art Therapy program, through whom my professional development has been stimulated, directed, and nurtured. In particular, I would like to acknowledge my research mentor, Dr. Debra Linesch, for her inspiration and guidance in this research.

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IRB approvals: The IMPAACT Study received approval from the LMU IRB (PI: Tarleton, 2016 SP 13, expires February 8, 2017) and from the State of California Committee for the Protection of Human Subjects (PI: Tarleton, Project No.: 14-02-1507, expires October 7, 2016).

## Dedication

This research paper is dedicated to any person who has sought comfort, developed interpersonal connections, or found healing through the creative process.

#### Abstract

This research examines the experience of a long-term creative arts project within a women's cancer support group. Specifically, the research explores the effects of a creative arts project on quality of life. Literature describing cancer support groups has been reviewed, as well as literature published which specifically studied the effects of art therapy with those living with from medical illnesses including, but not limited to, cancer.

Qualitative data was gathered through surveys, interviews, and by analysis of the creative art projects. Group participants were offered the directive to create an altered book in which to express their cancer journey. The art directive was a long-term project, with participants given the opportunity to work on their altered books over the course of six months. Both the processes by which the creative art projects were created as well as the content of the finished products were evaluated. Four prominent themes were discovered during analysis of data; time, a sense of life and growth, gratitude for social connections, and the creative process. These findings were then examined in the context of the general literature as well as art therapy literature on medical support groups. The research supports general literature which identifies that cancer diagnoses and treatment can create social isolation, creating a vital need for social relations and connection. The art therapy research studied chose to focus more on the art product, whereas this research also greatly considers the process of the art-making as significant data.

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#### Introduction

#### The Study Topic

This study examines the experiences of women cancer survivors who participated in an art-making process within a support group setting. It is an attempt to investigate the impact of the art-making process within a group setting on quality of life. Quality of life has been considered the principal variable which art making in a support group setting may affect.

The research topic is guided by questions about the potential benefits of or drawbacks to creating art within a group setting, and explores the experience of the artmaking process. The art-making technique employed, the creation of altered books, was strategically offered because of the intrinsic narrative qualities. The altered books serve as a platform for the group participants to reflect and explore their cancer experience as well as to create a concrete object, which may serve as a way to honor their journey.

#### Significance of the Study

This study is warranted because if shown to enhance quality of life, more support groups that utilize art making, specifically the creation of altered books, may be established. The creation and completion of altered books holds many rich and complex metaphors through which therapy can be applied, yet there is scarcity of literature surrounding this specific art making technique. The research is important to me

personally because I feel a deep sense of loyalty to the field of art therapy and for bringing exposure to and recognition of the healing benefits of art making.

#### **Background of the Study Topic**

Cancer is the second cause of death in the US, followed only by heart disease, and is presently the cause for 1 in 4 deaths in America (American Cancer Society, 2015). A diagnosis of cancer affects not only the patient, but the primary and extended family, caregivers, friends, co-workers, and more. This diagnosis is prevalent and affects not only the patient's physical health, but also their mental well being and that of their family, friends, and caretakers. Mental health treatments such as art therapy can be particularly beneficial and effective for not only the patients, but also for their family and caregivers (Eliasov et al., 2010).

There is an abundance of general research conducted on cancer patients, which speaks to the prevalence of the disease. In reviewing the art therapy literature that presents the efficacy of support groups that employ art therapy, it became evident that the addition of art-making into the support group setting was beneficial. Specifically, the utilization of art therapy within in support group setting was often found to increase the quality of life (Speigel, 2012). Health-related quality of life (HQL) has been thoughtfully considered as a vital factor in which art therapy intervention may improve and thusly informed the data collection portions of this research.

#### **Literature Review**

### Introduction

The following review investigates a variety of psychosocial interventions that have been implemented with cancer patients, survivors, and their families. General literature as well as art therapy literature has been explored and reviewed. The literature has been organized into sections, first by general literature and then by art therapy literature. After this distinction, the literature has been organized again and arranged by theme. The topic of gender and mental health treatment seeking was chosen as a theme within the general literature, as it is a contemporary and relevant subject, and also because the research is informed by gender. The focus of the research is on gynecological cancers, thusly the research has been conducted only with female participants. Then, the general literature is arranged by cancer and gender, cancer and support groups, and finally by cancer and quality of life. These themes were chosen because the research is seeking to explore the potential impact of cancer support groups on quality of life and the research is focused on women who have survived cancer or are currently being treated for cancer.

The art therapy literature has been divided and arranged into art therapy within cancer support groups and art therapy and quality of life.

#### General Literature

The topics of gender and the seeking of general mental health treatment were noted at many points within the research, particularly in current studies. Gendered, cultural, and social stigmas are contemporary and problematic barriers impeding many

men from seeking mental health treatment, as Kessler, Brown, and Broman first revealed in their 1981 study of gender differences in psychological help-seeking persons. Hammer, Vogel, and Heimerdinger-Edward's more contemporary study revealed that community size impacts adherence to culture's dominant masculine norms and that rural men "reported stronger norm conformity" and "more self-stigma" (Hammer, Vogel, and Heimerdinger-Edwards, 2013, p. 71) compared to men living in bigger communities. The authors speculate that a reason for this may be a lowered sense of confidentiality in smaller communities. Educational levels were also a factor, as more-educated men "exhibited a weaker association" in adherence to cultural norms of masculinity (Hammer, Vogel, and Heimerdinger-Edwards, 2013, p. 71).

Franklin, Chen, N'cho, Capawana and Hoogasian (2015) recently researched African-American men, a more specifically marginalized population due to not only stigmas of masculinity, but also factors of race and ethnicity. The authors established a therapeutic support group for African-American men, focused on issues surrounding gender and race in everyday experiences. The group was presented not as mental health treatment, but rather as a preventative model built on "self-reliance" (Franklin, Chen, N'cho, Capawana, and Hoogasian, 2015, p. 266) skills. The researchers were able to identify that the men, within the safety and comfort that the support group provided, were able to express emotions and communicate about their relationships, life stressors, and other personal information. Group cohesion was also recognized and noted by their "ability to share personal things with the group that they could not share outside of the group" (Franklin, Chen, N'cho, Capawana, and Hoogasian, 2015, p. 270). The research reinforces the perspective that support groups for men, especially men of ethnic

minorities, are indeed effective, though recruitment and attendance may prove challenging.

Another population that has traditionally received psychosocial services through the conduit of therapeutic support groups is those afflicted with cancer. Support groups to help patients cope with the emotional and mental challenges of a cancer diagnosis have been an important resource to individuals, families, and also caretakers who can "share their loneliness, frustration, anxieties and cultural differences" (Eliasov et al., 2010, p. 1127) within a supportive group setting. A considerable amount of research has been conducted on cancer support groups, and this review discusses a sample of more current articles.

Sautier, Mehnert, Hocker, & Schilling (2014) explored the satisfaction levels of those who participated in cancer support groups during and post-cancer treatment in a long-term study. Over one thousand people were surveyed, both during cancer rehabilitation (at the beginning and end of treatment) and again one year later, though the one year later participant pool was slightly smaller (due to deaths, participants who had moved, and those who did not want to participate in the survey). A majority of the patients surveyed at the one-year point (64%) named support groups as "very helpful" (Sautier, Mehnert, Hocker, & Schilling, 2014, p. 144). Those who participated in support groups also reported higher levels of active problem-solving coping and emotion-oriented coping abilities. Additionally, over 50% of support group participants communicated a need for further support.

From a global perspective, Eliasov, Zalman, Fletcher, Vorobeichik, Halevi-Gurevich, Levi, and Bar-Sela (2010), based in Haifa, Israel, conducted research based on

in-hospital support group treatment. The model of a standard Community Meeting, abbreviated as CM by the researchers, is described as a commonly used weekly meeting typically between staff and patients in psychiatric hospitals. The general purpose of a psychiatric hospital CM is to provide a forum in which to articulate patient's needs, address inter-personal relationships and to discuss management of department tasks. The researchers implemented the CM into a non-psychiatric hospital setting, and also included the patient caregivers. Diverging from the traditional use of the CM, the type of meeting the researchers conducted was based on promoting "open communication and empathetic interaction between members" (Eliasov et al., 2010, p. 1126). The Community Meetings were also established to provide a setting in which thoughts and feelings could be expressed. Hypothesized goals of the CM were an "improvement of perceived quality of care" (Eliasov et al., 2010, p. 1126) as well as better coping skills for both patients and caregivers. The researchers conducted CM's in the Radiotherapy department, and also noted that they could locate no published research describing the application of a CM within a general hospital setting, and thus their work is groundbreaking. The rationale behind choosing the Radiotherapy department was that patients in this unit generally tend to have a longer stay than in other hospital departments (an average of 5 weeks) and they also tend to have more regular interactions with others, namely other patients, staff, and family/caregivers. Participation in the CM was voluntary and participants could leave and enter the weekly session at their discretion. The participants were a range of patients, family/caretakers, and hospital staff with diverse religious and cultural backgrounds, and the meetings were conducted in Hebrew, the dominant language of the population, and translated into several additional languages as

needed. The meetings were conducted and researched for 3 years, among varied patients, staff, and family members. Common themes emerged over the course of the group meetings, and they were clustered into topics unique to patients, family/caregivers, and the staff. The researcher's notably subjective view of the meetings were that they were successful in giving the patients and family/caretakers a space for emotional ventilation as well as professional information (from staff) and they gave the staff a lens from which to view patient and family needs and concerns. This concept of holistic care, treating the patient as person within a family system and not just as a diagnosis is where the researchers hope their works leads.

