Spring 5-6-2016

A Pilot Project of Art and Eating Disorders: A Self-Advocacy Campaign Through Video Narratives

Sarah Pray
Southern Illinois University Edwardsville

Follow this and additional works at: http://spark.siue.edu/atcfinal

Part of the Art Practice Commons, Art Therapy Commons, Music Therapy Commons, Other Film and Media Studies Commons, Social Work Commons, and the Women's Studies Commons

Recommended Citation
http://spark.siue.edu/atcfinal/1

This Final Project is brought to you for free and open access by the Art & Design at SPARK. It has been accepted for inclusion in Art Therapy Counseling Final Research Projects by an authorized administrator of SPARK. For more information, please contact gpark@siue.edu.
A Pilot Project of Art and Eating Disorders: A Self-Advocacy Campaign through Video Narratives

by Sarah Pray, Bachelor of Arts

A Research Project Submitted in Partial Fulfillment of the Requirements for the Degree of Master of Arts in the field of Art Therapy Counseling

Advisory Committee:

Megan Robb, Chair

Shelly Goebl-Parker

Gussie Klorer

Graduate School
Southern Illinois University Edwardsville
April, 2016
PROJECT SUMMARY

A PILOT PROJECT OF ART AND EATING DISORDERS: A SELF-ADVOCACY CAMPAIGN THROUGH VIDEO NARRATIVES

by

SARAH PRAY

Chairperson: Professor Megan Robb

This pilot project of Art and Eating Disorders was approved by The Emily Program Foundation (TEPF) (Emily Program Foundation, n.d.), a 501(c) (3) nonprofit working to eliminate eating disorders through advocacy, social outreach, and collaboration with community partners.

Between July and August 2015, TEPF recruited five artists. Artists were interviewed by Sarah Pray and artwork digitally recorded at various locations, filmed and edited by videographer, Eve Daniels. Artists brought artwork and other creative work related to their recovery. The resulting videos were uploaded to the TEPF website (www.theemilyprogramfoundation.org) weekly, between November 17 and December 15, 2015. The goal of the pilot project was to measure the project's ability to document stories of recovery from an eating disorder, to provide a supportive and creative environment to create film narratives of recovery, and to increase public awareness of eating disorders through its online platform. This proposal demonstrated the need for online resources that support recovery and promote advocacy for the treatment of eating disorders.

Keywords: eating disorders, art therapy, recovery, narrative inquiry, advocacy
### TABLE OF CONTENTS

PROJECT SUMMARY .................................................................................................................. ii

ACKNOWLEDGEMENTS ........................................................................................................... vi

LIST OF FIGURES ................................................................................................................... vii

LIST OF TABLES ...................................................................................................................... viii

Chapter

I. INTRODUCTION ................................................................................................................. 1
   Assessment of Need/Statistics .............................................................................................. 1
   Project Overview .................................................................................................................. 4
   Key Individuals .................................................................................................................... 5
      Project Coordinator/Art Therapy Student
      The Emily Program Foundation
      Keri Clifton
      Eve Daniels
      Essential Sessions Studios
      Kyle Meadors
      The Artists
   Definition of Terms .............................................................................................................. 9
      Eating Disorder
      Advocacy
      Recovery
      Psychological Well-being

II. LITERATURE REVIEW ..................................................................................................... 12
   Narratives Therapy and Eating Disorders .......................................................................... 12
   Narratives Inquiry and Eating Disorders .......................................................................... 13
      Etiology
      Recovery as Non-linear
      Readiness to Change
      De-identification with the Illness and a Changed Self-Concept
      Acceptance of the Self and Emotions
      Social Connection
   Art Therapy and Eating Disorders ..................................................................................... 17
   Recovery Narratives and Advocacy .................................................................................... 18
   Eating Disorders and Advocacy ......................................................................................... 20

III. PROJECT PURPOSE/GOALS & OBJECTIVES .............................................................. 23

   iii
Goals and Objectives ................................................................. 23

IV. WORK PLAN .................................................................................. 25

Participation Eligibility and Recruitment ........................................ 25
Procurement of Recording Time and Equipment .............................. 27
Procedure for Recording the Videos ............................................... 27
   Pre-recording
   Recording Sessions
   Post-recording and Editing
   Website Implementation and Presentations

V. EVALUATION OF GOALS AND OUTCOMES ............................... 30

Logistical Outcomes ........................................................................ 30
Artist Feedback .................................................................................. 30
   Rating Scale Results
   One Thing Learned from the Filming Experience
   Impact of the Filming Experience on Self-Understanding
   Changes to the Filming Experience
   Reactions to the Video Narratives
   Changes to the Final Videos
   Artists’ Takeaway
Theoretical Orientation ..................................................................... 34
Themes in the Full Audio Interviews ................................................. 35
   Supportive Factors in Recovery
   Etiology of the Eating Disorder
   The Roles of Art in Recovery
   The Role of Society
   Themes in Joey’s Interview
   Reason for Participation

Audience Feedback and Public Awareness ........................................ 51
   Audience Survey
   Social Media Outcomes

VI. DISCUSSION/CONCLUSION/RECOMMENDATIONS ..................... 56

Discussion ......................................................................................... 56
   Ethical Aspects
Application for Art Therapists ....................................................... 60
Limitations ......................................................................................... 62
Future Recommendations ............................................................... 63
Personal Reflection ............................................................................ 64

REFERENCES ..................................................................................... 65
APPENDICES .................................................................................................................. Page

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A.</td>
<td>Artist Feedback Form I</td>
<td>70</td>
</tr>
<tr>
<td>B.</td>
<td>Artist Feedback Form II</td>
<td>71</td>
</tr>
<tr>
<td>C.</td>
<td>Audience Survey</td>
<td>72</td>
</tr>
<tr>
<td>D.</td>
<td>Project Coordinator Resume</td>
<td>73</td>
</tr>
<tr>
<td>E.</td>
<td>Call for Participants</td>
<td>74</td>
</tr>
<tr>
<td>F.</td>
<td>IRB Approval and Consent Forms</td>
<td>75</td>
</tr>
<tr>
<td>G.</td>
<td>NEDA Guidelines for Sharing Your Story</td>
<td>76</td>
</tr>
<tr>
<td>H.</td>
<td>Interview Questions</td>
<td>77</td>
</tr>
<tr>
<td>I.</td>
<td>Data from Artists Feedback Questions</td>
<td>78</td>
</tr>
<tr>
<td>J.</td>
<td>Word Cloud: Supportive Factors in Recovery</td>
<td>79</td>
</tr>
<tr>
<td>K.</td>
<td>Word Cloud: Etiology of the Eating Disorder</td>
<td>80</td>
</tr>
<tr>
<td>L.</td>
<td>Word Cloud: The Roles of Art in Recovery</td>
<td>81</td>
</tr>
</tbody>
</table>
ACKNOWLEDGMENTS

I would like to thank my family, Thomas Kivi, Jessica Winslow, The Emily Program, The Emily Program Foundation, Keri Clifton, Eve Daniels, and my SIUE professors Megan Robb, Shelly Goebl-Parker and Gussie Klorer for their support and encouragement throughout this journey.
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Deborah</td>
<td>7</td>
</tr>
<tr>
<td>2.</td>
<td>Kelly</td>
<td>8</td>
</tr>
<tr>
<td>3.</td>
<td>Kristine</td>
<td>8</td>
</tr>
<tr>
<td>4.</td>
<td>Marsha</td>
<td>8</td>
</tr>
<tr>
<td>5.</td>
<td>Joey</td>
<td>9</td>
</tr>
<tr>
<td>6.</td>
<td>Kristine and her sister working on her song</td>
<td>43</td>
</tr>
<tr>
<td>7.</td>
<td>Marsha’s binder</td>
<td>45</td>
</tr>
<tr>
<td>8.</td>
<td>Deborah’s earrings</td>
<td>45</td>
</tr>
<tr>
<td>9.</td>
<td>Kelly’s art</td>
<td>45</td>
</tr>
<tr>
<td>10.</td>
<td>Deborah’s hand-spun yarn</td>
<td>46</td>
</tr>
<tr>
<td>11.</td>
<td>Kristine playing the drums</td>
<td>46</td>
</tr>
<tr>
<td>12.</td>
<td>Kelly painting</td>
<td>47</td>
</tr>
<tr>
<td>13.</td>
<td>Joint drawings by Joey and his daughter</td>
<td>49</td>
</tr>
<tr>
<td>14.</td>
<td>TEPF gallery exhibit</td>
<td>51</td>
</tr>
<tr>
<td>15.</td>
<td>TEPF YouTube channel view time</td>
<td>55</td>
</tr>
</tbody>
</table>
LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Alternate Research Terms</td>
<td>12</td>
</tr>
<tr>
<td>2.</td>
<td>Recruitment Location and Status</td>
<td>27</td>
</tr>
<tr>
<td>3.</td>
<td>Project Timeline</td>
<td>29</td>
</tr>
<tr>
<td>4.</td>
<td>YouTube Analytics Comparison on TEPF Channel</td>
<td>55</td>
</tr>
</tbody>
</table>
Chapter I

Introduction

This project was guided by the following question: Can video shorts of artists who have struggled with an eating disorder document authentic stories of recovery, provide a supportive and creative environment to the artists, and increase public awareness of eating disorders? The pilot project, Art and Eating Disorders, was as an advocacy campaign approved by The Emily Program Foundation (TEPF) (Emily Program Foundation, n.d.), a 501(c) (3) nonprofit working to eliminate eating disorders through advocacy, social outreach, and collaboration with community partners. The resulting five video narratives—four videos from individuals recovered or recovering from an eating disorder and one video from a father’s perspective—can be viewed on the TEPF website at http://emilyprogramfoundation.org/our-work/programs/art-and-eating-disorders and on the SIUE Women’s Studies Program Blog at https://siuewmst.wordpress.com/2016/03/28/art-and-eating-disorders-a-self-advocacy-campaign-through-video-narratives.

Assessment of Need/Statistics

In the United States, 20 million women and 10 million men suffer from a clinically significant eating disorder at some point in their lifetime (Wade, Keski-Rahkonen, & Hudson, 2011). Eating disorders have the highest mortality rate of any mental illness, yet many cases are not being reported (Arcelus, Mitchell, Wales, & Nielsen, 2011). Only 33.8% of adults suffering with anorexia, 43.6% with bulimia, and 43.2% with binge eating disorder are receiving treatment (Hudson, Hiripi, Pope & Kessler, 2007). In addition, many people struggle with sub-clinical disordered eating attitudes and body dissatisfaction. For example, 70% of 12th grade females in Minnesota reported trying to lose weight, while only 17% were overweight or obese according to body mass index (Minnesota Student Survey Interagency
Team, 2010). This is particularly distressing because body dissatisfaction has been identified as the "best-known" contributor to the development of an eating disorder (Stice, 2002, p. 4). Videos from Art and Eating Disorders provide online support in the form of recovery stories for those who have not yet sought treatment and those suffering from sub-clinical eating disorder symptoms.

The treatment of eating disorders has long suffered from a lack of understanding resulting in unsupportive and even destructive insurance practices. Such misunderstanding about the serious nature of the disease breeds stigma and shame, impeding individuals from seeking treatment (Missouri Eating Disorder Association, n.d.). Eating disorder advocacy groups tend to focus on prevention techniques, improved treatments, and access to care. While these are necessary areas of advocacy, efforts should also promote cultural change towards a world that treats people with "the love, care and respect they deserve" (Grefe, 2012, p. 297). Several studies demonstrate a need for advocacy, and a deeper understanding of eating disorder course and etiology in order to combat the stigma surrounding eating disorders (Grefe, 2012; Pandya, 2012; Weaver & Pye, 2010; Wingfield, Kelly, Serdar, Shivy & Mazzeo, 2011).

Personal self-narratives are an important tool for reducing stigma and increasing understanding of serious mental illnesses (Pandya, 2012). For example, The National Eating Disorders Association (NEDA) provides online access to Stories of Hope, a series of written testimonies concerning eating disorder recovery (“National Eating Disorders Association, n.d.). Yet, video and audio resources about eating disorders are lacking. TEPF’s interest in promoting recovery videos is a testament to the need for advocacy and resources to captivate the public visually. Art and Eating Disorders also provided a unique opportunity for those recovered and recovering to practice self-advocacy through artful expression.
Websites that promote recovery are needed to counter the growth of pro-anorexia websites. "Pro-ana" websites present eating disorders as an alternative lifestyle and promote the thin ideal in the form of "thinspiration" images, quotes, lyrics, and weight-loss stories. Believing anorexia to be a legitimate quest for control and empowerment, users of pro-ana sites receive advice and support that tragically and ironically render them "weaker in the name of strength" (Taylor, 2002). Pro-ana sites can be triggering for those without eating disorders too. After viewing a pro-anorexia site, a large sample of female undergraduate students experienced greater negative affect, lower self-esteem, a perception of being heavier, and a greater likelihood to exercise and think about weight in the near future (Bardone-Cone & Cass, 2007). Online interventions such as Art and Eating Disorders are part of the pro-recovery movement that has been growing in response to pro-ana sites and other harmful online media (Taylor, 2002).

The synthesis of art therapy and narrative therapy is particularly useful to the eating disorder population in which self-blame, and fear of self-expression and assertiveness are common. Research by Robbins and Pehrsson (2009) found that narrative therapy, in conjunction with poetry, offered participants the opportunity to create an authentic and assertive voice, shifting blame from the self to the eating disorder. This has implications for Art and Eating Disorders in that the video narratives can be both therapeutic to the artist and inspiring to those suffering from eating disorders in the community.

Art-making, in and of itself, strengthens one’s ability to externalize “the problem” (Carlson, 1997; Riley, 1997). Art can capture hidden aspects of the self, enriching the narrative therapy approach, in which a person is called to re-author a dominant narrative. Because the use of art literally externalizes ideas onto paper, the art acts as a tool to help observe, discover, or re-invent alternative outcomes to one’s story (Riley, 1997). Similarly,
the narrative and artistic format of Art and Eating Disorders provided a platform for people to give voice to their own narrative arcs, countering the dominant narrative and shifting the problem from personal to political—from a personal mental health issue to a larger, social issue.

**Project Overview**

The three main project components of Art and Eating Disorders were: (1) the documentation of video narratives of recovery; (2) the provision of a supportive and creative environment to create the narratives using artwork and video; and (3) advocacy to increase public awareness of eating disorders through an online platform.

First, Art and Eating Disorders documented the stories of individuals overcoming a history of disordered eating. Through the assistance of TEPF, five artists were recruited to participate in filming personal stories of recovery. I interviewed the artists for 30 to 50 minutes at a location chosen by the artist. Videographer Eve Daniels filmed and edited the interviews into videos that range from 3:04 to 4:11 minutes. Artists evaluated the recording process and final video through verbal and written feedback (Appendix A and B).

Secondly, Art and Eating Disorders created a supportive and creative environment for people with eating disorder histories to create a video narrative of recovery. Artists identified supportive factors in their recovery, which were then documented in the final videos. As the project coordinator, I used reflective practices to "tune in" to hidden aspects of growth in the artists' stories as documented in the full audio interviews. Artists shared artwork as part of their recovery stories.

Once edited and approved by the artists, the five videos and full audio interviews were launched publicly, through an online platform, and presented at various events, with the purpose of increasing public awareness of recovery from an eating disorder. The online
platform was launched on the TEPF website November 17, 2015, and the videos and full audio interviews were uploaded to it, one at a time, on a weekly basis between November 17, 2015, and December 15, 2015. Each week following the release of a video, TEPF sent out a social media press-release that included a link to the audience survey (Appendix C). Between November 17 and January 26, I tracked YouTube analytics for the videos.

Key Individuals

The project coordinator/art therapy student. I am a candidate for a Masters in Art Therapy Counseling, with a Bachelors of Arts degree in Studio Art. I have seven years of recording experience as an intern and creative director of two recording studios, and as a musical performer. During this time, I have also served as an advocate for eating disorder awareness through TEPF, supporting Recovery Night events, Art and Eating Disorder events, and lobbying efforts in Washington, D.C. See Appendix D for my resume.

As the project coordinator, I was responsible for overseeing the outreach, procurement, and scheduling of artists, and website implementation. I also served as the art therapist who facilitated the recording process in collaboration with the artists. I interviewed the artists and provided structure, guidance, support, and encouragement during the recording process. As an art therapist in training, I used art therapy and counseling skills to provide a contained environment for the artists to explore their narrative. It is important to note, however, that the recording sessions were not considered therapy nor a substitute for treatment. Rather, I considered my role to be one of a collaborator and co-advocate.

The Emily Program Foundation. Since 2007, TEPF has developed a broad range of interventions, through community education, legislative advocacy, and awareness events. TEPF provides seminars for professionals, classrooms, community workshops, and other forums, to increase awareness and facilitate effective interventions for eating disorders.
TEPF also funds advocacy efforts through the Eating Disorder Coalition and through a financial assistance program to help individuals cover the cost of treatment (“The Emily Program Foundation,” n.d.).

From its inception, TEPF has held the belief that artwork helps individuals discover and assert their voices: “Artwork allows those living with an eating disorder to express themselves in ways that are often difficult to put into words. This artwork enhances the public’s understanding of eating disorders as a serious illness that impacts individuals, families, and communities” (“The Emily Program Foundation,” n.d.). Sharing artwork in multiple avenues, TEPF has held annual art exhibitions and participated in public art exhibits throughout the Twin Cities. TEPF also partners with Penumbra Theatre’s Summer Institute, teaching the next generation of artist activists (“The Emily Program Foundation,” n.d.).

TEPF provided the platform to host the videos on their website and social media sites. The website content manager from TEPF was responsible for hosting the content and designing the Art and Eating Disorder page on the TEPF website. The content manager also reported web traffic analytics to the project coordinator for analysis.

**Keri Clifton.** Administrative and Outreach Manager of TEPF, Keri Clifton works to raise awareness about eating disorders and related issues in the community through the coordination of TEPF’s community education and outreach efforts. She speaks to schools, health care professionals, and anyone who wants to learn more about eating disorders. She also coordinates the TEPF’s volunteer program. As the project liaison between TEPF and myself, Keri helped conceptualize the goals of the project, recruit artists, provide additional support to the artists during the recording sessions, and evaluate project goals.

**Eve Daniels.** Eve Daniels is an independent videographer from Minneapolis, MN, experienced in directing, filming, and editing a wide variety of video projects. Drawing from
her experience creating online video content, Eve applied knowledge of content marketing strategy to the Art and Eating disorders project. Typically, Eve charges $10,000 for a project of this size, at the rate of $2000 per video. However, Eve generously offered to film and edit all five videos for $1300 because of her interest in eating disorder awareness.

**Essential Sessions Studios.** Essential Sessions Studios is a full-service recording studio in St. Paul, MN, that donated its facilities, recording equipment and software as needed to the Art and Eating Disorders project. Familiar to the concept, Essential Sessions had previously donated recording time and equipment for four recording sessions to an earlier version of this project in 2012. Eve Daniels worked independently from Essential Sessions Studios, but used its facilities for recording Joey’s interview.

**Kyle Meadors.** Audio production student at Webster University, St. Louis, Kyle Meadors recorded the background music for all videos.

**The artists.**

**Deborah Taillon.** Deborah is a fiber artist, who makes her own yarn, needle-felts, and knits. She also makes jewelry, primarily in brass and silver. Her business is called Taillon Made (See Figure 1).

*Figure 1.* Deborah.
Kelly Reinhardt. Kelly is a painter, drawer, and cupcake artist at Nadia Cakes in Maple Grove, MN (See Figure 2).

Figure 2. Kelly.

Kristine Strangis. Kristine is a songwriter, drummer in her family band the Sals Sisters, and student at Hamline University (See Figure 3).

Figure 3. Kristine.

Marsha Beede. Marsha is a creative writer and blogger at https://mbeede1234.wordpress.com (See Figure 4).

Figure 4. Marsha.
Joey\textsuperscript{1}. Joey is a full-time songwriter and musician, and father to his adult daughter in recovery from an eating disorder. He also wrote and performed all background music for the videos, recorded by Kyle Meadors at Webster University (See Figure 5).

Figure 5. Joey.

Definition of Terms

For the purposes of this research, the following terms will be defined as follows:

Eating disorder. The most prevalent eating disorders among adolescents and adults are anorexia nervosa, bulimia nervosa, and binge eating disorder (Swanson et al., 2011). Diagnostic criteria for anorexia nervosa include the restriction of energy intake, an intense fear of weight gain or persistent behaviors that interfere with weight gain, and a disturbance in body image. Bulimia is diagnosed based on recurrent binge eating and purging to prevent weight gain, and the influence of body shape and weight on self-evaluation (APA, 2013). Binge eating disorder includes recurrent and persistent episodes of binge eating, marked distress regarding binge eating, and absence of regular compensatory behaviors. Binge episodes, constituted by eating much more rapidly and eating large amounts of food than normal, are typically accompanied by a strong sense of guilt, self-disgust, and loneliness (APA, 2013). Associated features of eating disorders can include obsessive-compulsive

\textsuperscript{1} Last name is omitted for this artist.
traits, a desire for control or loss of control, feelings of ineffectiveness, inflexible thinking, restrained emotional expression, and symptoms of depression and anxiety.

**Advocacy.** According to the World Health Organization (WHO) (2003), advocacy for mental health consists of "various actions aimed at changing the major structural and attitudinal barriers to achieving positive mental health outcomes in populations” (p. 18). WHO considers advocacy to be one of the eleven areas for action in any mental health policy because it produces benefits for people with mental disorders and their families. Advocacy actions typically include "the raising of awareness, the dissemination of information, education, training, mutual help, counseling, mediating, defending and denouncing" (p. 25).

TEPF defines advocacy as "[t]aking action to bring about change, having a voice, being part of the solution, and engaging others in eating disorder support, treatment, and prevention." The objective of advocacy is to "[e]ngage communities and community partners in sending mission-related messaging (eating disorder support and prevention) to the general public, legislators, and key decision makers. We believe advocacy must be integrated into all of our activities” (“The Emily Program Foundation,” n.d.).

**Recovery.** While mental health research defines what eating disorders are, there is no single definition of recovery in the literature for eating disorders. Couturier and Lock (2006) found that rates of recovery varied greatly, from 57.1% to 94.5%, depending on the definition used. Fitzsimmons and Bardone-Cone (2010) defined full recovery through physical, behavioral, and psychological components in contrast to partial recovery through physical and behavioral components only. These researchers called for a consistent definition of recovery in order to aid in the comparison of research outcomes. As a person who has experienced disordered eating, I believe recovery to be a personal affirmation. For the purposes of this project, “recovery” will be understood as both a personal affirmation,
and a state of well-being measured by the absence of intensive clinical treatment within the previous year.

**Psychological well-being.** Ryff et al. conceptualized psychological well-being (PWB) as six, interrelated components: autonomy or self-determination, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance. Tomba, Offidani, Tecuta, Schumann and Ballardini (2014) assessed PWB in outpatient individuals with eating disorders. They found that the paucity of PWB was not dependent on the severity of the eating disorder. This finding supports the theory that PWB is not simply the inverse of psychological maladjustment, but an independent construct impacting psychological functioning (Ryff et al., 2006). Thus, PWB may offer an alternative perspective on recovery—one that provides insight onto the factors that constitute and maintain recovery.
Chapter II

Literature Review

This review of literature attempts to bridge a gap between the disparate themes of narrative therapy, narrative inquiry, art therapy, eating disorder advocacy and self-advocacy. Few studies examined eating disorder recovery from a narrative, art-based or art therapy-based approach, and seemingly none through the realm of advocacy. Some overlap occurred between art therapy and narrative approaches, so this category was further subcategorized. A list of alternate research terms follows (See Table 1).

Table 1

Alternate Research Terms

<table>
<thead>
<tr>
<th>Eating Disorders</th>
<th>Recovery Narratives/Narrative Inquiry</th>
<th>Advocacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anorexia</td>
<td>Narrative Art Therapy</td>
<td>Self-advocacy</td>
</tr>
<tr>
<td>Bulimia</td>
<td>Poetry Therapy</td>
<td>Inclusive Research</td>
</tr>
<tr>
<td>Binge Eating</td>
<td>Recovery Stories</td>
<td>Mental Illness Stigma</td>
</tr>
<tr>
<td>Disordered Eating</td>
<td>Art Therapy</td>
<td>Recovery</td>
</tr>
<tr>
<td>Full/Partial Recovery</td>
<td></td>
<td>Empowerment</td>
</tr>
</tbody>
</table>

Narrative Therapy and Eating Disorders

Narrative therapy developed through a social constructivist perspective. This philosophy holds that the meaning ascribed to experience shapes a person's life (Riley, 1997). A major goal of narrative therapy is to externalize the problem, which has come to be internalized as part of one's identity. According to Epston, Morris and Maisel (1995), the process of deconstructing a dominant narrative to reveal how that dominant narrative has shaped one's life provides the awareness necessary to make alternative life choices.