A modern technological platform for the support group setting has entered the mental health field through an online format. Elder and Burke (2015) explored the effectiveness of this style of support group and by studying parents who had lost a child due to a brain or spinal cord tumor. Potential participants were approached via advertisements, e-mails, and other forms of outreach through the Children's Brain Tumor Foundation (CBTF). The parents were invited to participate in an internet-based bereavement support group, focused on using chat rooms to conduct the group sessions. Their research discovered that a majority of the parent participants felt the online support group was both "supportive" as well as "convenient" (Elder and Burke, 2015, p. 183). They also expressed that the privacy of the online setting was a positive factor, along with being a healthy alternative when local resources were lacking or unavailable. Specific logistical challenges for this method of support group work are Internet availability and consistency, time differences between members located throughout the country (and potentially internationally), and the fast-paced nature of Internet chat room

conversations. Other challenges included not being able to hear tone or volume of other's voices, as this led to some messages being misconstrued.

Enhancing quality of life is a common goal and outcome of many support groups. The next several articles will look at what effects cancer has on quality of life, and what resources have been implemented to mitigate the effects of a cancer diagnosis and to enrich quality of life.

Reiche, Nunes, & Morimoto (2014) recently studied the effects of psychological stress on physiology. Psychoneuroimmunology, the field this study is categorized under, examines the effects of psychological stress, including "major life events, trauma, abuse, or factors related to the environment in the home, workplace, family, or neighbourhood" (Reiche, Nunes, & Morimoto, 2014, p. 618). The team identified research that suggests that the effects of stress and depression among people with cancer have been shown to increase the development of tumors in some cancer patients, though these findings are difficult to study. Similarly, Spiegel and Giese-Davis (2003) propose that cancer often leads to depression and, consequently, adversely affects their quality of life. These researchers argue that the "possibility that effective treatment of depression/anxiety may affect the course of the disease as well as the patient's distress" (Speigel and Gisese-Davis, 2003, p. 273). Speigel has long-studied the effects of supportive group psychotherapy on quality of life, as well as for pain reduction and increased survival rates in cancer patients. His 2012 article Mind Matters in Cancer further explains the positive effects of psychosocial support groups for patient stress management which, in turn, could potentially affect cancer patient's tumor growth rate.

The literature presents the idea that support groups offer patients a place to not only be the receiver of advice from others, but also to be givers of strength, wisdom, and resilience to others and to themselves. The following articles explore the addition of art therapy to the support group concept.

#### Art Therapy Literature

Serlin, Classen, Frances, & Angell (2000) explain a model of expressivesupportive psychotherapy developed at Stanford University, which aims to "help patients" live their lives more fully in the face of a life-threatening illness" (Serlin, Classen, Frances, & Angell, 2000, p. 124). Researchers at Stanford University's Psychosocial Treatment Laboratory were approached by breast cancer patients and providers from a rural county in the Sierra Nevada Foothills. They came to suggest ways to offer support to cancer patients in remote areas. The group of women, who had formed because of their shared breast cancer diagnosis and treatment, approached the researchers with a proposal for ways to create a support network for women currently afflicted by the illness (or just ending treatment, as this time was identified as an emotionally fragile point during their timeline of the disease). Through their collaboration, "workbook-journals" were produced of women's stories, thoughts, and poems about their personal story of breast cancer, as well as information with medical breast cancer referral sources. Offerings of blank pages give invitations for the women receiving the workbook-journals to offer their own thoughts, drawings, collage, or any other creative endeavors they wish to add. The workbook-journals are intended to be a "support resource" (Serlin, Classen, Frances, & Angell, 2000, p. 135-136) and were being tested in a pilot study during article

publication. The concept of the support group actually creating the material to support future patients was especially of note in this article. The idea developed from the support group's recognition of how helpful having a therapeutic space in which to discuss not only the intricacies of the cancer treatment itself, but also for "expressing anxieties and fears about cancer and recurrence, observing other coping strategies, knowing that they weren't alone, and the ability to help other women with breast cancer" (Serlin, Classen, Frances, & Angell, 2000, p. 134). Their desire to help other women with the same diagnosis who were unable to receive the benefits of a support group because of logistical and financial reasons led to the creation of the workbook-journals.

Geue, Richter, Buttstadt, Brahler, & Singer (2013) also evaluated the effects of art therapy interventions for cancer patients, but in ambulant after-care. The researchers saw a need for studying the interventions because of the detrimental psychological impacts often associated with a cancer diagnosis. Additionally, they extended their research to include a 6 month post-intervention evaluation, as they noted that there are not many opportunities for interventions available to patients who have completed routine medical treatment. A group intervention with the art directive of creating a book to "allow participants to 'bundle' their thoughts or experiences" (Geue, Richter, Buttstadt, Brahler, & Singer, 2013, p. 346) was the method with which the researchers ultimately conducted 10 different course groups which ran for 22 weekly 90 minute sessions. The course groups were offered for just over two years and each group consisted of 5-8 members of varied gender and age. The sessions took place in a room at the Psychosocial Counseling Center at the Leipzig University Hospital. Participants were recruited by letter, flyer, and informed by hospital staff about the study. Participants were tested before the

intervention, after the intervention, and again 6 months later using the Hospital Anxiety and Depression Scale (HADS), the Perceived Adjustment to Chronic Illness Scale (PACIS) and the Freiburg Questionnaire on Coping with Illness. A control group, who could not receive the art intervention because of logistical reasons or because of disinterest was also established. The researchers noted that more women than men participated in the art intervention, and that this phenomenon has been noted in previous studies. The researchers found a decrease in anxiety levels at the end of the intervention and again a decrease at the six month post-intervention marks. Ultimately, the findings concluded that while there were no changes in the depression levels for the art intervention groups, this group did have increases in attendance in group activities and they overall "showed higher activity and more initiative to cope with their disease" (Geue, Richter, Buttstadt, Brahler, & Singer, 2013, p. 350) than members of the control group.

The use of art therapy for treatment of coping skills and to enhance quality of life is prevalent and growing. As the following research suggests, art therapy within a support group setting is a relevant and effective treatment modality. The following articles assess how and in what settings art therapy was applied, as well as the outcomes on quality of life on participants who received art therapy.

Borgmann (2002), an experiential therapist, followed three women of varying ages who have been diagnosed with different types and stages of cancer. Borgmann presents a brief case study for each woman, explaining first each woman's specific cancer diagnosis, a short portrayal of the woman, and then describes an individual therapy session with each woman conducted by Borgmann in which an art intervention was

employed. A more detailed background of the participants, as descriptions of the women contain no information about socio-economic status, gender identification, and only one woman is described ethnically, may have been considered by the author. This would have provided a richer perspective from which to analyze the women's artwork. It is also unclear where the sessions are taking place- in hospital, private practice, etc., as well as how these individuals became involved with the art therapy sessions run by Borgmann. A more exhaustive evaluation of the artwork itself, in which perhaps multiple sessions over time, or a single piece of artwork that the client may work on in several sessions, may have led to a more deeply informed conclusion. However, despite its shortcomings, this article does touch on the benefits of art therapy, particularly with cancer patients, as social-isolation, lowered self-confidence, and grief are common side effects from this medical diagnosis (Serlin, Classen, Frances, & Angell, 2000).

Walsh, Martin, & Schmidt (2004) conducted a study at a regional cancer center that provided creative arts interventions (CAI) to family caregivers of cancer patients. The oft-overlooked population of cancer patient caretakers was tested for levels of stress, anxiety, and general feelings over a 6-month period. The art interventions were administered by "nurse-artist intervention teams" (Walsh, Martin, & Schmidt, 2004, p. 216) who were trained by the researchers on how to implement the CAI. The article notes that the CAI had been created and tested by Walsh and other researchers throughout the 1990's. This particular study was specifically testing the effects of the CAI among Hispanic and non-Hispanic family caregivers. Participants for the study were recruited after receiving a verbal explanation of what a CAI was as they were either at the bedside of the cancer patient or while they were at the regional center's chemotherapy site.

Before the CAI was administered, each participant completed 3 self-report pretest measures, including the Beck Anxiety Inventory. One hour after the CAI was dispensed, the participants were tested again. The results of the study were overall positive, with lowered levels of stress and anxiety and increased positive emotions being reported. It was unclear whether the participants were able to engage in the CAI only once, or if there were repeated opportunities to engage in the art intervention over time. Despite optimistic findings, the researchers note that there are potential problems with putting creative arts into the hospital setting. Funding for programs such as the one described here, as well as staffing, are both potential drawbacks or barriers from the creative arts being instituted in hospital or medical settings. This study only tested subjects after a 6-month period post-CAI, so results are categorized as short-term effects. It is unclear whether the research stopped at this time period because of researcher constraints. If long-term post-CAI surveys could be given, the results may be useful to the field of creative art therapies being employed in medical settings.

Many studies investigating specifically breast cancer patients and quality of life have been conducted. Between 2001-2004, Öster, Tavelin, Thyme, Magnusson, Isaksson, Lindh, and Åström looked at both the short and long-term effects of mental health services for women with breast cancer. In their initial study, 42 women with a thenmedian age of 66 years and from varying socioeconomic and educational backgrounds were randomized to participate in art therapy interventions. The women were recruited for the initial study by referrals from the Department of Oncology at Umeå University in Northern Sweden. Participants were provided with individual art therapy sessions once a week for 5 weeks, weeks which coincided during the weeks of their radiotherapy

treatment sessions. A control group was also established. Both groups (intervention and control) were given the Coping Resources Inventory/CRI, an instrument used to identify stress management resources. The results revealed that "anxiety, depression, somatic symptoms and general symptoms decreased in the intervention group" when compared with the control group, for 6 months after the study (Öster et al., 2014, p. 36). The researchers also found that the art interventions offered the women a space for "elaborating experiences and giving legitimacy to their own interpretations" (Öster et al., 2014, p. 36).

The researchers identified the lack of long-term follow up studies on art therapy treatment modalities and conducted a 5-7 year (depending on the participant's initial study start year) follow-up study with breast cancer patients in an attempt to provide much-needed long-term research, publishing this study in 2014. From the original participant pool of 42 women, 37 women chose to participate in the follow-up study. Again, the CRI was implemented, to compare current results to results from the 2001-2004 study, as well a coping and quality of life questionnaire which was identical to the questionnaire the women received in the previous study.