Prominent therapist in the field of eating disorder treatment, Zerbe (2008) discussed the importance of encouraging the individual to develop and trust one's subjective voice, particularly since the body has served as the primary mode of expression and communication.
though the eating disorder. Zerbe (2008) stated that the therapist acts as the guide or companion to help the client tune-out the critical voice and "tune-in" to those hidden aspects of one's story, transforming the material into emotionally "manageable feelings and stories" (p. 54). Through the telling and re-telling of the narrative, an authentic voice is discovered. Zerbe (2008) stated that visual art, letter writing, and journaling can help begin and expand the verbal narrative process. In addition, Brown, Weber, and Ali (2008) proposed a combination of feminist and narrative therapies that emphasizes women's resistance to gender roles of self-regulation through the postmodern notion of “living storied lives” (p.92).

**Narrative Inquiry and Eating Disorders**

Since the release of the DSM III in 1980 to the present, research on the etiology and treatment of eating disorders has focused on behavioral parameters to measure treatment outcomes (Fitzsimmons & Bardone-Cone, 2010; Peters & Fallon, 1994). Though a minority voice in eating disorder research, some studies have explored eating disorders through subjective appraisals of recovery. Such qualitative, phenomenological studies “broaden the conceptualization of recovery” beyond the absence of behavioral symptoms, weight restoration, and fear of weight gain (Bowlby, Anderson, Hall, & Willingham, 2015, p.1).

Themes apparent in the recovery narratives suggest that long-term recovery involves comprehensive changes, involving internal shifts that are non-quantifiable, such as shifts in identity, meaning-making, interpersonal relationships, and the relations to self, body, family and culture (Bowlby et al., 2015; Peters & Fallon, 1994). Narrative inquiry research also amplifies the voices of women with eating disorders, allowing them to “teach us” how they define and perceive recovery, and what they learn through the process (Peters & Fallon, 1994). I categorized themes revealed through narrative inquiry as follows: etiology, recovery
as nonlinear, readiness to change, de-identification with the illness and a changed self-concept, acceptance of the self and emotions, and social connection.

**Etiology.** Subjective accounts of 70 women recovered and currently suffering from anorexia revealed that the most commonly perceived causes of the disorder were weight loss, dieting, stressful experiences, perceived pressure, and dysfunctional families (Tozzi, Sullivan, Fear, McKenzie, & Bulik, 2003). Accounts of 30 women recovered from bulimia revealed themes of denial, alienation and passivity as felt experiences of bulimia (Peters & Fallon, 1994). Analysis of their accounts revealed that, during recovery, denial shifted to reality, alienation shifted to connection, and passivity shifted to personal power.

**Recovery as nonlinear.** Two phenomenological studies, one interviewing recovered clinicians (Bowlby et al., 2015), and the other interviewing individuals recovered from anorexia (Garrett, 1997), found recovery to be nonlinear and comprehensive. Participants in Garrett’s study (1997) often defined recovery as an ongoing process or sometimes avoided the definition altogether. For example, one participant observed, “I see the myth of recovery as part of the attitude which produces anorexia.” Another participant said, “the word recovery feels like too final a term and that there is an expectation . . . to always be perfect” (p. 264). In analyzing qualitative experiences of later phases of treatment, setbacks or relapses could reflect “a process of recognizing loss and grief on a journey towards reconciliation” (Pettersen, Thune-Larsen, Wynn, & Rosenvinge, 2013, p. 98).

**Readiness to change.** In a number of studies, the individual's own willingness to change was viewed as critical to recovery (Keski-Rahkonen & Tozzi, 2005; Peters & Fallon, 1994; Rorty, Yager & Rossotto, 1993). Interviews from 40 women revealed factors stimulating recovery were increased motivation to live a better life (80%), “hitting rock bottom” (63%), and increased self-esteem that provided motivation or strength to recover
(23%) (Rorty et al., 1993). Peters and Fallon (1994) described “readiness to change” as an existential shift from passivity to personal power—a shift from seeing bulimia as a solution for control to taking a more proactive stance on life. Discontent with powerlessness, “the feeling of drifting through life or waiting for change,” provided motivation for learning how to take action (p. 349). Often this transformation included a shift from compliance to outrage over the cultural standards and media messages pertaining to women and food. This sentiment was articulated by one person in recovery: “One major aspect of recovery for me has been stepping outside the social norms; outside the stereotype of what’s appropriate for a woman in our culture” (Garrett, 1997, p. 264).

**De-identification with the illness and a changed self-concept.** In a narrative analysis of inpatient individuals, recovery appeared as desirable but was often seen as unattainable or unimaginable (Malson et al., 2011). Malson et al. (2011) theorized that a person’s ability to externalize the eating disorder and imagine a changed identity plays a role in determining recovery success or failure. Accordingly, other narrative inquiries found that ceasing to identify with the eating disorder was often seen as essential to recovery (Bowlby et al., 2015; Keski-Rahkonen & Tozzi, 2005). Bowlby et al. (2015) described how individuals developed a sense of purpose through changing their attitude toward the self. Ambivalence, in later phases of recovery, was often related to existential issues in searching for a new identity (Pettersen et al., 2013). Peters and Fallon’s inquiry (1994) emphasized adjustments in sexual identity and relationships, which were sometimes characterized as moving from a childlike dependence on a significant other to becoming more self-reliant.

The Bardone-Cone et al. (2010) study on self-esteem, self-efficacy, and self-directedness, corroborated the importance of a changed attitude toward the self. Compared to individuals who met criteria for an eating disorder or were “partially recovered,” fully
recovered individuals had higher scores on self-esteem and self-efficacy than the active eating disorder group. They concluded that improved self-concept may be an integral part of full, eating disorder recovery.

**Acceptance of the self and emotions.** Kelly and Carter (2013) underscored the importance of self-acceptance and self-compassion as an antidote to shame. Shame is a prominent factor in eating disorders as symptoms may be conceptualized as a way of managing shame affect. Their analysis supported the theory that, among individuals with eating disorders, higher levels of self-criticism are present and are mediated through feelings of shame. Compassion towards the self and others helps modulate one’s threat system through feelings of safety and trust, in effect, reducing one’s susceptibility to feel shame (Kelly & Carter, 2013).

Participants in Peters & Fallon’s study (1994) identified an awareness and acceptance of affective states as important to recovery. In the Pettersen et al. (2013) study, part of this emotional process was accepting loss, processing unrealistically high expectations of oneself and others, and forgiving oneself for loss. Participants also perceived coping with the “emergence of intense feelings and relationships,” once eating disorder symptoms had been removed, as a necessary hurdle to recovery (Pettersen et al., 2013, p. 93). Similarly, participants in Björk and Ahlström’s (2008) study perceived recovery as permitting, accepting and dealing with emotions without shame or self-destructive patterns. These recovered participants identified emerging themes including acceptance of the self, the body, one’s social environment and one’s relationship to food (Björk & Ahlström, 2008). Other research reported a marked transition from “emotion-oriented coping” in partially recovered individuals to “task- and avoidant-oriented coping” in fully-recovered individuals, supporting
the idea that self-acceptance strengthens one’s coping skills (Fitzsimmons & Bardone-Cone, 2010, p. 468).

**Social connection.** Acquiring meaningful relationships is essential to recovery (Bowlby et al., 2015). In many recovery accounts, reducing alienation and increasing connections reduced feelings of shame (Peters & Fallon, 1994). Similarly, Garrett (1997) conceptualized recovery as a return to community connection. Tozzi et al. (2003) reported that supportive non-familial relationships, most commonly a supportive romantic partner, was among the three most commonly cited factors contributing to recovery, in addition to maturation and therapy.

Disclosure of bulimia was often the first step from isolation to connection. Another part of recovery was developing the ability to be assertive in social interactions—from a silent, “good girl” to being direct, articulate, and assertive in relationships (Peters & Fallon, 1994, p. 346). Björk and Ahlström (2008), also finding social interaction to be essential to recovery, produced subthemes that emphasized a more active role in relationships: “being active to create a social life,” “attaching great importance to social relations” and “listening to others” (p. 938). These qualitative studies are confirmed by research showing that recovery is associated with an “active coping style, a less evasive or passive reaction, and the active pursuit of social support” (Davies, Bekker, & Roosen, 2011, p. 246).

**Art Therapy and Eating Disorders**

While there are many theoretical papers and case studies from the 1970s to the present, evidence-based research on art therapy with eating disorders is lacking. In her seminal work, Bruch (1973) theorized that artwork is a means of stimulating an awareness and ownership of feelings for people with anorexia. Feelings of shame, anger, and sadness associated with an eating disorder can be eased through the nonverbal medium of art.
Matto (1997) theorized that intellectualization is a common defense for individuals with eating disorders, creating a schism between the thoughts of the mind and the feelings of the body. She proposed art-making as a way to externalize and confront affect (Matto, 1997). Similarly, Gillespie (1996) theorized that art therapy accesses nonverbal means of exploring discontent with the inner-self and the projection of feelings about the self into concrete body images.

In her extensive analysis of case studies, Rehavia-Hanauer (2003) identified six major conflicts of anorexia manifested in the art therapy process. She theorized that a person with anorexia concretizes his or her experience through the drama of food and body because he or she is functioning at a pre-symbolic level (Rehavia-Hanauer, 2003; Schaverien, 1994). Similarly, drawing from her experiences with an art therapy group, Wood (2000) theorized that the tangible nature of art materials provided a concrete reflection on the relationship between body and mind.

In support of these theoretical writers, Anzules, Haenni, and Golay (2007) determined from semi-structured interviews that a six-session art therapy program provided access to inner resources, promoted self-awareness, and improved self-esteem. In the Ki study (2011), client evaluations of a non-clinical art-based group revealed themes of control, safety, self-awareness, and emotional well-being, suggesting that art-based support groups can offer therapeutic benefit when individuals are unable to enter treatment.

**Recovery Narratives and Advocacy**

Pandya (2012) found personal self-narratives to be an important tool for decreasing stigma and increasing understanding of serious mental illness. Brennan and McGrew (2013) evaluated the efficacy of NAMI In Our Own Voice, a program which included stories, videos and discussions presented by persons with mental illness. The majority of audience
responses were positive, and reported enhanced knowledge of mental illness. The study found another NAMI program, Smarts for Advocacy, to likewise have a real impact on consumers. Smarts for Advocacy is an advocacy-training program that helps people living with mental illness transform their passions and life experiences into grassroots advocacy. Trainees learn how to tell a compelling story that is inspiring and moving to policymakers (National Alliance on Mental Illness, n.d.). Such peer-led, self-advocacy programs included online resources that help consumers lead “self-directed” and “affirming” lives beyond the constraints of traditional treatment (Pandya & Myrick, 2013). More research is needed on the efficacy and reach of “technology-enhanced” interventions to estimate the public health impact of eating disorders (Bauer & Moessner, 2013, p.508).

Self-advocacy efforts are most prevalent in research on individuals with disabilities and children. For example, Grover (2005) discussed the psychological benefits of self-advocacy with children who have faced great adversity, establishing a link between the children's advocacy and their resilience. Self-advocacy emphasized a child's right to dignity and self-preservation, as opposed to a passive recipient of treatment. In a study of adolescents with autism spectrum disorder, self-advocacy skills were found to be a significant predictor of student Individualized Education Program participation (Barnard-Brak & Fearon, 2012).

Likewise, women from a low-income area and experiencing depression participated in a feminist relational advocacy program. The program encouraged the mutual growth between advocate and participant, as well as the recognition of external causes of distress. The participant evaluations highlighted the importance of presenting issues from the participants’ perspectives, the importance of the women’s narratives, and the centrality of the advocacy relationship (Goodman, Glenn, Bohlig, Banyard, & Borges, 2009). Such
recommendations are pertinent to Art and Eating Disorders in that participants can empower themselves through advocacy-work and de-pathologize disordered eating when it is executed through a collaborative process, in which individuals are given the opportunity to share their stories through their own words and images.

**Eating Disorders and Advocacy**

Individuals suffer real consequences due to the stigma associated with mental illness. Perlick et al. (2001) found that the effects of self-stigmatization are enduring, negatively impacting life chances and the well-being of persons labeled with mental illness. Eating disorder advocacy groups tend to focus on prevention techniques, improved treatments, and access to care. While these are necessary areas of advocacy, efforts should also promote cultural change towards a public that has a more accurate understanding of eating disorders and more compassion for those who suffer (Grefe, 2012; Pandya, 2012; Weaver & Pye, 2010; Wingfield et al., 2011).

For instance, in a study on college students' perceptions of people with an eating disorder, it was found that characters perceived to have bulimia were viewed as more self-destructive and responsible for their eating disorder than those with anorexia, who were viewed as more self-controlled. Characters assigned a biological etiology were perceived as more likeable than those with an ambiguous etiology. Participants' perceptions were also influenced by the character's ethnicity and gender (Wingfield et al., 2011).

Federal advocacy in the United States is led by the Eating Disorders Coalition for Research, Policy, and Action (EDC) founded in 2000, whose mission is to advance the federal recognition of eating disorders as a public health priority (Cogan, Franko, & Herzog, 2005). The EDC advocates for change in federal policy to make resources more accessible and to improve treatment and prevention. Another prominent organization promoting eating
disorders awareness, NEDA, formed in 2001 to advocate for those affected by eating disorders through campaigns for increased prevention, research, and access to care. NEDA also provides online access to Stories of Hope and calls for ongoing written submissions ("National Eating Disorders Association," n.d.). More recently, NEDA organized The Marginalized Voices Project in collaboration with the editor of Everyday Feminism, Melissa A. Fabello. This project focused on underrepresented stories that fight the stereotype of eating disorders as a “young, privileged, white woman’s disease.”

Launched in 2009, Proud2Bme is an online community created by teens as a means of encouraging positive body image and healthy attitudes about food and weight ("Proud2Bme," n.d.). The website includes written stories of teens who have experienced an eating disorder. One teen wrote, "I didn’t think sharing my feelings or admitting that I had an eating disorder was 'appropriate,' which only enhanced my self-hatred and shame. But when we speak up, we help people know that they’re not 'overreacting,'…or 'being dramatic.'" Research on Proud2Bme affirmed that providing a platform for individuals to share experiences and find recognition may be “one of the most important ingredients for successful e-health initiatives aimed at improving patient empowerment” (Aardoom, Dingemans, Boogaard, & Van Furth, 2014, p.350). This is especially important in light of pro-eating disorder websites that serve as portals to connect people who suffer from disordered eating, which encourage disordered eating behaviors.

_Someday Melissa: A Story of Loss and Hope_ is an eating disorder documentary designed to raise awareness of eating disorders ("Someday Melissa,” n.d.). The Someday Melissa website provides a space for "Someday Videos," where individuals can submit videos about their recovery stories. Project Heal ("Project HEAL,” n.d.), while primarily focused on funding treatment, shares the recovery stories of its founders online and promotes
social media campaigns such as Recovery Is. The Recovery Is campaign urged individuals to send "selfies" with written statements about what recovery means to them. The photos were posted to the site and featured in an exhibition to raise awareness of eating disorders.

In summary, findings related to narrative therapy/inquiry and eating disorders was followed by research regarding the synthesis between narrative therapies and art therapy. The research highlighted the therapeutic benefit and empowering nature of discovering the subjective and authentic voice. Through the telling of the narrative, art can play an important role in containing and revealing the emotional heart of the story. Literature on the use of art therapy with individuals with eating disorders emphasized the various roles art can play in recovery, and the ability of art to present concrete reflections on the recovery experience.

Finally, research on the use of self-narratives as advocacy, and the latest developments in eating disorder advocacy, underscored the need for more supportive online resources due to the very real effects of shame and stigma associated with eating disorders.
Chapter III

Project Purpose/Goals and Objectives

Art and Eating Disorders operates under the premise that social change is crucial to combating the stigma associated with mental health issues. The project educated the public on the individualized and embodied experience of overcoming an eating disorder through the use of audiovisual accounts of recovery. Through these online videos, Art and Eating Disorders shared the vision of TEPF to shape new, informed conversations through advocacy and social outreach (Emily Program Foundation, n.d.). Ultimately, Art and Eating Disorders served to further the mission of TEPF, which is to save lives, change minds, and work to eliminate eating disorders.

The online video platform of Art and Eating Disorders created a space in which artists could literally give voice to their story of recovery, resiliency, and well-being, through video recordings that include personal narratives and other creative works such as visual, musical, and poetic work. Art and Eating Disorders sought to document versions of the recovery narrative that acknowledge both the struggles and strengths, but ultimately provide hope and community to those suffering in silence. In the process, Art and Eating Disorders also supported the artists’ growth as advocates.

Goals and Objectives

**Goal 1.** Art and Eating Disorders will document stories of recovery of individuals with eating disorder histories.

*Objective 1a.* With the assistance of TEPF, between two and four people will be recruited to participate in recording personal stories of recovery.

*Objective 1b.* With the assistance of Eve Daniels and TEPF, between two and four artists will be interviewed on their recovery narratives.
**Objective 1c.** Artists will evaluate their recorded story through written feedback.

**Goal 2.** Art and Eating Disorders will provide a supportive and creative environment for people with eating disorder histories to create a video and audio version of their recovery stories.

**Objective 2a.** Artists will identify supportive factors in their recovery, which will be documented and shared with the artists.

**Objective 2b.** The project coordinator will generate themes in the narratives to share with the artists.

**Objective 2c.** Artists will share artwork as part of their recovery stories.

**Goal 3.** Art and Eating Disorders will increase the public awareness of eating disorders and the roles that art can play in overcoming an eating disorder.

**Objective 3a.** Audiences will demonstrate improved understanding of eating disorders and the roles of art in overcoming an eating disorder.

**Objective 3b.** Videos and audio interviews will be uploaded to the webpage between November 17 and December 15, 2015.

**Objective 3c.** The project coordinator will measure the impact of the videos on the TEPF YouTube channel.

**Objective 3d.** TEPF will track the number of video plays between November 17, 2015 and January 26, 2016 on YouTube.
Chapter IV

Work Plan

The work plan for Art and Eating Disorders includes participation eligibility, recruitment procedure, the procurement of recording time and equipment, and the procedure for recording, including pre-recording, the recording sessions, and post-recording, editing, and website implementation.

Participation Eligibility and Recruitment

To be eligible for Art and Eating Disorders, artists must have been 18 years or older, and are of any identified genders. Artists must have qualified for an eating disorder diagnosis in the past. Preferably, artists would not have sought intensive treatment for any psychological disorder during the past year. Intensive treatment is defined as treatment taking place three or more times per week. Artists may have had multiple diagnoses in the past. Artists had to bring some form of creative work(s) to contribute to their recovery narrative.

The recruitment process consisted of various outreach methods carried out by Keri Clifton or myself. For the months of June and July 2015, Keri posted a “call for participants” on the TEPF website, and TEPF social media sites: Facebook, twitter, and Tumblr (Appendix E). She also posted on a message board to clinicians, and emailed TEPF board of directors. She emailed seventy artists from past Art and Eating Disorder annual gallery exhibits, and a pool of TEPF volunteers, several times, through the TEPF electronic newsletter.

I also posted the “call for participants” link on my Facebook page, wrote twelve messages to various Meetup group organizers, and contacted four people who had worked with Keri on a past iteration of this project. Finally, I made a personal contact as an art
therapy intern at McCallum Place Eating Disorder Center in St. Louis at a “Family Day” event.

There were twelve initial responses. After sending a follow-up email including the location and details, four people did not respond. The eight remaining potential artists met with Keri to discuss the possibility of participation and assess the psychological readiness of participation. Keri chose artists based on the following criteria: psychological readiness, description of the artist’s recovery story and artwork, and the diversity of diagnoses, artwork, and socio-cultural backgrounds represented amongst artists.

Two of the meetings ended without further participation. One was not an artist, and did not realize it was specifically about art in recovery. The other was a past artist in the “Art and Eating Disorder” show. Though eager to represent people with Binge Eating Disorder, she was currently struggling and decided she was not ready to participate. The eligibility requirements were altered to allow a father of a daughter in treatment to participate. The SIUE Institutional Research Board (IRB) revised approval per Joey’s participation with his daughter’s written consent.

The remaining six artists agreed to move forward with the filming (See Table 2). Potential artists reviewed the Audio Video Digital Recording Consent form and Recruitment Statement, which includes a discussion of the risks and benefits of participation (Appendix F). Artists were also asked to review the NEDA Guidelines for Sharing your Story Responsibly (2014) (Appendix G). Because of the limited time allocated to filming, we had to postpone filming one of the artists until September. However, when the time to record was approaching, the artist decided that it would be best to withdraw, and participate in a future version of the project.
Table 2

Recruitment Location and Status

<table>
<thead>
<tr>
<th>Name</th>
<th>Recruitment Location</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joey</td>
<td>Personal contact from McCallum Place, St. Louis</td>
<td>Filmed</td>
</tr>
<tr>
<td>Kristine Strangis</td>
<td>TEPF volunteer newsletter</td>
<td>Filmed</td>
</tr>
<tr>
<td>Kelly Reinhardt</td>
<td>Former artist for TEPF event</td>
<td>Filmed</td>
</tr>
<tr>
<td>Deborah Taillon</td>
<td>Coordinator’s Facebook post</td>
<td>Filmed</td>
</tr>
<tr>
<td>Marsha Beede</td>
<td>Past artist from 2011</td>
<td>Filmed</td>
</tr>
<tr>
<td>Anonymous</td>
<td>Writing group on &quot;Meetup&quot;</td>
<td>Cancelled</td>
</tr>
</tbody>
</table>

Procurement of Recording Time and Equipment

Eve Daniels provided all technical support and equipment, including microphones, cameras, lighting, cables, headphones, and tripods. Essential Sessions Recording Studio provided additional recording and editing time as needed. One of the artists, Joey, set up a recording session at Webster University with audio production student Kyle Meadors to provide recordings of background music for the videos, which I facilitated.

Procedure for Recording the Videos

Pre-recording. I confirmed a recording time and location though email as well as provided sample interview questions to the artists who wanted them. Artists were asked to select a location or locations that would be meaningful to their story, and to bring artwork, poetry, lyrics, previous recordings, or photographs to support and expand their narrative.

Recording sessions. I facilitated the recording process, providing structure, support, and encouragement, while Eve filmed and assisted in directing as needed. The recording sessions consisted of a semi-structured interview, guided by questions about the artist’s
history with an eating disorder and roles of art in their recovery (Appendix H). The second portion of the recording session consisted of recording “b-roll,” such as artwork and art-making. After each session, I gave artists a feedback form asking about the recording process (Appendix A). Finally, musical elements were recorded and edited at Webster University and Essential Sessions at a later date.

**Post-recording and editing.** The interviews, which were 30 to 50 minute in length, were edited into videos between 3:04 and 4:11 minutes. By the second video, Eve and I developed an editing procedure that seemed to be most time efficient. First, I selected quotes from the interviews based on the following criteria: 1) what I found personally moving; 2) what artists hoped to highlight in their final video based on verbal and written feedback; 3) what quotes supported the TEPF mission. Then, Eve arranged a transcript for me to approve before sending a video draft to the artist. Using this procedure, minimal edits were made after this point. In addition to the final videos, I edited the full audio interviews, ranging between 22 and 37 minutes after Essential Sessions Studios assisted in mastering the audio files.

Finally, the artists viewed and reflected on the coherence of their videos and audio interviews (Appendix B). Artists gave through approval, through email, that the final videos, video description, and full audio interviews, could be uploaded online.

**Website implementation and presentations.** As shown in Table 3, the videos were uploaded to YouTube by TEPF content manager Kiki Schmit and shared through their website and social media sites between November 17 and December 22, 2015. Kiki posted a new video every Monday during that time period and re-posted the video with the online survey every Wednesday. Between November 14 and December 10, 2015, the videos were displayed as part of the third annual art exhibit hosted by TEPF at The Art Institutes International Minnesota Art Gallery, entitled Art and Eating Disorders – Building
Community Awareness 2015. Also, on November 17, 2015, I presented a film screening and
discussion as part of the SIUE Women’s Studies program event series. One of the artists,
Joey, was able to attend and be a part of the discussion. Audience feedback surveys were
made available online, at the film screening, at the art exhibit, and at a class presentation, in
which one of the videos was previewed.

Table 3

*Project Timeline*

<table>
<thead>
<tr>
<th>May-Aug</th>
<th>Aug 3-7</th>
<th>Sept-Nov.1</th>
<th>Nov 17- Jan. 26</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruit artists</td>
<td>Film artists</td>
<td>Edit videos</td>
<td>Implement videos to website, social media, Minneapolis art show, and SIUE film screening</td>
</tr>
<tr>
<td>Obtain consent</td>
<td>Artist feedback I</td>
<td>Final consent from artists</td>
<td>Survey feedback</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Artist feedback II</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Project evaluation</td>
</tr>
</tbody>
</table>
Chapter V

Evaluation of Goals and Outcomes

In measuring goal one, Keri and I assessed our recruitment procedures through written documentation and discussion. The full, unedited recordings from each session served to document the narrative process along with my written reflections. The project evaluation results informed the budget, timeline, recruitment procedures, and filming techniques for potential future programming of Art and Eating Disorders. Goal two was assessed through content analysis of the themes from the full audio interviews, artist’s feedback on the recording process, and artist’s feedback on the final video and audio interviews. Goal three was assessed through written audience feedback on the videos, and on analytics collected from YouTube.

Logistical Outcomes

Art and Eating Disorders documented stories of recovery of individuals with eating disorder histories. Objectives (a) and (b) of goal one were completed by recruiting six artists, five of whom were able to record video narratives. Consequently, Art and Eating Disorders recruited and recorded more than the projected goal of “two to four artists.”