The aim of this study was to identify and describe coping resources and quality of life in women who have been diagnosed with and treated for breast cancer 5-7 years after receiving a short session of art therapy interventions. Specific questions that the researchers sought to answer surrounded any remaining differences between the intervention and control groups regarding coping resources and quality of life five to seven years post art therapy treatment. The results of this study showed no long-term (5-7 years) effects on the art therapy intervention group compared with the control group. The

researchers named possible changes in stage of life (as many of the women became retirees during the 5-7 year break between studies, and this may have impacted their answers on the CRI), and also that the participant pool was small. The researchers note that the positive results found six months after the original art therapy intervention suggest that longer art therapy treatment period may have resulted in longer-term effects.

Though this study did not support the long-term efficacy of art therapy interventions, it is noteworthy. The researchers report that this study was the "only study of art therapy given parallel to cancer treatment which includes a long-term follow-up" (Öster et al., 2014, p. 38) that they could locate.

Puig, Goodwin, and Sherrard (2006) produced a pilot study in 2006 which evaluates a range of emotional, spiritual, and psychological factors that could be affected by the creative arts therapies in those newly diagnosed with cancer. Specifically, the study was seeking to answer whether art therapy interventions could help patients express themselves emotionally, enhance their psychological well-being, and increase their selfreported spirituality levels.

The researchers focused on women with Stage I or Stage II breast cancer and the participant pool was 39 members with a mean age of 51 years old. The participants were randomly selected to participate in the first treatment group or were placed in the control group (and would receive identical creative arts interventions 4 weeks after the first group). Before the interventions, the women in both the treatment group and the control group were given a Profile of Mood States (POMS). The POMS was completed at the conclusion of the interventions, as was the Emotional Approach Coping Scale (EACS) and the Expressions of Spirituality Inventory-Revised (ESI-R). During the arts

interventions, licensed mental-health counselors led participants individually through guided meditation aimed at connecting the participant with their body and increasing body awareness. Offerings of varied art media (paint, pastels, pencils, and drawing and painting tablets) were made and the women were encouraged during their sessions to freely explore the materials without a directive. At each of the 4 sessions, different aspects of spirituality were also considered. Existential questions to help make meaning of the breast cancer diagnosis were offered at the first session, with further intervention themes surroundings body-emotion awareness, spiritual awareness through the lifespan, and intervention series was ended with themes surrounding life and death. Results from the study revealed that after the creative arts interventions, participants in the treatment group experienced significantly lower scores in the areas of "tension-anxiety, depression-dejection, anger-hostility, and confusion-bewilderment" (Puig, Lee, Goodwin, & Sherrard, 2006, p. 223) than those in the control group. Through the exit interview questionnaire, researchers also found the participants would recommend creative arts therapies to those with a health problem. Furthermore, some participants reported feeling "surprised at their ability to enhance their sense of well-being and to reframe" (Puig, Lee, Goodwin, & Sherrard, 2006, p. 224) their experience of cancer and use it as an opportunity for self-growth and transformation.

Nainis, Paice, Ratner, Wirth, Lai, and Shott's 2006 research study was published in a medical journal aimed at management of pain and symptomatology. The researchers first give a comprehensive definition of clinical art therapy and they cite several art therapy studies and programs that have proven to be beneficial to cancer patients. Their own study was conducted within an oncology inpatient department. Participants were

recruited over 4 months, and qualifiers to participate were having cancer, being over 18 years old, having the ability to communicate in English, being cognitively intact, and having an interest in participating in one art therapy session. Pre and post-test methodology, using the Edmonton Symptom Assessment Scale (ESAS) and part of the Spielberger State-Trait Anxiety Index (STAI-S) were employed to measure results. This study sought to measure levels of anxiety and other emotional indicators as well as physical symptoms such as pain both before and after the art therapy intervention. After establishing interest and meeting criteria requirements, participants were approached in their hospital room by a registered art therapist who offered them an array of art supplies. The participant was told they had one-hour for an art therapy session and were asked what goals they wished to achieve within this time. Stated goals within the sessions ranged from "light entertaining distraction to investigating deep psychological issues" (Nainis et al., 2006, p. 164). During the session, the art therapist encouraged the patient, assisting in the art if the patient was physically limited or felt discomfort using the art materials. A focus on the process of the art-making, rather than the product, was reinforced. After the one-hour session, the art therapist offered to leave art materials for the patient to use at their leisure. After the art therapist exited the room, a research assistant entered the room to administer post-intervention measures as well as qualitative questions. Results of the study demonstrated significantly lowered scores in eight of the nine symptoms surveyed in the ESAS, such as depression, pain, and anxiety. Qualitative data revealed that the participants, who were from a very diverse background as far as age, education-level, ethnicity, and diagnoses, were very receptive to the art therapy intervention.

The researchers recognize that there was no control group sampled for this study and there were factors that may have affected the outcomes (such as patients receiving medication right before an art therapy session). Also, this study shows the effects immediately after one single art therapy session, rather than examining the potential impact of more sessions over time. However, the researchers see their study as the "beginning evidence for the efficacy of art therapy in reducing a broad spectrum of symptoms"(Nainis et al., 2006, p. 167) within an assorted sample of patients. The authors considered their audience, the medical field, and by thoroughly defining what clinical art therapy is, set a stage for which their study may be considered valuable by other medical professionals unfamiliar with the creative arts therapies.

#### Conclusion

This review has shown that the literature is replete with research on effective and supportive resources for those affected by cancer. This speaks to the prevalence of cancer diagnoses, which do not discriminate by age, gender, socio-economic status, or other biological and social factors.

The gradual integration of art therapy, as a complementary therapy to medical treatment, into the broader medical field is a promising sign of attitudes towards the creative arts therapies within medical settings shifting. Many of the articles identified the need for more research into the efficacy of art therapy interventions within the medical community, with only a few being allotted the time and funding to conduct long-term research. As with most aspects of art therapy research, more, and specifically quantitative, research is necessary to provide the platform for which funding to implement art therapies into a range of applicable settings may become available.

#### **Research Approach**

Qualitative research defined as "an approach for exploring and understanding the meaning individuals or groups ascribe to a social or human problem" (Creswell 2014) informed this research study. The purpose of selecting this research approach was to gather, study, and analyze data which is based on the perspective or "the standpoints of the participants (Kapitan, 2010, p. 17). Due to constraints stemming from the original research project from which participants were recruited, pre-test measuring capabilities were unavailable. This limited the Principal Researcher's ability to use a mixed methods research approach, and thusly, Principal Researcher utilized several qualitative research methods.

A voluntary questionnaire evaluating the participant's thoughts and feelings I several aspects of their support group experience was administered at a halfway point through the series of seven support group meetings. The questionnaire also offered space for the participants to add additional comments regarding their experience. Lastly, the questionnaire invited participants to volunteer for a future, in-depth telephone interview with Principal Researcher.

Participants who elected to partake in an in-depth, semi-structured telephone interview were given an outline of questions that would likely be asked during the interview, to give participants familiarity with the direction that Principal Researcher would be inquiring (Appendix E). This semi-structured interview was considerably

informed by the Exit Questionnaire employed in research conducted by Puig, Lee, Goodwin, and Sherrard (2006), Appendix F.

Data analysis examines both the process of art-making as well as the products created. Kapitan suggests that an art-based analysis may produce knowledge "as a new awareness and insights from artmaking" (Kapitan, 2010, p. 171).

#### Methods

This section includes definitions of terms necessary to comprehending the data. Definition of Terms

*Health Related Quality of Life (HQL)* is " a multi-dimensional construct encompassing perceptions of both positive and negative aspects of dimensions, such as physical, emotional, social and cognitive functions, as well as the negative aspects of somatic discomfort and other symptoms, produced by a disease or its treatment" (Osoba, 1994, p. 608).

*The IMPAACT (Improving Physical Activity After Cancer Treatment) Study* "aims to examine the effects of combining aerobic exercise with strength training on risk factors for cancer recurrence and risk of chronic disease among cancer survivors. The IMPAACT Study is a collaborative research project shared by six faculty members in the Department of Health and Human Sciences at Loyola Marymount University (LMU) in Los Angeles, California. Female participants will be randomly selected from a list provided by the Los Angeles County Cancer Registry. (Protocol Request for CPHS Approval, Committee for the Protection of Human Subjects, Protocol #14-02-1507 p. 4-

#### **Design of Study**

1. **Sampling**: Participants for this study were recruited from an existing project (IMPAACT study). The participants were offered the opportunity to participate in the *Exploration of the Process of a Creative Art Project with Women Cancer Survivors* as an alternative to being unable to participate in the IMPAACT study due to logistical or physical limitations. The participants are all female, as this was a requirement to participate in the IMPAACT study. The small sample size was preferred by Principal Researcher, whom will also be referred to as PR within this document, in order to obtain and analyze complex, qualitative data. Demographic information regarding age, ethnicity, and education level of participants was not gathered by Principal Researcher, but participants stated their ages during last group session. Participant's ages ranged from 53 years old to 66 years old. The participant's experience of having cancer ranged from being in remission for 7 years to currently being treated for terminal cancer. Participants have been given pseudonyms and measures have been taken to maintain participant's confidentiality.

2. Gathering of Data: Prior to administering data collection methods, informed consent describing the research study was distributed to participants. Qualitative data was also collected throughout the seven support group sessions, which were held once a month for two hours in the evening. PR collected visual and process data throughout the seven sessions, particularly during the culminating group session.

Data was collected from group participants by using a questionnaire to evaluate the participant's experience in the cancer support group. Following the survey, participants were asked if they would like to volunteer for an in-depth, semi-structured interview conducted by principal researcher and employed qualitative research methods. Each interview was initially to take place confidentially on the LMU campus and last between 45- 90 minutes. However, after feedback from participants interested in being interviewed, they requested that the interview take place over the telephone, due to transportation challenges and time constraints. After consultation with research mentor, adjustments were made regarding the interview process. The interviews were conducted over the telephone by principal researcher who was in a confidential location. The interviews lasted an average of 25 minutes.

3. Analysis of Data: Data was gathered using three methods: survey, interviews, and through analysis of the art process and final product. A short survey was used to first gauge participant's experience during support group. This survey was also used to invite interested participants to partake in an interview with Principal Researcher regarding their experience in the group.