Artist Feedback

I used the Artist Feedback Form I (Appendix A) to evaluate the recording experience and Artist Feedback Form II (Appendix B) to evaluate the artist's response to the final video and overall experience.

Rating scale results. Based on a rating scale from 1 (Strongly Agree) to 5 (Strongly Disagree), 4 out of 5 artists “Strongly” agreed that they felt comfortable sharing their stories, that they felt prepared for and informed about the recording process, that the art had enhanced their ability to tell their stories, that they were able to identify supportive factors in
their recovery stories, and that the recording process was overall a “very positive”
experience. Four out of five artists also said that their participation “really helped” them in
understanding their experience or stories. All five artists strongly agreed that their art
enhanced their final video narrative (Appendix I).

One thing learned from the filming experience. In response to the question, “what
is one thing you learned from the experience of filming your recovery story,” the artists
shared a range of comments such as, “I really have found it easier to share what I went
through with less guilt than what I usually felt in the past,” it “helped me realize I have made
a lot of progress,” “that there is power in sharing my story,” that “sharing my story is a
healing experience for me,” and that “it is a rewarding feeling to help others struggling.”
Another artist wrote, “I learned (a lesson I keep learning) that when I take an emotional risk
by truly revealing myself, it leads to a greater – not lesser – feeling of safety, and opens a
door for others to do likewise.”

Impact of the filming experience on self-understanding. In the weeks following
their recording sessions, all five artists felt that the recording process helped them better
understand their story in some way. The process provided “insight to continue to move
forward,” and “a reminder of how far I have come.” One artist stated the process “helped me
reflect on my experience,” while another stated, “Every time I share my story I find out more
about myself…I discover new things that help me understand what I went through.”
Similarly, another artist said, “I don’t really know what I think until I speak aloud, so when I
tell my story I find out what I think.” The process provided one artist confidence in sharing
her story:

Before, I kind of doubted myself and whether or not I would be able to go beyond my
“writing” voice and genuinely share my story. The great thing about this experience is
that I realized that my story is mine to tell, and therefore, there is no right or wrong way to present it; being able to be vulnerable for the sake of helping others is a huge step forward in my recovery journey.

**Changes to the filming experience.** Before viewing the videos, artists also provided feedback on what aspects of their stories were missed in the interview and what they would change about the experience. Three artists mentioned aspects of their childhood and adolescence, such as life transitions that contributed to the development of the disorder, and their timelines for receiving treatment and experiencing relapses. Two artists mentioned a discussion of triggers and lessons from treatment as helpful topics to include in the interviews. Two artists mentioned wanting to review notes or to have the questions printed, stating it would help them be more thoughtful. One artist stated he may have expanded on the ways nurturing the inner child through creativity has been an important aspect of his relationship with his daughter. He also would have preferred to include the interviewer in the video, because the dialogue between two parties was more interesting to him.

**Reactions to the video narratives.** After artists had viewed their final video for the first time, I asked them to comment on their reactions. One artist wrote, “I’m honored that I got to be a part of this project, and I’m amazed at how beautiful it turned out.” Another wrote that she was “astonished” and found the video to be “captivating and attentive to detail.” Another artist wrote, “I got emotional. It was sad to hear my own voice describing my childhood and hear how much I felt broken… I still struggle with that feeling and so it felt weird to hear my voice saying it. It made it more ‘real.’” One artist stated the video was “beautiful and inspiring” and that she was “impressed” with how her story was transformed into “an uplifting and eloquent piece of art.” She wrote, “Both my family and I have benefited from this tremendously, and it will forever be a piece in my journey that reminds
me, and others, to stay strong because recovery truly is worth it.” Another artist commented on liking the “visual balance,” and “variety of camera angles,” though he found the stock footage of the ballet dancer to be “a little jarring.” Overall, he said, “I love the video, and am especially grateful for the companion-piece, the full-length (albeit somewhat edited) audio version of our conversation.”

**Changes to the final videos.** Two out of five artists said they would not change anything about the final videos. The remaining artists had suggestions of adding another family member’s perspective, including more artwork, including more background information about one’s childhood, and having a longer version of the video that would incorporate the conversation between artist and interviewer. Similarly, when asked if the video missed important aspects of their story, two said no, while three sighted various themes. One artist would have included “the story about my tattoos because I feel that they really related to my recovery and the music aspect.” Another artist said, “If anything, I would have liked to touch more on my faith and how that played a role.” The artist also would have included the role of Disney in her story, stating “It’s hard to explain, but through treatment my team used Disney to help me learn about myself and…overcome some big obstacles using characters I love and really relate to.” One artist realized that the video did not delve into the underlying set of mood disorders contributing to the eating disorder. Given more resources, a longer version of the video including an in-depth discussion of underlying causes would be valuable.

**Artists’ takeaway.** In response to the question, “what will you take away from your participation,” 3 out of 5 artists described the videos as a reminder—a reminder of “everything that I have worked for,” a reminder to “stay strong,” to “continue to care for myself and continue on the path of recovery,” a reminder of “how far I’ve come,” and “an
inspiring piece of art to hold onto forever.” Two artists discussed family in their feedback. One artist valued the positive feedback she got from family and friends, and another stated how her family is grateful for the experience. Two artists recalled the recording process as impactful, sharing gratitude for the opportunity to explore his/her experience with “compassionate and insightful companions.” Another mentioned that talking through the journey made her more “self-aware.” Two artists recalled the community building aspect of the project—the “gift” to have met others involved in advocacy. Another artist stated she now finds herself to be a community advocate and that her “greatest reward” would be to have a positive impact on those currently struggling with an eating disorder.

In summary, Art and Eating Disorders recruited and recorded five artists, and received artist feedback, after the recording session and after video completion, as stipulated in goal.

**Theoretical Orientation**

Within the traditional research model, there is “no place for recovered women to instruct us about the process of change” (Peters & Fallon, 1994, p. 339). Art and Eating Disorders believes that amplifying marginalized voices can counter the dominant cultural narratives that sustain eating disorders. Feminist philosopher Susan Bordo (2004) argued that cultural pressures do not simply make women particularly vulnerable to eating disorders; they lay the necessary groundwork for them to occur. Biological factors that predispose individuals are irrelevant without recognizing the igniting cause of gender inequality, and the objectification of both women and men. It would be more accurate to look at eating disorders not as pathology and abnormal but as an addictive, learned activity modeled after consumer culture.
According to Bordo (2004), consumer culture serves to “discipline” female bodies in the knowledge of their limits and possibilities. A central strategy in the maintenance of power relationships, consumer culture teaches women self-restraint, shame in indulgence, and suppression of getting their needs met. Mainstream culture teaches women to be most gratified by feeding and nourishing others, that food is a private substitute for human love, that slenderness equals success, power, attention, control, love, and escape from domesticity. Because the silencing of the self is rooted in these gender role expectations, there needs to be more platforms for amplifying female voices, including those who have experienced oppression in the form of an eating disorder.

Because of the project’s feminist perspective, which values a co-created, equal-power relationship between artists and project facilitators, I identify artists by their names when addressing themes in the full audio interviews. To equal the power dynamic between coordinator and artist, I also disclosed my eating disorder history throughout the project.

**Themes in the Full Audio Interviews**

Artists successfully identified supportive factors in their recovery and shared artwork as part of their recovery stories, as stipulated in goal two. The full audio recordings served to document themes in the artists’ narratives. I shared these themes with the artists in the form of word clouds, before the videos were released (Appendix J, K and L). The major categories from the audio recordings were: supportive factors in recovery; the etiology of the eating disorder; the roles of art in recovery; reason for participation; and the role of society. Themes in Joey’s narrative are addressed separately from the thematic analysis. While his narrative contained some similarities to the other artists, his role as a father is categorically different. Some themes arose organically, but most were in response to my questions. Consequently, it is the themes within these broader categories that are of interest.
Supportive factors in recovery. Quotes related to supportive factors in recovery are subcategorized and sequenced in order of how many artists commented on each subcategory (Appendix J). Elaboration on each subcategory follows.

Recognizing the need for professional help. It is a major hurdle and giant step towards recovery to recognize the need for help. All five artists recalled arriving at this realization. For some, this moment came well into treatment. Marsha, who had recognized body image issues in her teens, had been “quiet” about her eating disorder for years. As a teenager, she turned to her mother for help concerning alcohol use; however, her eating disorder “sat within” her thoughts during her years of treatment for chemical dependency and bipolar disorder. It was not until after raising her kids that she knew the eating disorder was “beyond her control” and that she needed help.

Deborah said she didn’t know exactly what she was doing but she “knew it wasn’t healthy.” She started researching online to find out what she was doing, and with the support of her parents, she decided to seek treatment. After two years of treatment, Kristine reached a point where she was sick of the eating disorder. Gradually slipping back into eating disorder behaviors in college, she recognized her behaviors were a sign of the eating disorder controlling her and not the other way around. She knew she “needed help.” Kelly’s eating disorder got “very loud” during her senior year of high school. She told herself “maybe it’s time to tell someone,” but feared her family’s reaction to finding out that her eating disorder had gotten worse. She kept going to the treatment center website and telling herself “you can do this, you can get help,” but another part of her told her she was “not thin enough” due to the misconception that one has to be emaciated to seek treatment. Eventually, with the support of her family, Kelly sought treatment.
Recovery is a journey and relapse is expected. All four artists felt that their first experiences in treatment were not sufficient. Kristine said her first, yearlong experience in treatment was a good starting point, but because she needed to be hospitalized and her parents made that choice for her, she was still “rebellious.” Kelly, too, said her parents forced her to go the first time in treatment: “Part of me wanted to go to treatment, but it was terrifying. That’s when I turned my art into a destructive force.” Deborah said her first time in treatment was quite lonely “because I wasn’t finding the right group…my symptoms didn’t fit the mold.”

Three artists conveyed the idea that recovery is “not linear,” but a “journey with highs and lows.” Kristine said she used to think she needed to be “recovered.” She came to realize, “there is no end point or happy ending to my story,” but rather, “life is full of new beginnings.” Kristine views recovery as something to work on and fight for every day. Likewise, Kelly said that body image is something she still struggles with even today.

Present moment. Three artists identified mindfulness and staying in the present moment as an important factor in their recovery. When feeling overwhelmed, Marsha finds that removing herself from the environment can change how she feels. Simply going for a walk helps her focus on the present moment, especially on rugged nature paths where putting one foot in front of the other takes concentration. In recovery, Deborah does not “count days.” Being “gentle and kind” to herself in the present moment, she accepts a tough day for what it is, telling herself, “That was a tough day…let’s move on now.” Kristine too, does not count days, but rather lives recovery as “a journey or process to take by moment.” For her, recovery is about meeting herself wherever she is at in the present moment.

Power. Two artists used the word “power” and “powerful” in discussing recovery. When Kelly would hear co-workers and customers at the cupcake shop talk about guilt over
calories, she used to attach herself to those thoughts, “take them and run.” Kelly visibly lit up in stating how “powerful” she felt “to now go into work and feel like ‘I own you cupcake!’…Being around something that once had so much power over me, to just own it feels really, really good.” Kristine addressed power stating the urges “don't ever really go away, but I've learned to not give them power.”

**Identity and self-esteem.** Three artists identified self-esteem as a factor in their recovery. Kristine said, “You start to see yourself again…The eating disorder put my life on pause and I had to find out who I was again.” “Tending to self-esteem” was an important factor in Deborah’s recovery, in which learning how to “care for myself and love myself, and remembering what feels good” took priority. For Kelly, working at the cupcake shop was a place to develop trust and confidence in herself.

**Relationships.** Two artists specifically identified nurturing relationships or socializing as an important factor in recovery, though all artists seemed to find social support helpful. Finding the right groups in treatment helped Deborah feel less isolated. She said, “Sticking with the program and going to group” have been the most important factors in maintaining her recovery. Marsha finds that simply being around people improves her mood, as isolation had contributed to her eating disorder. While her family has been a negative factor in her recovery, Marsha’s “greatest support” is her wife because of their “open communication,” and mutually sharing of emotions. Marsha has learned “to sit” with the things her family says—to “not react to it, and move forward” with herself. Family support for Kelly was “powerful.” That her dad would “engulf” her in giant hugs every time he left the treatment facility, helped her realize that her parents believed in her, and that she was not the “disappointment” she had come to believe.
**Hard work.** Two of the artists stated that recovery is hard work. It generally takes a lot of time and energy, and the process can be painful because as Deborah puts it “you’re talking about your stuff, potential old stuff” that you have “to cope with and address in order to get better.” Kristine says, “It’s something that you have to keep working at...but it does get easier every day.”

**Flexibility and balance.** Both Kristine and Deborah talked about the importance of flexibility and balance in overcoming an eating disorder. For Kristine, recovery is about finding a place where there is both structure and flexibility—to have a plan for the future, but know that there can be “flexibility within that.” Balance has played an important role in Kristine’s recovery, serving as a goal and “mantra” that she is “on a journey to finding balance, forever searching.” Deborah said, “It’s important to be flexible” in recovery “because there will be days that are not perfect.” Deborah also cited “finding balance” as an aspect of well-being.

**Hope.** After seven years of therapy, Marsha realized she was always angry after leaving her therapist’s office. Her therapist asked, then why do you keep coming back? Marsha said, “Hope. Hope keeps me coming back.” In looking back, Masha discovered that hope was a “very important factor” that she needed. For Kelly, the Disney-inspired message, “believing the impossible is possible,” and her faith in God have been important aspects of her recovery.

**Awareness of triggers.** Deborah cited the importance of being mindful of triggers including life transitions such as moving, losing a job, and getting married. She said, “To know what it looks like keeps me from going there.” Although Deborah was the only artist to discuss triggers, I believe all the artists would agree that awareness of the underlying conditions influencing the eating disorder is important to recovery. All artists designated a
substantial amount of time discussing the etiology of the eating disorder. Artists discussed co-occurring disorders and underlying mental health issues in this context, as follows.

**Etiology of the eating disorder.** Quotes related to the etiology of the eating disorder were subcategorized and sequenced in order of how many artists commented on each subcategory (Appendix K). Elaboration on each subcategory follows.

**Co-occurring mental health concerns.** For Marsha, obsessive-compulsive disorder (OCD) went “hand in hand” with the eating disorder. She decided to work on her fear of gluten at an inpatient clinic specifically for OCD before returning to her eating disorder treatment team. Both Deborah and Kelly said that their experience in school with learning disabilities affected their self-esteem. In elementary school, overhearing parents and teachers frequently discuss her academics confused Kelly, who was not told she had a learning disability until middle school. She developed core beliefs that there was something “wrong” with her, that she was “broken,” and that she “would never amount to anything.” Kristine had a similar experience of feeling “different” and “excluded” due to her Attention Deficit Disorder (ADD) diagnosis in elementary school. In adolescence, Kristine’s ADD diagnosis faded into an obsession with “structure and control that the eating disorder latched onto.” Kristine also experienced a traumatic car accident when she was thirteen years old. Through treatment, she realized its connection to her eating disorder. In burying that trauma, she developed the mindset “that the world was a dangerous place, and that if I didn't control it bad things were going to happen.” This belief was the “foundation” for “all these rules that came up,” through which the eating disorder “provided a sense of security and safety.”

**Exclusion, isolation and bullying.** All four artists thought that loneliness or exclusion contributed to the development or staying power of the eating disorder. Marsha recalled struggling to eat in the cafeteria as a teenager, though she did not link her eating
disorder to “isolation” until discussing her “slip” into mental health issues after raising her kids. The three other artists reflected feeling “different,” “not normal” or “like a special human that didn’t function the way everybody else did” during childhood. They also described feeling “excluded from the crowd,” “bullied,” and “lonely.” Kelly said she used eating disorder thoughts and symptoms “to forget all the mean things that people said.” For Kristine, being the kid that was “never normal” and “always in special ed. classes” influenced her belief that “being normal meant getting all A’s and being obedient.” She said, “I thought that in order be loved and valued as a person I needed to…be what society thought as the perfect ideal.” In essence, Kristine was seeking an “image of perfection” just to feel “normal” and feel loved.

**Self-hatred, shame and punishment.** Three of the artists used a variety of words to describe the self-hatred, shame, or desire to punish oneself, underlying the eating disorder. Marsha explained, “I didn’t like myself, I didn’t like what I saw” nor “find any comfort in myself.” As a kid, Kelly felt that something was wrong with her, so much so she “wanted to be invisible,” “wanted to hide,” and felt she deserved to be “punished.” Early in treatment, Deborah said she was holding on to a certain amount of shame, “feeling weak,” and “lacking confidence.”

**Control or perfectionism.** “Lack of structure and control” or a “desire” for control, as identified by three artists, can play a role in the development of an eating disorder. One artist, Kristine, specifically mentioned perfectionism as a factor contributing to the eating disorder. She stated that achieving an image of perfection developed from a desire for control, and the need to be loved. For these artists, the eating disorder may have provided some sense of control in an environment where bullying, or navigating a learning disability,
felt out-of-control. During this vulnerable time, it is easy to turn to the media for its clear (but misleading) image of the ideal women.

**Not about food, weight or exercise.** As Deborah stated, it was a striking realization for her that her eating disorder had “nothing to do with food” and “everything to do with some much deeper things going on that you have to address in order to get better.” Likewise, Kristine said her eating disorder was not about “weight or exercise,” but rather structure, control, safety, and protection.

**Rumination.** Two artists mentioned rumination as a contributing component to their eating disorder. Marsha explained how her eating disorder thoughts tend to ruminate if she does not practice mindfulness or process her emotions through writing. Kelly considered her eating disorder itself to be “a rumination” about difficult experiences from her childhood.

**Protection, comfort, or a way to numb.** Two artists addressed how the eating disorder served to protect, comfort, and numb pain. Kristine explained how the rules of the eating disorder provided an illusion of “security and safety” meant to protect her. In the eating disorder mindset, if she followed these rules, she could achieve control and prevent “bad things from happening.” Kelly described how the eating disorder was not only a way to comfort herself and numb the pain of feeling broken, but also to punish herself. The eating disorder served to both comfort and punish at the same time, supporting two opposing feelings within.

**The roles of art in recovery.** Quotes related to the roles of art in recovery were subcategorized and sequenced in order of how many artists commented on each subcategory (Appendix L). Elaboration on each subcategory follows.

**Identity.** All four artists discussed art-making as part of their identities—something that comes from “deep inside,” that “I have always been,” and that is “my own.” For
Kristine, it is something that gives her a “voice” and “a sense of who I was” before the eating disorder. From her lyrics to “Letting Go,” it appears she has externalized the eating disorder, and found her authentic self through “letting go” of the eating disorder (See Figure 6):

I’ve been broken and I’ve been bruised by your short temper and fuse.
This is the life I have been living for so long. No more forgiving you, no more listening to you, no more letting you tell me what to do…I used to think of you as a dream reaching for you out of desperation, striving for something that only existed in my imagination. All you ever wanted was for me to be perfect. Skinny and beautiful those words don’t mix. I am beautiful inside and out and I don’t need you to make me doubt. Who I am and who you want me to be are two very different things, so just stay away from me.

*Figure 6.* Kristine and her sister working on her song.

**Sharing and social feedback.** All artists discussed the benefits in sharing art or the art-making process with others. Beyond the benefit of self-understanding, Kelly and Kristine describe benefiting from sharing their experience with others as a shame-reducing, corrective experience. Kelly described how much of her art made in recovery was “a way to show what it was like” and “to describe what was in my head.” For Kristine, the family band with her
sisters provided a way for her to share her story and be vulnerable. It also provided a way to share a love of music together.

Marsha had always considered herself a writer, but had “lost interest” for many years, until she was in Boston working on her eating disorder. There she wrote a poem and shared it in group therapy. The response she got was “overwhelming.” The group asked her why she had stopped. From that point on, Marsha continued to write and share with others, which has since played an important role in her post-eating disorder identity. Deborah, who struggled socially in her youth, found art to be the “one place” she could receive positive feedback from her peers. As her eating disorder took root and rendered her confidence “non-existent,” Deborah was able to use her artistic abilities to rebuild confidence. Deborah stated, “art has always served me to build confidence,” suggesting that even a small amount of positive reinforcement from her youth made an impact on her.

A reminder. All artists identified the creative arts either as a motivator, reminder, or a symbol to concretize learning. The physical creation of objects enriched the artist long after those objects were created. Two artists used their art as daily reminders, Marsha creating a binder of her writings as daily reminders of the things she had written, and Deborah creating jewelry to wear as a daily reminder of the natural and celestial world that keeps her “calm” (See Figure 7 and 8). Marsha’s binder helps her see her emotions on paper, instead of “ruminating.” Marsha also described the image of a ticking clock as a helpful reminder to stay in the present moment. Similarly, Kristine discussed how her tattoos, which she regards as artful self-expression, remind her to “stay strong” and to “keep fighting every day.” I suspect, too, that Kristine’s song “Letting Go” serves as a reminder. Every time she plays the song, it is a concrete symbol of her recovery. Kelly used art as source of motivation, at one point destructively, then later, as motivating symbols of recovery.
Joy and Play. Three artists stated that art brings them joy, a sense of adventure, comfort, or satisfaction. For Deborah, spinning yarn and needle-felting “feels great” and is ultimately “satisfying” to keep or give to others. Kelly described art as an “adventure” and described tearing her “destructive” drawings into “confetti.” The art materials seemed to invite a sense of play that was helpful in approaching difficult feelings, offering a certain amount of control or distance. Kelly described the experience as “powerful,” stating, “It was horrifying, but once I started tearing it up…it was all over the place...turning into a piece that was saying, ‘I’m done with this.’ It felt really cool.” Her ability to transform destructive art into something fun shifted the power exerted by the eating disorder into her own hands. The ability to invoke humor, adventure, or joy into a situation can be a source of power, which art materials readily facilitate (See Figure 9).

Purposeful. The energy and determination needed to fuel an eating disorder can be channeled into something fulfilling such as the creative arts. Three artists spoke of transforming eating disorder symptoms into something positive or purposeful. Deborah finds
strength in knowing that her art serves a purpose. When using systems, “you use them and then it’s done and you’re left feeling emptier than when you started. You’re trying to fill yourself up and it just never gets there…with making something physical, you end up with a product you can enjoy.” She also found purpose through making art for her baby: “It’s just a nice place to go where I can make something for myself but also make something to share with her that she can have for many years.” Similarly, Kristine talked about “turning obsessions into passions” and “using that drive and determination for good things.” It is easier to “let go” of the eating disorder if she can give in to her passions, such as music and advocacy. Finally, Kelly discussed turning her art “into a positive,” making a goal for herself to “never go back” to the self-destructive art.

**Meditative.** Three artists identified art as a meditative or a calming practice, whether it is mixing the colors with the paintbrush, feeling the fibers between the fingers, or sitting at the piano. Deborah said spinning yarn brings “instant calm” and “focus to my world,” and is “a tool to get back to reality” and “find balance” (See Figure 10). For Kristine, music helps her “stay in the present moment” and “cope when those urges come on” (See Figure 11).

![Figure 10. Deborah’s hand-spun yarn.](image1.png)

![Figure 11. Kristine playing the drums.](image2.png)

Kristine stated, “music centers me, lets me go back into myself and out of eating disorder mindset when I feel lost.” Like a muscle that strengthens through exercise,
meditative art-making provides a sense of control over one’s thoughts and emotions, learning through practice that one can divert the mind to a calm place.

**Understanding.** Another theme present in two interviews was the notion of art illuminating understanding. For Marsha, writing offered a unique understanding—a way to “organize my thoughts,” a way to look back at what I wrote and “identify with it.” Similarly, Kelly’s art often includes the impetus “to make peace,” and “to find a reason for what I went through.” In her painting, the figure in isolation is unaware that the hand, representing God, has a purpose for what she is going through (See Figure 12).

**Control and reality.** Two artists discussed the role of art in relation to control and reality, although with opposite intentions. Kelly enjoyed the stark contrast between the limitlessness of art-making and the strict rules of the eating disorder: Art is “an adventure whereas, with the eating disorder, it’s ‘you got to stay behind this line.’ It’s like a punishment. With art, you are supposed to cross that line. You’re supposed to…explore and see what else there is to create.” She also discussed the ability to be transported, or to “exit reality,” through her art. Kelly stated that the kind of art she makes on a daily basis is usually about creating characters and worlds. These worlds offer Kelly a refuge—a feeling of “home.” While Kelly used art to escape the strict rules and limitations of the eating disorder, Deborah used art to gain a “sense of control” in her life and “get back to reality.” She said, "I think what triggered my eating disorder was just a feeling of lack of control in my life…I was trying to gain control through all of these
different symptoms I was using.” Art helped replace the eating disorder as a more sustainable means of feeling in control.

Confidence and empowerment. The themes of confidence and empowerment are closely aligned with the theme of identity previously addressed. With respect to identity, I cited Kristine’s description of the power inherent in sharing one’s story and finding one’s voice through art. Two other artists expressed comments related to confidence and power. From a young age, Deborah used her artistic talent to build confidence and “mastery.” Kelly frequently used the word “powerful” to describe her art process, doing such things as tearing up and transforming her destructive art, burning some of her art in the fire, and in “declaring I’m not a number” in one of her drawings.