Qualitative data was gathered from semi-structured interviews with two voluntary participants. Principal Researcher identified themes from these interviews.

Qualitative data was also gathered from analysis of artwork created by participants during course of cancer support group. The artwork was photographed at several stages throughout the six art-making sessions and the seventh cumulative meeting of the support group. During the final meeting of the support group, the group members

were able to share their altered books as well as their thoughts and feelings on their experiences participating. The art process and art products, including the use of color and content of imagery and text, were analyzed by Principal Researcher in order to identify major themes.

#### Results

#### **Presentation of Data**

Within the data, there are three different sets that were collected and evaluated. The first set of data includes the results of the short online questionnaire administered to participants at a midpoint of the group. Details about the questionnaire, as well as the questionnaire results, are reviewed. Data is then presented from the responses and discussion that developed from the individual interview process. Themes identified from each interview are presented, and themes concurrent between interviewees are identified.

Next, data gathered from analysis of the art is presented and discussed. The presentation and analysis is guided first by individual themes and then by themes coexisting between group members. Emergent themes are identified and deeply explored within the analysis of data. The four themes identified are time, a sense of life and growth, gratitude, and the creative process.

#### Survey

At the fifth group session, members were given the option of participating in either a paper survey or an online version of the same survey. Three group members participated in the online survey and one participated in the paper survey. One group member later reported wanting to complete the online survey but experienced technical difficulties that prevented her from partaking in the survey. The survey was used to evaluate participant's experience with the creative support group process as well as to ascertain participant interest in an in-depth interview regarding their experience. The survey contained four questions regarding participant's experience in the group. The questions and responses are provided below. Possible answers to survey questions were "extremely satisfied", "very satisfied", "satisfied", "somewhat satisfied", and "very unsatisfied". Four out of four survey takers responded to Questions 1-3. Three out of the four survey takers responded to Question 4.

Survey Q1 Rate your general experience of the women's support group you have participated in.	1 participant responded "extremely satisfied, 1 responded "very satisfied", 1 responded "somewhat satisfied", and 1 responded "satisfied".
Survey Q2 Rate your experience of the art- making process during the support group.	2 participants responded "very satisfied", 1 responded "somewhat satisfied", and 1 responded "satisfied".
Survey Q3 Rate your experience of meeting other women within the support group.	1 participant responded "extremely satisfied", 1 responded "very satisfied" and 2 responded "somewhat satisfied".
Survey Q4 Your view of your experience is very important. Please feel free to add any additional information about your experience.	See answers below.

"The atmosphere in the Art Therapy class was warm and caring. I felt the women who attended had a connection and certainly were concerned with each other's health and well-being. For me, writing about my experience having ovarian cancer was cathartic but unfortunately it proved to be too difficult for a number of women who first attended. I honestly wish there was something we could have done to ensure their participation. One idea may be to (with their permission) videotape group interviews each class without the pressure of writing down our experience. Another idea might be to create small doable art projects each session such as creating a prayer flag or mandala. Since we had several hours each time we could have finished a project in an 1-1.5 hours and then talked about what we wrote." *-Participant Denise* 

"I enjoyed meeting the other women and was sad when they didn't come back. I wonder if a more frequent format would have helped that. "- Participant Ruth

"Didn't get enough time to talk with other participant (sic)."- Participant

Patricia

### Telephone Interviews

Two participants (Ruth and Patricia) from the creative arts support group elected to participate in a telephone interview regarding their experience. Principal researcher prepared a script of potential questions but the interview process was semi-structured and led by participant's answers. Below is a list of questions prepared before interview.

Interview Q1 Did you think it was helpful to participate in this creative arts therapy
experience?
Interview Q2 Would you recommend this process to someone else with a health
problem?
<i>Interview Q3</i> What was the most important thing that happened to you as a result of participating in the
creative arts therapy exercises?
Interview Q4 What did it trigger for you?
Interview Q5 What made you want to join?
Interview Q6 What, if any, were you expectations from participating?
Interview Q7 Were you expectations different from what actually transpired?
Interview Q8 How did you feel about meeting the other women?
<i>Interview Q9</i> How has making the art been for you?
Interview Q10 How was the book aspect for you?
Interview Q11 Describe your art-making process?

### Participant 1: Ruth

Principal Researcher interviewed Ruth first, based on her availability. Ruth's overall tone during the interview could be described as cheerful and positive. In response to Q7, Ruth stated that she " figured it would be really fun". During the interview, Ruth identified herself as a writer and that being involved in a visual arts experience was new for her. She named that the creation of an altered book, which encourages the deconstruction of a book, to be difficult for her. Principal Researcher mentally noted this challenge during the first few sessions of the support group. Ruth appeared to shy away from certain processes that other group members were engaging in, such as cutting book pages or painting over text. Ultimately, Ruth did engage in the deconstruction and reconstruction of an altered book. During the process, Ruth stated several times that she " didn't have a plan", and appeared to enjoy experimenting with the art media, specifically

the bleeding art tissue paper (Figure R-1). Ruth revealed in the interview that the support group and creation of altered book triggered for her "timing". She further explained that her cancer diagnosis had come toward the end of what had been a successful year for her, career-wise, and that the "cancer had blotted out" the more positive memories of that year. Ruth named the altered book creating as helping her to remember that year more clearly. Timing of the group was also a factor that Ruth described as being "not meeting close enough in sequence, too much distance between sessions". Ruth also missed several support group sessions due to conflicting obligations. Ruth indicated that she would recommend the process of a creative arts support group to others with medical ailments because " being creative is so uplifting". Ruth also emphasized the "delight in meeting other women" within the support group. Towards the end of the interview, Ruth made a connection to the creative arts support group as possibly relieving the writer's block that she had been experiencing for some time. Ruth stated, "Maybe....it inspired me to write again."

# Participant 2: Patricia

During the time of data gathering, participant Patricia was receiving treatment for her ongoing cancer diagnosis. This impacted her ability to participate in all of the support group sessions, though she attended almost all sessions. Despite this, Patricia appeared motivated and determined to finish her altered book, "as a gift to my daughters". She suggested that more time would have been beneficial in her creation of the altered book, as she felt that her hospital stays, which prevented her from working on her

book between group sessions, set her back in the process. During the interview, Patricia reported that she chose to participate in the creative arts support group because she "needed something of an outlet to express things about the sickness". She indicated that she had some initial anxiety about the creation of the altered book but that once she began the process, she "loved it". Patricia also reported her interest in meeting the other participants, as "... always helps when someone shares their feelings with you". Reflecting on the creative process, Patricia stated, "...try to produce. Whether it's very beautiful or amazing or not, just have to be contented on what we can produce because of the sickness."

Between the two interviewees, the data gathered from the interview process revealed shared themes related to time, happiness in making new friends, and the positive aspects of having a creative outlet.

# Creative Art Project: Altered Books

Participants took part in the creative art project support group for 6 months, resulting in seven total sessions. Principal Researcher, research mentor Debra Linesch, and two members from Principal Researcher's research cluster attended the support group sessions to provide technical support and guidance through the creative art process. The first six sessions were considered 'working' sessions, and participants were invited to use a variety of art media to construct their altered books as well as consult with Principal Researcher, research mentor, and research cluster members. The seventh support group meeting was a session in which participants were allotted space together to voluntarily share their altered books with each other and to discuss their experience participating in the group and in the art process. Several participants (Denise and Patricia) requested to take home their creative arts project, to work on them during the month-long interims between support group sessions. This resulted in Principal Researcher's inability to photograph some of the creative art projects as they were in process. There were four participants whom Principal Researcher classified as main participants (Ruth, Patricia, Denise, and Lee), meaning that they had attended at least three support group sessions by the fifth session. Debra Linesch presented the concept of the altered book to the group during the first session. A template, which provided a suggested method of book organization, was offered to participants, to help provide guidance and structure in the organizational process of creating the altered book. Examples of prompts on the template were akin to the structure of a traditional book, such as "dedication", "introduction", and "chapters". Three of the main participants indicated that they had no recent or previous visual arts experience beyond grammar school level. One participant, Denise, reported having experience with graphic arts. Due to the large amount of visual data gathered from the altered books, PR elected to include images in which participants discussed the process or product during group session or images that PR identified as supportive of an overall theme among participants.

# Participant 1: Ruth

Group member Ruth participated in the online survey, a telephone interview, and in the creation of an altered book. In this section, images of Ruth's process of art-making and imagery from her final product are presented. The content of the imagery as well as examination of her process is explored in the data analysis section.

# Process

Ruth attended the first several sessions of the support group and appeared to be eager and excited to begin the art-making process. She became particularly interested in a specific art media, which was new to her. The media, bleeding art tissue paper, is a relatively uncontrollable material which often produces irregular, watercolor results. She spent an entire session (Session 2) creating the images in Figure R-1.

# Figure R-1



Observations of Ruth's process were noted particularly because she missed several sessions after creating the images in Figure 1, which she attributed to conflicting obligations. She had great difficulty, noted in her hesitance to rip or tear pages, in the physical deconstruction of books, during her beginning process. Ruth appeared to not have an exact plan, as evidenced by her stating such, and she appeared to enjoy the support group experience both as a time for conversation with other group members as well as for a the search for collages images in magazines. Figure R-2 depicts several art methods that Ruth combined. Ruth arranged her entire book during session six, and she informally presented her finished book to the group during this time. Ruth did not attend the final group session.

# Figure R-2



#### Content

The content of Ruth's imagery depicts an overall color of green, both in her choices of bleeding art tissue as well as collage images. Her text often references friends and the support they offer as well as, towards the end of her book, new beginnings. Images of the body and movement are also prevalent and may be connected to physical limitations due to side effects of cancer treatment that she incurred. Figure R-3 depicts an example of her integration of images created in Figure R-1 with collage images. Ruth's decision to place these two images side by side may reflect their similarity in color as well as deeper content such as many colors representing a myriad of emotions that she was experiencing during the time of her cancer diagnosis and subsequent treatment. The image chosen of a human figure running may be running away from something or someone. PR postulates that this could be a reference to the desire for more physical ability, or perhaps the running away from and avoidance of confronting deep emotions that may have been stirred during the creation of images in Figure R-1.