The role of society. Two artists discussed the role society played in the development of their eating disorder. Kristine reflected on how her desire for perfection translated into a desire to achieve thinness, stating, “In our society, thin means that you are happy and successful…I have learned that people tend to value who you are on the inside if you are confident with who you are.” Kelly agreed that society plays a “big role” because “it feels like if I look that way, I’ll be happy.” She has learned to question the hidden messages behind media images that present a narrow image of beauty and womanhood, stating, “Well I don’t have that so am I not a woman?”

Themes in Joey’s interview. Themes present in Joey’s full audio interview included the etiology of his daughter’s eating disorder, his reason for participation, how he views his role in supporting his daughter, his inner experience as a father, and the role of music in his life.

Etiology of his daughter’s eating disorder. Consistent with the other artists, Joey found that his daughter’s eating disorder was “not a life-style choice” and that professional
help was necessary, as it was “not something she could pull herself out of without help.” He suggested that the myth that weight loss is a life-style choice, especially for a dancer, might have prolonged his daughter from seeking help. He said, “People misunderstand the problem and think someone can choose to act differently…Because of her long time work as a dancer, I was aware of the pressures…and I saw her weight loss as related to that and didn't peg it as the mental illness that it is, rooted in depression.”

**Role of music and art in his life.** Similar to the other artists, Joey’s comments suggested creative expression is a part of his identity—that music is how he “processes an experience,” and “expresses” himself. Art also provides a meaningful connection with his daughter because she is also an artist who likes to express herself through dance, music, and visual art. The two often create images and poems together, organically reacting to each other’s contributions, taking turns line-by-line (See Figure 13). The relational give and take, he conjectured, is “a way that we express love for each other.” The playfulness, whether it is “playing around with a tune” or in connection with his daughter, seemed to be a significant theme in Joey’s approach to music and life.

![Figure 13. Joint drawings by Joey and his daughter.](image)

**Role as supporter.** Joey discussed his role as a support for his daughter. He said that perhaps the hardest part is that “I know that I can’t fix the problem. I have to be a loving,
patient and yet a firm presence in support of my daughter, and I'm learning gradually how to do that.” With tangible emotion, Joey stated, “One thing that I have learned is what’s most important is not knowing what to say or how to respond, but what matters is that I’m there and that I will always be there.” He went on to say that listening and “checking in” has played an important role in their relationship. Joey also reflected on humor as a source of strength in his relationship with his daughter, evident in their routine of creating poems and drawings together.

**Inner experience as a father.** Beyond reflecting on his role as a supporter, Joey described his inner experience as a father with a daughter in treatment. He said, “It’s heart-breaking to see her submit to something she doesn’t want to do, to give up her autonomy.” In addition to finding solace in music and art, Joey said that “whatever way we might find to honestly reveal ourselves,” and be “fully open somehow about what’s going on” is helpful to him. Another helpful way of dealing with his experience has been the opportunity to meet other family members, “to realize that we are not alone in this experience of supporting someone who is in treatment.” Joey reflected on the film Inside Out, as it relates to the kind of journey or “rollercoaster” that he and his daughter are on. The film struck a chord for him in that it addressed how emotions of joy and sadness can share a space together. At the end of the film, joy and sadness finally learn that they are “co-owners” of a person’s memories:

Joy doesn’t have to worry about losing them to sadness and it is ok for there to be sadness as we experience these changes…and that’s good learning for me…I see a lot of value in countering adversity in life and in many ways it brings out the best in us. Our better angels are called upon to rise to the occasion. It is a very hard and long road but not without its beauty.
**Reason for participation.** Among the reasons for participation, artists (including Joey) wanted to instill hope for those still struggling, and to show that eating disorders are treatable. Others wanted to encourage more individuals to share their story, to create better access to care, to de-stigmatize eating disorders, and reduce shame through telling one’s story. Some artists wanted to debunk myths such as eating disorders are a choice, and that one has to be emaciated to ask for help. Joey, too, wanted to help “de-mystify and de-stigmatize” eating disorder to help family members feel more comfortable talking openly. In his feedback, Joey wrote, “I hope I said something about “the value of open communication about eating disorders and the importance of seeking help without shame.”

**Audience Feedback and Public Awareness**

Art and Eating Disorders increased the public awareness of eating disorders and the role that art can play in overcoming an eating disorder, as stipulated in goal three.

**Audience survey.** I used the Audience Survey (Appendix C) to evaluate community responses to the videos. Twenty-eight audience surveys were completed; 8 online, 5 by attendees at the TEPF art show at the Minneapolis Institute of the Arts (See Figure 14), 9 by attendees at the SIUE Women’s Studies film screening event, and 6 students of a SIUE feminist theory class that saw Deborah’s video only.

**Improved understanding of eating disorders and the roles of art in recovery.**

Viewers demonstrated an improved understanding of eating disorders and the role that art can play in overcoming an eating disorder (objective 3a). Based on a rating scale from 1 (Strongly Agree) to 5 (Strongly Disagree), 10 viewers “strongly agree” and 12
“agree” that the video(s) improved their understanding of eating disorders. 15 viewers “strongly agree” and 13 “agree” that the video(s) improved their understanding of the role of art in overcoming an eating disorder. Viewers with personal experience or who have known someone to have an eating disorder were more likely to “agree” than “strongly agree” for both questions. The opposite was true for viewers with no experience with eating disorders, who were more likely to circle “strongly agree” for both questions.

**Most interesting thing learned.** The next question from the survey was “what is the most interesting thing you learned from watching the video(s)?” 17 of the 28 responses mentioned art in some way. Of the 17 art-related responses, 8 described the diverse use of art in some way: the diverse ways in which art has served the artists, the range of art media used, and the varying definitions of art. The remaining responses centered on realizing the therapeutic and expressive potential of art-making (8), and art as a means of “taking control” of one’s life (1).

Of the 11 viewers that did not mention art, 2 people said they enjoyed hearing a family member’s perspective (Joey’s video). Another two people wrote, “that eating disorders aren’t just about food.” Two people stated that recovery is a “constant battle,” or an “everyday goal” as opposed to an “end goal.” Two people stated that they “loved that people want to share their stories” or “healing process.” One viewer wrote, “To be open about eating disorders. When you bring them out into the open and confront them, you can begin to heal.” Another viewer wrote, “You are worth it, fight for your life” and “recovery is possible.” Finally, someone wrote, “How talented and strong these ladies are.”

**Unanswered questions.** The audience survey revealed 16 questions that viewers would have liked to ask the artists. Five questions centered on the artist’s reaction to sharing their story publicly:
• How did you feel not only telling your story, but being taped?
• How has your experience been now that the videos have been made public?
• How do you feel watching the videos?”
• Did participating give an additional form of empowerment and a new art form?
• How is your struggle now?

These questions came from the women’s studies film screening event in which one of the artists, Joey, was present. I suspect this layout created more interest in how he and the other artists felt about watching their own video. The remaining questions were:

• Was your engagement in the arts something that was encouraged by therapists, or did you discover the power of the arts on your own? If it was through the suggestion of a therapist, how was that suggestion communicated to you?
• How have other people responded to your outward changes?
• Who inspired you and helped you through difficult times. How did they help?
• How can the public help?
• Have you considered teaching your form of artwork to others?
• Do you utilize a higher power?
• For someone who has never really been artistically creative, how do I start?
• What do you think of the way that eating disorders are portrayed in the media?
• What has helped you the most in staying true to your recovery?
• What made you change your art from “bad” into “good” therapy? (To Kelly)
• Would you define yourself as "recovered" or do you see recovery as a continuous process?

Additional audience comments. Fourteen people left additional comments. The adjectives used in order of frequency were “inspirational,” “beautiful,” “great,” “well-produced,” “moving,” “touching,” “powerful,” “wonderful,” “awesome,” and “articulate.”

Three of the comments emphasized the importance of advocacy: “The videos allow us to bring the conversations about eating disorders into the light,” “It normalized the experience,” and “is more positive than other videos online about eating disorders.”

Three people in the feminist theory class who had only seen Deborah’s video had suggestions for change: “the clips from this interview seemed vague about her recovery process,” “more of her story!” and “If it was put all into a documentary you could add more
of each story.” One person stated, “I would include places at the end to go for help if you are struggling with an eating disorder.”

**Social media outcomes.** The five videos and audio interviews were posted to the TEPF webpage weekly, between November 17 and December 15, 2015. Posts to social media outlets were released twice a week during this time period, the first containing the video, and the second containing the link to the survey. The number of video plays on YouTube was tracked between November 17, 2015 and January 26, 2016. YouTube views as of January 26, 2016 recorded that Deborah had 525 views, Kelly had 224, Kristine had 96, Joey had 76, and Marsha had 48 (See Table 4). The table compares the views, watch time in minutes, average percentage viewed, average view duration, and the number of likes and shares to the average video on the TEPF YouTube channel.

In determining the impact of social media press-releases made by TEPF, I studied the number of YouTube plays per day. YouTube analytics suggested that all five videos had more than 90% of their views within the first three days of being uploaded and posted to social media (TEPF Facebook and Twitter pages). Compared to the average YouTube video from the TEPF, the average Art and Eating Disorders video had a longer view duration. The videos of Deborah, Kelly and Kristine had the same or a higher average percentage viewed as other TEPF videos. The videos of Joey and Marsha had a lower average percentage viewed compared to other TEPF videos (See Table 4). Finally, there were significantly more views on the TEPF YouTube channel during the weeks in which the Art and Eating Disorder videos were posted than the rest of 2015 (See Figure 15).
Table 4

**YouTube Analytics Comparison on TEPF Channel**

<table>
<thead>
<tr>
<th>Video</th>
<th>Views</th>
<th>Watch Time (min)</th>
<th>Average Percentage viewed (%)</th>
<th>Average View Duration</th>
<th>Likes</th>
<th>Shares</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average TEPF Video</td>
<td>331</td>
<td>482</td>
<td>56</td>
<td>1:09</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>Deborah</td>
<td>525</td>
<td>1662</td>
<td>75</td>
<td>3:06</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Kelly</td>
<td>224</td>
<td>483</td>
<td>68</td>
<td>2:21</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Kristine</td>
<td>96</td>
<td>268</td>
<td>67</td>
<td>2:49</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Joey</td>
<td>76</td>
<td>132</td>
<td>51</td>
<td>1:45</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Marsha</td>
<td>48</td>
<td>80</td>
<td>58</td>
<td>1:46</td>
<td>2</td>
<td>4</td>
</tr>
</tbody>
</table>

Figure 15. TEPF YouTube channel view time, in minutes, from January 1, 2015 to December 12, 2015. Art and Eating disorder videos were posted between November 17 and December 15, 2015. From YouTube.
Chapter VI

Discussion, Conclusion and Recommendations

Art and Eating Disorders pilot project may have implications for future advocacy work, community arts projects, as well as provide insight into the subjective experience and supportive factors of recovery. It proposes that there is a space in which advocacy, the arts, and personal well-being may collaborate and grow together. With this collaborative space in mind, what follows is a discussion of results, implications for art therapists, limitations of this pilot project, future recommendations, and a personal reflection.

Discussion

Through the filmmaking process, I learned that advocacy, the arts, and personal well-being can enrich one another. The recording process allowed the artists to further explore their story and/or build confidence in telling it. The artists also identified many more roles of art in their recovery than were specified in the art therapy literature—themes such as playfulness and adventure, social aspects of sharing and receiving feedback, empowerment, meaning-making, art as a meditative practice and a way to gain a sense of control, identity, self-efficacy, confidence, and motivation to continue the recovery journey. Just as art-making can provide the tools for individuals to define recovery for themselves, advocacy-work can provide the conduit for sharing that definition with others. Together, art and advocacy can be a means to explore, express, and experience empowerment (Peters & Fallon, 1994).

At the same time, public response to the videos demonstrated increased understanding of the complex, subjective and individualized nature of eating disorder etiology and recovery, as well as the varied ways in which art can support overcoming an eating disorder. Eating
disorders are not “just about food.” This myth was especially clear to audience members who had viewed all five videos. In short, reducing stigma is an important aspect of recovery from an eating disorder. Advocacy work can lessen the divide between those labeled healthy and sick, reducing the very real effects of shame for those who suffer (Goodman et al., 2009; Pandya & Myrick, 2013; Perlick et al., 2001).

**Ethical aspects.** The IRB at Southern Illinois University Edwardsville approved the project proposal on May 6, 2015 (Appendix F). As the recruitment process began, TEPF and I decided to request two changes to the artist eligibility requirements: one to allow an artist who was receiving intensive outpatient treatment at the time of recruitment, and the other, to allow a father of someone who was in treatment at the time of participation. IRB approved these changes to the eligibility requirements under the condition that we would receive additional consent. The process illuminated several ethical dilemmas involving the definition of recovery, and navigating multiple, potentially conflicting, roles as the project coordinator.