Figure R-3



### Participant 2: Patricia

Group member Patricia participated in a paper survey, telephone interview, and in the creation of an altered book. Patricia's process of art-making and the content of the imagery created are presented. Due to the profoundly personal content of the cards and letters with which Patricia filled her book, Principal Researcher made the decision to not capture images of these, to instead focus on the image of her book cover and discuss her process and discussion of her book

### Process

Patricia began the altered book process with some hesitation. Between sessions one and two, she consulted with Principal Researcher, research mentor, and both members of the research cluster on how she should approach creating her altered book. Technical options, including use of the template, and encouragement to let the process guide her were main points given to Patricia to help her begin her creative course. Once she began, however, she appeared motivated and worked with purpose and intention. She first created her book cover, seen in Fig. 2 below, and then began bringing in typed paragraphs she had written regarding her cancer experience as well as cards and notes of support from her family and friends. Patricia was currently in treatment for active cancer and often took her book home between sessions. She sometimes worked on it between

sessions but other times stated that she had been feeling "too weak" to add to it at home. Despite her ongoing illness, Patricia attended all but one support group session (she was driven to the sessions by her husband, who waited for her outside of the group room during the sessions). Patricia used the final session to continue working, despite the initial intention of the final group to be a space to present the books and experiences. PR and research cluster members felt it necessary to allow Patricia to the space to continue working, as it appeared vital to her. The remaining group members, Lee and Denise, encouraged Patricia to keep working, and it seemed to represent her continued endurance in her struggle against cancer. Patricia maintained that she planned on surprising her daughters with the book when it was finished.

### Content

Patricia's book cover, seen in Fig. P-1, depicts lush flowers and plant growth, a tree branch above her name, as well as many star stickers. The arrangement of these elements, along with the book title of "Fighting Cancer...My Own Way" appears empowering and strengthening to Patricia. The star stickers, which Patricia noted in final session as being arbitrary in choice, may be subconsciously symbolic. Throughout the course of the support group sessions, she made repeated references to "hope" and "miracles" which stars, often representative of wishes or luck, may signify. The stars are placed around the book title creating a solid border, as well as under Patricia's name.

Patricia's book contains an abundance of cards and letters she has received from family and friends since she received her terminal cancer diagnosis (in December 2014).

These personal messages, which she shared with the group during the final session, appeared to be deeply moving to her. Patricia became overcome with emotion when describing receiving letters of love and support from people from many different times in her lifetime, many of whom she had not kept in contact with for many years

# Figure P-1



#### Participant 3: Lee

Group member Lee experienced technical difficulties, which prevented her from participating in both the survey and the interview, though she later reported to Principal Researcher that she would have liked to have participated in both. Lee attended almost all group sessions and participated in the creation of an altered book. Lee's process of artmaking and the content of her imagery, including images of her final product are presented in this section.

# Process

Lee began the process of art-making with enthusiasm, as she experimented with various art media and methods. She stated particularly enjoying the process of searching for collage images in magazines, and amassed a large collection of images throughout the group sessions but described not knowing what she was going to do with them. Lee also brought some of her own materials and supplies to some group sessions (ribbons, etc.) but she did not implement them in her book. During session 6 of the group, her process changed and she appeared to work much more methodically than in previous sessions. She fervently arranged images and text onto her book pages, frequently not appearing to have specific intentions for how the images were arranged. She sometimes kept the text

from the original book and incorporated it into her story, as in Figure L-2. She stayed past the designated end time of this session, after other members had left, and reported to Principal Researcher and research cluster members that she had been experiencing emotional turbulence due to challenges with her adult son who was currently struggling with substance addiction. Lee noted that it was difficult for her to create art about her cancer experience, as she noted that she feels that she did not believe that her experience had been quite as difficult as other group members, and therefore not especially life changing for her. She was, however, interested in attending support group sessions as mean of "distraction" from great challenges with her son. Lee reported that she would like to continue having a creative outlet after the IMPAACT group culmination, specifically indicating that she wanted to continue to make collages on her own. During the final group session, Lee described a desire within her process as wanting to "feel my way...didn't have a plan and didn't want a plan".

Lee reported that she had been working in a journaling group through a church, an experience she described she would not have taken part in if it had not been for the positive experience she gained from attending this support group. Lee also reported that she had recently become interested in finding more support groups and was considering taking art classes within her community.

### Content

Lee created the cover of her book, Figure L-1, from two separate books. It appeared important to her to keep the title of "The Jewelled Flower". She cut this book title and adhered it to a blue book that suited her size needs better than the book the title

was originally on. As described earlier, Lee had collected many images throughout several sessions and arranged them in the sixth session. Figure L-2 depicts two human figures hiking on path, dominated by a tree. The text that Lee chose to keep with this image describes an initially comatose patient who awakens to discover that he does not have complete facility over his body. Latent content within the decision to keep this text, and place the image of the tree with it, may suggest Lee's feelings of inferiority against the forces of nature, or her medical diagnosis. Lee shared during the concluding session that she began planning for what would happen if she did die from her cancer diagnosis, including making arrangements with her husband for her home. She revealed that felt emotionally distant from her diagnosis and, being that she is typically "very analytical" she again applied that practicality to her illness. She expressed a desire to, during the support group, not want to be her typically analytical self and instead "really wanted to unzip my life".

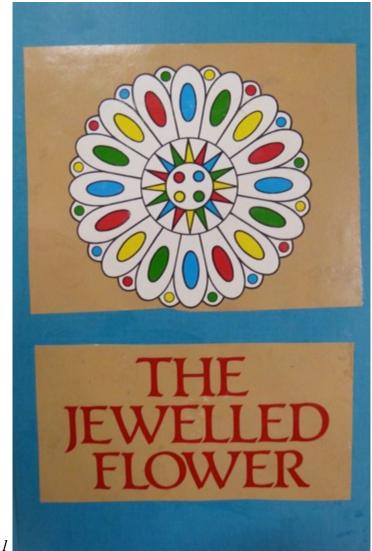
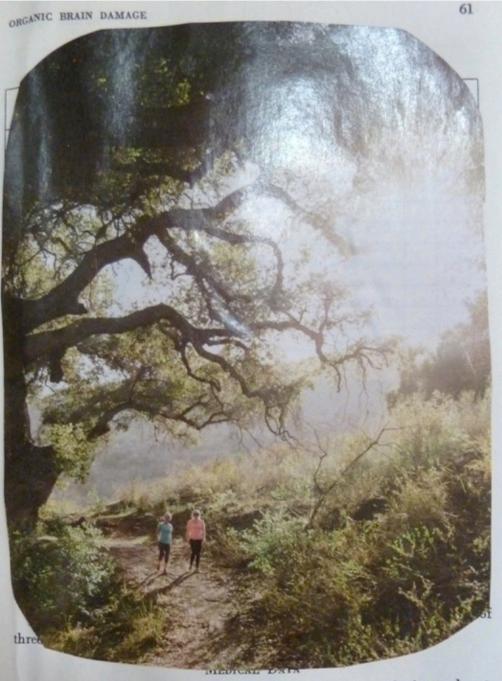
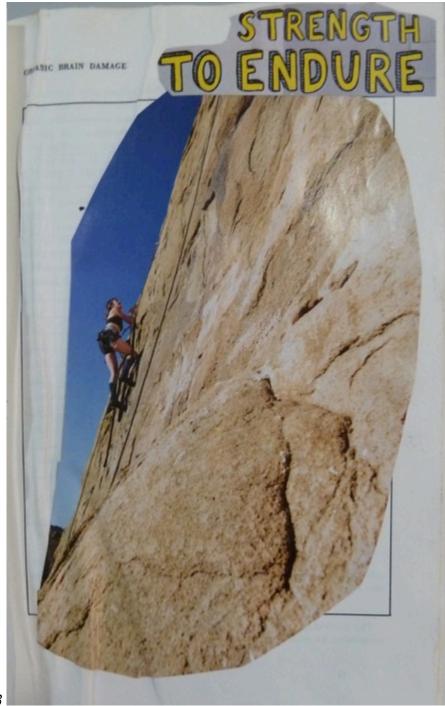


Figure L-1

Figure L-2



Following the injury the patient remained comatose, combative and restless. As he regained consciousness, he became more combative, but moved the right side less. When consciousness was regained, there was a definite right-sided hemiparesis, with a right-side Babinski and positive Hoffmann's sign on the right upper extremity. Gait was spastic. X-ray of the skull revealed





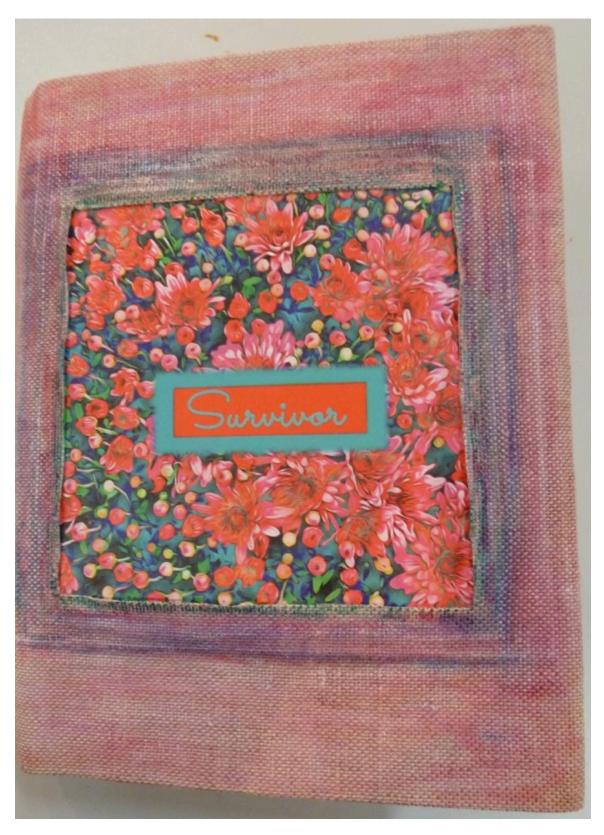
# Participant 4: Denise

Group member Denise participated in the online survey but elected not to participate in the interview process. She attended many of the support group sessions, but experienced a health issue unrelated to cancer that prevented her attendance in all sessions.

### Process

Denise appeared to grasp the concept of the altered book and began organizing her ideas for book during the first session, and consequently executed her ideas both in sessions and at home. She had a distinct vision of what she desired her final art-product to reflect, both aesthetically and within the emotional content. Her process was guided by use of computer in order to type and format her story, and she did not appear to experiment with the myriad of art supplies offered. Denise included many blog entries, which she completed and published on various cancer blogs during her cancer treatment. She also included many personal photographs taken during her cancer journey, many of them taken by her son who documented her cancer experience.

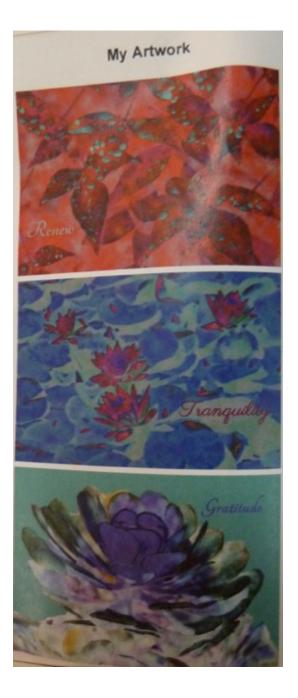
Figure D-1



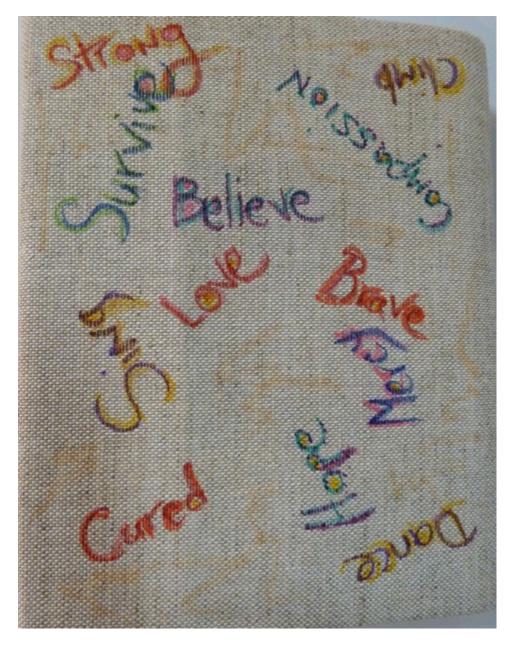
### Content

Imagery within her final product was sparse, as many pages were filled with text from blog entries created during her cancer treatment. Denise did add some visuals, seen in Figure D-1, which was also her book cover, which were images from photographs she took and then graphically manipulated. This process was completed before her involvement with the support group. Her finished product reflects a story much as one would find in a traditional book, and arranged chronologically. It was important for Denise to implement exact measurements in creating the book and she used tools that would support this (rulers, X-Acto knife). Her need for structure may indicate a sense for reflection on her cancer experience to be clean and straightforward, and perhaps not much space has been allotted to experience emotions. Figure D-3, which Denise created on the back cover of her book, reflects a deviation from this more polished product. The information here is perhaps more revealing than the visuals she provided in Figures D-1 and D-2. Here, the placement of words are scattered in a dynamic composition, suggesting movement and perhaps some anxiety. The handwritten lettering, compared to her generally preferred style of typing, lends a more personal impact to the words she chose to denote.

Figure D-2







### Analysis of Data

In this section, the presented data is explored for richer meaning and symbolic content. Data is analyzed for individual themes and examined for themes that were concurrent through the group. The data collected from the surveys is presented first, followed by interview data and, lastly, data from the creative art project.

### Surveys

Due to a small sample size (four participants), the survey data is not analyzed however the findings generally indicated an overall positive experience.

### Telephone Interviews

The Principal Researcher noted that the decision of two participants to partake in a telephone interview, as well as the interest of a third participant (who was unable to partake due to time constraints) may indicate the emotional significance that the support group had on the members. The small size of the support group may have been a positive factor in keeping the main participants motivated to attend session.

A lack of time within the support group was identified as a major theme in several senses throughout the process of the creative project. Time became a factor as it was considered a reason for some main participant's inability to commit to monthly sessions due to previous commitments. Time was also named in the sense that once a month was not frequent enough to explore and complete the process of the altered book project.

A sense of gratitude regarding new social connections was named as an effect of the support group by both interviewees, and this was also a theme discussed during the final support group session.

Both interviews revealed an overall improvement in quality of life, which may be attributed at least in part, to the social connections established as well as the healing process that was encouraged through the course of art-making and the ultimate creation of an art product. Participant Ruth's self-reflection into her creative process, which she connected to being possibly stimulating in her career as a writer and at the least a positive conduit for her creativity, was insightful. All of the main participants strongly expressed interest in further support groups for those struggling with medical diagnoses.

# Creative Art Project

Data gathered from the art process and product revealed themes of both unplanned and organic processes (Ruth and Lee) as well as methodical and direct intentions (Patricia and Denise). The former may indicate both a sense of safety and support within the group, the ability to explore the art materials without risk of judgment or critique from others in the group. A deeper aspect of letting the subconscious guide the art could be that it may trigger emotions that one has not explored fully, if at all, which may result in retreating from the process (as possibly evidenced by Ruth missing several sessions, including the final session, after creating images in Fig. 1). Conversely, at the time of the support group, Patricia was battling a terminal diagnosis of cancer and Denise revealed within the last several group sessions that though she has been in remission from cancer for several years, she is constantly worried about relapse. Perhaps the structure

and straightforward approaches that both Patricia and Denise lent to their creative process and altered book creation could be attributed to their need for pragmatism in processing the devastating realities and possibilities of their illnesses. This may be an attempt to guard emotions and to create distance through rationality. Patricia's inability to complete her book by the last session of the support group may indicate deep meaning. Principal Researcher postulates that Patricia may have unconsciously equated finishing her book with giving up hope against her cancer battle.

The Principal Researcher also postulates that the structure of a traditional book, which altered books use as a basic template, may encourage one to employ more logical and "known" applications and processes in creating their own book.

Data gathered from all of the altered books revealed a sense of life and, more specifically, growth. The use of the color green was prevalent in many of the altered books. Imagery depicting trees and/or flowers was in found in all four of the finished altered books. Principal Researcher postulates that this symbolism may indicate a sense of participant's cancer journeys to recovery, from barren or sparse winter trees and flowers, to more thriving, lively greenery.

A subtheme identified within the larger theme of life and growth was the likening of the cancer journey to undertaking the climbing of a mountain or a similar physical feat. Lee's depiction of a person scaling the side of a mountain, along with the text "strength to endure" seen in Figure L-2, as well as Denise's motivational "climb" (Figure D-3) which was written on book's back cover represent this theme. Denise also reported that a significant event during the end of her cancer treatment came when she set out for a major hike up a mountain and managed, though exhausted, to succeed in this challenge.

She found this experience to be parallel to her battle with cancer and appeared to find great relief and inspiration in her physical ability to "take on" and overcome this challenging endeavor.

A sense of gratitude, specifically regarding social connections, was also a theme identified throughout the six working sessions, and most specifically during the final session. Support systems became particularly prevalent during the final group session, as group members each disclosed how integral social connections had been during their past or current cancer treatments. A sense of pride in one's art project as well as a desire to share their altered books and stories with fellow group members was a theme noticed by the Principal Researcher during the final group session. The three main participants who attended the support group's final session (Patricia, Denise, and Lee) employed efforts to exchange contact information with each other, as well as with PR and research cluster members. They spoke with each other about future contact and expressed interest in the findings from this research project.

Participant's age may have been factors in the selection of methods of art they employed, as content of imagery, and in the excitement of creation of new friends.

### Meanings

This section first summarizes the findings from the analysis of the data. These are the four themes were identified from the data analysis; time, a sense of life and growth, gratitude, and the creative process. In the following section, these four themes are further elaborated. Then, connections to themes from the literature review are examined.

Time

The first theme, time, became a noted factor in many ways. The passage of time was of note to all participants, particularly the time during their cancer treatment. Time was relevant for some in that as time passed during their remission, the possibility of relapse over time was a major concern. In the present sense, time became a factor in whether the participants could commit to the support group yet it was named during all three sets of data collection that meeting once a month was not enough time.

# Life and Growth

A sense of life and growth was concurrent among group members. Each main participant included imagery of flowers and/or trees within their books and many described stories about how nature had been somehow significant in their cancer treatment. A connection to the natural, perhaps alluding to the healing qualities of nature, may be explored as important. A theme of time again may be ascertained through the four season's indications, as trees and plants reflect the passage of time by bearing and shedding fruit and foliage. PR postulates that participant's age may have been a factor in their identification of time with nature. Symbolism associated with seasons of life, or stages in life, may not have been choices that participants with less life experience may have chosen to symbolize their cancer journeys by.

# Gratitude

During the final session of the group, each member stated a sense of gratitude to be able to be present in their current lives. Some group members also shared this sentiment visually, as seen in Figure D-2. The group members also reported a sense of gratitude for social connections, both those that had been reestablished since receiving their cancer diagnoses as well new friendships and connections that have been formed because of their diagnosis.

# Creative Process

The creative process appeared to have been an important factor to all four participants. Participant Ruth considered the possibility of the creative art project to eliminate her long-standing writer's block. Lee had begun to take both creative writing and visual art classes in her community and acknowledged that she would not have done so if she had not been stimulated by art-making in the support group.

### Connection to Literature

Connections to, as well as deviations from, the aforementioned literature are explored in this section.

The three participants who attended the final meeting of the IMPAACT Support Group were all women, which supports the research found by Kessler, Brown and Broman (1981) stating that women are more likely than men to seek professional help for emotional distress. Principal Researcher does want to emphasize that this study was guided by the fact that only women were offered the option to participate in the creative art support group.

The expressed need from the IMPAACT group participants for further social support as well as creative outlets reinforces Sautier, Mehnert, Hocker, & Schilling, 2014, research which found that over half of their research participants desired further support after their group ended. Serlin, Classen, Frances, & Angell, 2000, identified social-isolation, lowered self-confidence, and grief as common side effects from a cancer diagnosis. PR noted a sense of social isolation and also a great deal of anxiety regarding relapse of the illness (or, as in Patricia's case, the current threat of the illness) as impacts of the battle against cancer. The IMPAACT support group's repeated theme of desire for social connection and support, expressed both visually and verbally, also corroborates Sautier, Mehnert, Hocker, & Schilling's 2014 work.

Nainis, Paice, Ratner, Wirth, Lai, and Shott's 2006 research studied the effects of art therapy interventions on patients who required hospitalization for their illness. This study differs from PR's research, as Nainis et al. focused on the process while this research considered both process and product. Another diverging factor is that within Nainis et al. work, the patient was asked what their focused goal of the session was, rather than utilizing a more organic approach to their creativity. This research allotted the participant to follow their own perception of needs or goals, and allowed space for their objectives to be modified or even unstated. This may result in a stifling of creativity within the art process and product, if a specific goal is being sought. Additionally, the researchers note that they evaluated patients immediately after a single art therapy

session. This may not give participants enough time to process their experience, but the researchers were hopeful that their study would help to set framework for more long-term work to be implemented and evaluated.

### Conclusions

In conclusion, Principal Researcher believes that the creation of an altered book did increase the participant's overall quality of life. Evidence of this may lie simply in that the main participants each sacrificed their time and energy to attend many of the seven sessions, suggesting that they were receiving a benefit from attending. All of the main participants appeared to have found value in their experience, and all in ways fitting their unique needs and reasons for joining the group. It was inspiring for PR to consider the physical and emotional demands that taking part in such a support group may have had on the participants and their dedication to the creative process and to group cohesion is treasured.

Principal Researcher firmly believes in the intrinsic desire for humans to create, as well as the healing power that the process of creating manifests. This specific research project allotted the participants the opportunity to verbally engage within the group setting or focus on their long-term art project. This allowed the participants to fulfill their specific needs during each group session.

Principal Researcher approached the concept of collecting qualitative data with some reluctance. This being PR's first experience in conducting clinical research, the seemingly subjectivity of this type of data initially felt insubstantial. However, through this experience, Principal Researcher's views have shifted. The ability of qualitative data

analysis to identify and deeply explore emergent themes has provided an enlightening and rich experience. Additionally, PR found the process of conducting clinical research an enlightening parallel to clinical therapy.

PR looks forward to engaging in further art therapy research in the future, to deepen her clinical work as well as to support and expand the field of clinical art therapy.

Potential changes to future support groups would be to create a schedule with less time lapsing between sessions. Weekly sessions may be difficult for members to commit to, but twice a month sessions may be a realistic goal. Another modification might be to emphasize the importance of attendance to all sessions, as it fosters a sense of consistency and routine within the group. Research mentor and PR had initially thought that asking participants to meet more than once a month may have been too big of a commitment, but in retrospect, it appears it may have been beneficial to the group for meetings to occur with more regularity.

Another consideration is that the sessions were held in a university setting, which may lend a more academic perspective to group participants. This may modify or dampen their creative process, as opposed to a therapeutic arts support group being held in a more creative setting such as an art studio.

The experience for Principal Researcher to both be present in the here and now, particularly through deep and intense emotional interactions and revelations during the sessions was a difficult space to navigate. Challenges presented themselves especially when participants revealed deeply personal information, both verbally and visually, and Principal Researcher did not feel comfortable deeply exploring these vulnerable spaces because of both time and space restrictions. Though participants were aware of the

research aspect of this support group, PR felt that the intimacy, which was created and fostered over six months, would be somewhat exploited by focusing on data collection in those moments. Principal Researcher found each participant's cancer journey and process of exploring their unique experiences deeply engaging. The honor of taking part in this process has lead PR to consider the need for support groups, particularly ones that encourage a creative process. PR has been interested in populations aged 50 and older, in terms of examining factors unique to this age group including empty nest syndrome, loss of spouse due to death or divorce, and/or increasing medical and mental health illness with increase in age. Being given the privilege of conducting a role within this support group has deepened PR's interest in seeking more opportunities to offer similar experiences to others in the future.

A more general takeaway from this experience is that the need for support and desire for human connection is strong. Our current modernized Western culture has possibly become hyper-focused on technological communication but perhaps at the cost of sacrificing intimacy experienced between interpersonal connections. This focus on contemporary methods of contact may also isolate older populations, which are growing substantially. Maintaining the ability to establish new social connections into and throughout the aging process, in those both with and without a major medical diagnosis, may be a key component to mitigating social isolation as the United States' baby-boomer generation approaches senior citizen status.

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# Appendix A: IRB Letter of Approval and Questionnaire

Dear Ms. Luz,

Thank you for submitting your IRB application for your protocol titled **Exploration of the Process of a Creative Art Project with Women Cancer Survivors**. All documents have been received and reviewed, and I am pleased to inform you that your study has been approved.

The effective date of your approval is **December 16**, **2015 – December 15**, **2016.** If you wish to continue your project beyond the effective period, you must submit a renewal application to the IRB prior to **November 1**, **2016.** In addition, if there are any changes to your protocol, you are required to submit an addendum application.

For any further communication regarding your approved study, please reference your new protocol number: **LMU IRB 2015 FA 45.** 

Best wishes for a successful research project.

Sincerely,

Julie Paterson

Julie Paterson I Sr. IRB Coordinator I Loyola Marymount University I 1 LMU Drive I U-Hall #1718 I Los Angeles, CA 90045 I (310) 258-5465

# LOYOLA MARYMOUNT UNIVERSITY IRB Application Questionnaire

#### 1. RESEARCH BACKGROUND

Please describe the purpose of your research. Provide relevant background information and briefly state your research question(s). You may provide relevant citations as necessary. (300 Word Max.)

This study is exploring the creative process experienced during the creation of an art project. It is part of a larger study in the Life Sciences Department (IMPAACT Study).

#### 2. SUBJECT RECRUITMENT

How will subjects be selected? What is the sex and age range of the subjects? Approximately how many subjects will be studied?

How will subjects be contacted? Who will make initial contact with subjects? Specifically, what will subjects be told in initial contact?

If subjects will be screened, describe criteria and procedures.

The participants were initially invited to participate in the IMPAACT study by researchers who coordinated that study. The participants will be asked in person if they would like to voluntarily participate in current study. The participants will be told that their participation in the study will consist of principal investigator administering a questionnaire about their experience creating the art project in a community setting with cancer survivors. In addition, the participants will also be invited to participate in a conversation/interview after the questionnaire. An individual conversation about their experience in creating an art project about their cancer story in a community setting with other cancer survivors will be conducted by the principal investigator. The participants are all female and the age range is 40-70 years old. Approximately 4-8 participants will be asked to participate in the study.

#### 3. PROCEDURES

Summarize fully all procedures to be conducted with human subjects.

The participants will engage in a telephone conversation with principal investigator and answer questions about their experience regarding the creation of art project.

In addition to the telephone conversations, principal investigator will engage in a qualitative, analytic discussion of the art imagery created with 3 art therapists who facilitated support group.

#### 4. RISKS / BENEFITS

Potential benefits are providing a space to reflect and process on their personal cancer experiences.

Potential risks are the possibilities of embarrassment, sadness, and feelings of invasion of privacy. Risks will be minimized in advance by principal investigator using clinical judgment during the conversation/interview process and by avoiding topics or questions that may be overly emotionally triggering for participants. In the event that a participant does become emotionally triggered, Jillian Luz and Debra Linesch will provide a list of community mental health resources.

#### 5. CONFIDENTIALITY

Will subjects be identifiable by name or other means? If subjects will be identifiable, explain the procedures that will be used for collecting, processing, and storing data. Who will have access to data? What will be done with the data when the study is completed? If you are collecting visual images of your subjects please justify this.

Participants will be given pseudonyms to maintain confidentiality. The principal investigator and research mentor Debra Linesch will have access to the data. The data will be destroyed upon completion of the study. I may be collecting audiotape of participants during focus group and/or telephone interviews. Principal investigator will take photographs of group participants artwork and will maintain participant's confidentiality by concealing any identifying markers on or within the art imagery. Digital images of artwork will be destroyed upon completion of study.

#### 6. INFORMED CONSENT

Attach an informed consent form or a written request for waiver of an informed consent form. Include waiver of written consent if appropriate. If your research is being conducted in another language, please include copies of the translated "Informed Consent" or "Waiver of Written Consent" forms.

Please see two attached Informed Consent forms. Informed Consent dated August 5, 2015 is for the support group and use of photography and artwork use. Informed Consent dated 11/17/15 is for support group permission to interview participants.

### **7.STUDENT RESEARCH**

When a student acts as principal investigator, a faculty sponsor signature is required on the application form.

This shall be completed.

8. RENEWAL APPLICATIONS

When the submission is a Renewal Application, include a summary of the research activities during the previous granting period specifically addressing: number of subjects studied and any adverse reactions encountered, benefits which have been derived, any difficulty in obtaining subjects or in obtaining informed consent, and approximate number of subjects required to complete the study.

N/A

#### 9. PAYMENTS

If subjects are to be paid in cash, services, or benefits, include the specific amount, degree, and basis of remuneration.

N/A

#### 10. PSYCHOLOGY SUBJECT POOL

When students from the Psychology Subject Pool (PSP) are to be involved as subjects, permission must be obtained from the PSP prior to running subjects.

Forms are available from the Psychology Office in 4700 University Hall. It is not necessary to inform the IRB of approval from the PSP, however the PSP requires IRB approval prior to permission for using the pool being granted.

N/A

#### 11. QUALIFICATIONS AND TRAINING

Describe the qualifications of, or method of training and supervision afforded student experimenters. This includes past experience, type and frequency of student/sponsor interactions during the experiment, and Human Subjects Protections Training.

Completed course MFTH 691: Research Methods and The National Institutes of Health (NIH) Office of Extramural Research training course "Protecting Human Research Participants" (see attached certificate).

#### 12. RANDOMIZATION

Describe criteria for assigning subjects to sub-groups such as "control" and "experimental."

N/A

#### 13. USE OF DECEPTION

If the project involves deception, describe the debriefing procedures that will be used.

Include, verbatim, the following statement in the consent form: "Some of the information with which I will be provided may be ambiguous or inaccurate. The investigator will, however, inform me of any inaccuracies following my participation in this study."

N/A

#### 14. QUESTIONNAIRES AND SURVEYS

Include copies of questionnaires or survey instruments with the application (draft form is acceptable).

If not yet developed, please so indicate and provide the Committee with an outline of the general topics that will be covered. Also, when the questionnaire or interview schedule has been compiled, it must be submitted to the Committee for separate review and approval. These instruments must be submitted for approval prior to their use.

Consider your population. If they are foreign speakers, please include copies in the foreign language.

See attached questionnaire draft.

#### 15. PHYSICIAN INTERACTIONS

To ensure that all patients receive coordinated care, the principal investigator is obligated to inform the primary physician (when not the principal investigator) of all studies on his/her patients.

N/A

16. SUBJECT SAFETY

Describe provisions, if appropriate, to monitor the research data collected, to ensure continued safety to subjects.

N/A

17. REDUNDANCY

To minimize risks to subjects, whenever appropriate, use procedures already being performed on the subjects for diagnostic or treatment purposes. Describe provisions.

N/A

#### 18. COUNSELING

In projects dealing with sensitive topics (e.g., depression, abortion, intimate relationships, etc.) appropriate follow-up counseling services must be made available to which subjects might be referred.

The IRB should be notified of these services and how they will be made available to subjects.

The participants will be referred to IMPAACT study principal investigator Dr. Heather Tarleton for counseling resources.

#### 19. SAFEGUARDING IDENTITY

When a research project involves the study of behaviors that are considered criminal or socially deviant (i.e., alcohol or drug use) special care should be taken to protect the identities of participating subjects.

In certain instances, principal investigators may apply for "Confidentiality Certificates" from the Department of Health and Human Services or for "Grants of Confidentiality" from the Department of Justice.

N/A

#### 20. ADVERTISEMENTS

If advertisements for subjects are to be used, attach a copy and identify the medium of display.  $N/A \$ 

#### 21. FOREIGN RESEARCH

When research takes place in a foreign culture, the investigator must consider the ethical principles of that culture in addition to the principles listed above.

N/A

#### 22. EXEMPTION CATEGORIES (45 CFR 46.101(b) 1-6)

If you believe your study falls into any of the Exemption Categories listed below, please explain which category(ies) you believe it falls into and why.

- Research conducted in established or commonly accepted educational settings, involving normal educational practices, such as (i) research on regular and special instructional strategies, or (ii) research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.
- Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), if information taken from these sources is recorded in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.
- 3) Research involving survey or interview procedures, except where <u>all</u> of the following conditions exist: (i) responses are recorded in such a manner that the human subjects can be identified, directly or through identifiers linked to the subjects, (ii) the subject's responses, if they became known outside the research, could reasonably place the subject at risk of criminal or civil liability, or be damaging to the subject's financial standing, employability, or reputation, and (iii) the research deals with sensitive aspects of the subject's own behavior, such as illegal conduct, drug use, sexual behavior, or use of alcohol.

All research involving survey or interview procedures is exempt, without exception, when the respondents are elected or appointed public officials, or candidates for public office.

- 4) Research involving the observation (including observation by participants) of public behavior, except where <u>all</u> of the following conditions exist: (i) observations are recorded in such a manner that the human subjects can be identified, directly or through the identifiers linked to the subjects, (ii) the observations recorded about the individual, if they became known outside the research, could reasonably place the subject at risk of criminal or civil liability, or be damaging to the subject's financial standing, employability, or reputation, and (iii) the research deals with sensitive aspects of the subject's own behavior such as illegal conduct, drug use, sexual behavior, or use of alcohol.
- 5) Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.
- 6) Unless specifically required by statute (and except to the extent specified in paragraph (1)), research and demonstration projects which are conducted by or subject to the approval of the Department of Health and Human Services, and which are designed to study, evaluate, or otherwise examine: (i) programs under the Social Security Act or other public benefit or service programs, (ii) procedures for obtaining benefits or services under those programs, (iii) possible changes in or alternatives to those programs or procedures, or (iv) possible changes in methods or levels of payment for benefits or services under those programs.

N/A

Please deliver to: Julie Paterson, IRB Coordinator, University Hall, Suite 1718 or jpaterso@lmu.edu.

#### **Appendix B: Experimental Bill of Rights**

#### LOYOLA MARYMOUNT UNIVERSITY

#### **Experimental Subjects Bill of Rights**

# Pursuant to California Health and Safety Code §24172, I understand that I have the following rights as a participant in a research study:

- 1. I will be informed of the nature and purpose of the experiment.
- 2. I will be given an explanation of the procedures to be followed in the medical experiment, and any drug or device to be utilized.
- 3. I will be given a description of any attendant discomforts and risks to be reasonably expected from the study.
- 4. I will be given an explanation of any benefits to be expected from the study, if applicable.
- 5. I will be given a disclosure of any appropriate alternative procedures, drugs or devices that might be advantageous and their relative risks and benefits.
- 6. I will be informed of the avenues of medical treatment, if any, available after the study is completed if complications should arise.

- I will be given an opportunity to ask any questions concerning the study or the procedures involved.
- 8. I will be instructed that consent to participate in the research study may be withdrawn at any time and that I may discontinue participation in the study without prejudice to me.
- 9. I will be given a copy of the signed and dated written consent form.
- 10. I will be given the opportunity to decide to consent or not to consent to the study without the intervention of any element of force, fraud, deceit, duress, coercion, or undue influence on my decision.

# Appendix C: Informed Consent Document LOYOLA MARYMOUNT UNIVERSITY

**Informed Consent Form** 

**Date of Preparation: 11/17/15** 

#### Loyola Marymount University

#### Exploration of the Process of a Creative Art Project with Women Cancer Survivors.

 I hereby authorize Jillian Luz, MA Candidate to include me in the following research study: title of study Exploration of the Process of a Creative Art Project with Women Cancer Survivors.

2) I have been asked to participate on a research project which is designed to explore the process of the creation of altered books with women who are cancer survivors. This process will last for approximately 90 minutes.

3) It has been explained to me that the reason for my inclusion in this project is that I am a woman who has/had cancer and was a participant in the IMPAACT study.

I understand that if I am a participant, I will complete a questionnaire and discuss the experience of creating an altered book within a group of women cancer survivors.
 The investigator(s) will interview me and ask questions about my experience.

These procedures have been explained to me by Jillian Luz, MA Candidate.

5) I understand that I may be audiotaped in the process of these research procedures. It has been explained to me that these tapes will be used for teaching and/or research purposes only and that my identity will not be disclosed. I have been assured that the tapes will be destroyed after their use in this research project is completed. I understand that I have the right to review the tapes made as part of the study to determine whether they should be edited or erased in whole or in part.

6) I understand that the study described above may involve the following risks and/or discomforts: Potential risks are the possibilities of embarrassment, sadness, and feelings of invasion of privacy.

7) I also understand that the possible benefits of the study are the ability to have a space in which to reflect on and process my cancer experience.

I understand that the following alternative procedures (and/or drugs) are available.
 The reason these are not being used is: \_\_N/A\_.

9) I understand that Debra Linesch, who can be reached at (310) 338-7674, will answer any questions I may have at any time concerning details of the procedures performed as part of this study.

10) If the study design or the use of the information is to be changed, I will be so informed and my consent re-obtained.

11) I understand that I have the right to refuse to participate in, or to withdraw from this research at any time without prejudice to (e.g., my future medical care at LMU.)

12) I understand that circumstances may arise which might cause the investigator to terminate my participation before the completion of the study.

13) I understand that no information that identifies me will be released without my separate consent except as specifically required by law.

14) I understand that I have the right to refuse to answer any question that I may not wish to answer.

15) I understand that if I have any further questions, comments, or concerns about the study or the informed consent process, I may contact David Hardy, Ph.D. Chair, Institutional Review Board, 1 LMU Drive, Suite 3000, Loyola Marymount University, Los Angeles CA 90045-2659 (310) 258-5465, <u>david.hardy@lmu.edu</u>.

16) In signing this consent form, I acknowledge receipt of a copy of the form, and a copy of the "Subject's Bill of Rights".

Subject's Signature \_\_\_\_\_

Date \_\_\_\_\_

Witness \_\_\_\_\_

Date \_\_\_\_\_

# Appendix D: Protecting Human Research Participants" Certificate of Completion

## **Certificate of Completion**

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Jillian Luz** successfully completed the NIH Web-based training course "Protecting Human Research Participants".

Date of completion: 08/12/2015

Certification Number: 1776243

# Appendix E: Research Interview Questions

(1) Did you think it was helpful to participate in this creative arts therapy experience?

(2) Would your recommend this process to someone else with a health problem?

(3) What was the most important thing that happened to you as a result of participating in the creative arts therapy exercises?

(4) What did it trigger for you?

(5) What made you want to join?

(6) What, if any, were you expectations from participating?

(7) Were you expectations different from what actually transpired?

(8) How did you feel about meeting the other women?

- (9) How has making the art been for you?
- (10) How was the book aspect for you?
- (11) Describe your art-making process?

# Appendix F: Exit Questionnaire developed by Puig, Lee, Goodwin, and Sherrard

(1) Did you think it was helpful to participate in this creative arts therapy experience?

(2) Would you recommend this process to someone else with a health problem?

(3) What was the most important thing that happened to you as a result of participating in the creative arts therapy exercises?