**The definition of recovery.** During the initial interview, one of the artists shared with Keri that she had recently sought intensive outpatient therapy after experiencing a relapse, and was currently seeking ongoing support as needed. To comply with the original requirement, artists must not have sought intensive treatment for one year. However, because this artist had been symptom free for several years, and a long-time volunteer for TEPF, Keri felt comfortable with her continued participation. The IRB responded, stating that they would approve the request with a letter of support from Keri Clifton, and an additional document with information on how to tell one’s story responsibly, signed by the artist (Appendix G).

After the filming, Keri was informed that the artist had terminated treatment against her therapist’s recommendation. Keri talked to the artist about her decision to end treatment.
From her conversation, Keri felt confident in trusting the artist’s desire to continue participation. We asked her to provide an additional letter of support from a therapist or physician as a final precaution. She assured me that she was comfortable, and wrote me a letter in which she discussed how advocacy work has been a “motivating” factor in her recovery.

Keri and I also wondered if terminating or delaying involvement would disempower the artist, communicating that we did not trust her own self-knowledge to act in her best interest. Ultimately, Keri and I agreed with the artist that it was a positive experience for her, and also that her story was an important one to tell—that the definition of recovery is flexible and that the process of recovery is a journey with much more complexity than the general public realizes. In response to viewing her final video, the artist’s feedback was overwhelmingly positive, suggesting to me that her involvement was meaningful to her and a motivational event in her recovery journey.

The ethical dilemma highlights the murky nature of recovery and relapse, as well as the gray areas between advocacy work and recovery or personal well-being. The TEPF and I felt it was important that the videos convey that relapse is a natural part of the recovery process, and not something for which people should feel ashamed. Research that illuminates the true, more cyclical nature of recovery beyond the absence of diagnostic criteria is not only important for clinicians to know, but also helps friends, family, and the general public better understand and empathize with those suffering. At the same time, it is possible that self-advocacy work could act as distraction from recovery. While there is a paucity of research on the relationship between self-advocacy and recovery, all five artists from this project suggested that participating in Art and Eating Disorders had contributed to their well-being or recovery journey in some way.
Multiple roles of the project coordinator. I met Joey at a Family Day event during my art therapy practicum at McCallum Place in St. Louis. Joey is a songwriter and also a father of a young-adult woman in recovery. I had worked with his daughter in a therapeutic art setting at McCallum Place for about two months. After discussing the project with his daughter, Joey said that he was interested in participating.

In regard to managing relationship boundaries, The American Counseling Association (ACA) instructs counselors to “avoid entering into non-professional relationships with former clients…or their family members when the interaction is potentially harmful to the client” and that “relationships with former clients…or their family members are prohibited for a period of 5 years following the last professional contact” (ACA, 2014, p. 5). When extending boundaries, “counselors take appropriate professional precautions such as informed consent, consultation, supervision, and documentation to ensure that judgment is not impaired and no harm occurs” (ACA, 2014, p. 5). To satisfy such requirements, IRB approved the change in recruitment upon written consent from Joey’s daughter, provided that Keri follow the same recruitment procedure.

In addition to obtaining consent, I was conscious of how Joey’s participation might affect his daughter. I generally copied Joey’s daughter in email conversations throughout the project. She also said she was comfortable sharing some of her artwork and poetry. I hoped that the presence of her art in the video would give viewers a hint of her personality and identity beyond the eating disorder, while maintaining her privacy.

Joey’s participation in Art and Eating Disorders was invaluable. Not only did he provide a family member’s perspective on eating disorders, but he also provided music for the videos and helped facilitate the SIUE women’s studies film screening event. As a fellow musician, the collaboration created a sense of comradery. At the same time, I was aware of
the multiple, overlapping roles in respect to Joey and his daughter. Simultaneously, I was a student, researcher, previous art therapist to his daughter, her facilitator for this project, his facilitator of this project, and a fellow musician. Although difficult to maintain, my primary obligation was to uphold the counseling relationship with his daughter. Consultation with an unbiased supervisor would be useful in teasing apart these multiple roles, and provide support in explaining such rules that can seem arbitrary or rigid to those unfamiliar with counseling guidelines.

**Application for Art Therapists**

In her video, Deborah said that the hardest part of having an eating disorder was “just being in it and not knowing how to get out.” Like the other artists, Deborah’s felt experience during her first attempts at recovery was one of trying really hard, yet not succeeding. Therapists should be sensitive to language such as “lack of motivation, “willingness” or “readiness to change”—words that are often used in the literature as necessary aspects of recovery (Rorty et al., 1993; Peters & Fallon, 1994, Keski-Rahkonen, & Tozzi, 2005). Motivation and readiness to change may be prerequisites to recovery, but not progressing in recovery does not mean a client has low motivation to change. Factors like self-compassion, reducing shame through experiencing deeper connections with others, and “being seen” through art, can jumpstart recovery, if the client is ready.

Furthermore, the artists in Art and Eating Disorders tended to support the theory that the definition of “recovery” is problematic, suggesting that art therapists should elicit from the client what recovery looks like to them (Garrett, 1997). It is also empowering for those suffering from an eating disorder to be able to define recovery for themselves (Peters & Fallon, 1994). Here, art is particularly useful as it can aid individuals in imagining and constructing their definition of recovery.
In fact, the ability to imagine full recovery is often a part of the healing process as it helps externalize the eating disorder from the self (Malson et al., 2011; Matto, 1997). Art therapy in any setting can help individuals develop an identity outside the eating disorder, which may include developing an artist’s identity. For example, artists in Art and Eating Disorders described a sense of confidence, self-efficacy, and purpose in identifying as artists.

Artists in Art and Eating Disorders dealt with low self-esteem and, at the same time, often used art to concretize understanding and awareness of affect—for example, through Marsha’s binder of poems. Indeed, art is useful in exploring discontent within the self in concrete form (Gillespie, 1996). Creating art can be particularly beneficial for those struggling with an eating disorder because of the concrete nature of eating disorders. In this way, art helps the therapist and client to tune-in to hidden aspects of the client’s story. Art also serves as a symbolic reflection on the relationship between the body, food, eating, and the mind (Rehavia-Hanauer, 2003, Shavieren, 1994, Wood, 2000; Zerbe, 2008).

Artists described multiple ways that art provided healing. In light of the inherent value in art-making, the role of the art therapist may be to facilitate and bear witness to this process. Thematic analysis of supportive factors does not substantiate evidence for treatment due to the small sample of artists. There were just as many differences as there were commonalities between narratives. Thus, an individualized approach that respects clients as a whole, and not merely a constellation of symptoms, is important (Rorty et al., 1993). In fact, addressing individual needs may be a major factor in recovery.

Artists in Art and Eating Disorders often expressed how art fostered empowerment and created social connection. Facilitating a move from “passivity to personal power” and from “secrecy to social connection,” as cited in narrative inquiries, should be the guiding compass of community art therapists working with individuals with eating disorder histories.
Art, among other things, creates the medium through which individuals can break free from dominant narratives about eating disorders and gender role expectations. The art also provides participants with a less threatening way of communicating feelings (Ki, 2011). At the same time, the community aspect of arts-based advocacy can provide an outlet for social support and a space for individuals to develop their voices. Community projects can be particularly beneficial resources to people in later phases of recovery, as found in Garrett’s (1997) study.

In summary, audience and artist feedback supported the literature that reducing stigma is an important aspect of recovery from an eating disorder. Art therapists can play an important role in developing community art projects that bridge advocacy and well-being. When recovery from an eating disorder is so closely linked to finding social connection and empowerment, and lessening secrecy and shame, it makes sense that community arts and advocacy projects may help those in later phases of recovery.

Limitations

The small number of artists limited the project in terms of its impact on the public. The project was also limited in the diversity of artists represented. Individuals with binge eating disorder, men, and many cultural differences were not represented, as is recognized in the Marginalized Voices Project (“National Eating Disorders Association,” n.d.). The project’s small budget also limited the amount of time dedicated to recording each narrative. Lifting time constraints would have ensured that the artists left feeling as though all important aspects of their stories were told. More time and resources could also be allocated to press-releases or paid advertisements to promote the videos.

In terms of the thematic content of the narratives, focusing on the subjective experience is a strength and limitation. In the search for meaning, artists may grasp onto
stressful experiences in creating a plausible story for why they developed an eating disorder (Tozzi, Sullivan, Fear, McKenzie, & Bulik, 2003). Thus, thematic analysis of the artists’ narratives does not generalize to a broader demographic.

**Future Recommendations**

Getting the videos in front of more people—this was the main recommendation from Keri and I. With more time and resources, one could create a Facebook ad campaign, hire a public relations professional, and reach out to more eating disorder and art therapy networks.

In terms of methodology, future iterations of this project could be implemented through a participatory action approach, an approach that is more collaborative with the artists. Time permitted, the artists could become more involved in deciding how their story will be filmed, edited and shared. The videos could serve as an extension of the artist’s creative work, perhaps highlighting the artistic process through a real-time performance of art.

I also recommend incorporating questions from audience responses, such as questions about a higher power, how the artists define “recovery,” and whether art was encouraged in therapy. Additional questions could be incorporated from the existing literature, such as what were the most helpful treatment-related experiences, what aspects of having an eating disorder were hardest to change, what did artists feel they gave up by recovering, and what were artists’ “beliefs about the potential for full recovery” (Rorty et al., 1993, p.249).

It is important to decide with the artists how much detail of one’s history or timeline should be narrated. A more thorough discussion between Keri and I about the interview questions may have clarified what parts of the narrative to capture. It is then important to precisely communicate these goals and intentions to the videographer, TEPF content manager, and artists.
Although outside the scope of this project, research on the intersection of self-advocacy and well-being would be useful in developing future projects similar to Art and Eating Disorders. In addition, more comprehensive research on the roles of art in eating disorder recovery is needed—research that goes beyond the role of art allowing individuals to express and concretize emotion. In particular, research could explore how art-making fosters social connection, promotes well-being, and provides joy, purpose, confidence, safety or a sense of control throughout recovery from an eating disorder.

**Personal Reflection**

Personally, I was surprised to hear just how much impact the creative arts had on the artist’s experiences. Discussions about art did not feel like side notes, but rather were an integrated and important factor in their stories. I was surprised because I had doubts about the importance of art within my own recovery story. At times, I have dismissed my interest in songwriting because, in some ways, I had used it as an excuse to isolate when I was struggling. In hearing others’ stories, I recognize that, while I may have used art destructively, art has also given me an identity and purpose, a space to express and understand my feelings, a sense of control, self-efficacy, and confidence. I consider their willingness to share their stories a gift toward understanding and accepting my own story as an artist.
References


APPENDIX A

ARTIST FEEDBACK FORM I
Participant Feedback Form I

1. Please comment on one thing you learned from the experience of filming your story.

2. What parts of your recording do you hope are highlighted in the final film?

3. What parts of your story were missed in the recording process?

4. Did the recording process help you better understand your story? If so, how?

<table>
<thead>
<tr>
<th>5. The recording process was a __________ experience</th>
<th>Very positive</th>
<th>Positive</th>
<th>Neutral</th>
<th>Negative</th>
<th>Very negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. I felt comfortable sharing my story</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>7. I felt prepared for and informed about the recording process</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>8. My art enhanced my ability to tell my story</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>9. I was able to identify supportive factors in my story</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
</tbody>
</table>

3. What would you change about this experience?

Additional comments:
APPENDIX B

ARTIST FEEDBACK FORM II
Participant Feedback Form II

1. Please comment on your reaction to the film.

2. Did the film highlight important aspects of your story? If so, what aspects?

3. Did the film miss important aspects of your story? If so, what aspects?

<table>
<thead>
<tr>
<th>4. My participation in &quot;Art and Eating Disorders&quot; was a ______ experience</th>
<th>very positive</th>
<th>positive</th>
<th>neutral</th>
<th>negative</th>
<th>very negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. The film represents my experience accurately and effectively.</td>
<td>strongly agree</td>
<td>somewhat agree</td>
<td>neutral</td>
<td>somewhat disagree</td>
<td>disagree</td>
</tr>
<tr>
<td>6. My art/music enhanced my story</td>
<td>strongly agree</td>
<td>somewhat agree</td>
<td>neutral</td>
<td>somewhat disagree</td>
<td>disagree</td>
</tr>
<tr>
<td>7. Participating in this project ______ understanding my experiences or story.</td>
<td>really helped me in</td>
<td>helped me</td>
<td>is not related to me</td>
<td>made me feel somewhat further from</td>
<td>made me feel very far from</td>
</tr>
</tbody>
</table>

6. What would you change about the film?

7. What do you think you will take away from your participation in Art and Eating Disorders?
APPENDIX C

AUDIENCE SURVEY
Art and Eating Disorders Survey

Check all that apply:
- I have had personal experience with an eating disorder
- I have a family member or friend who has experienced an eating disorder
- I have worked or volunteered in the field of eating disorder treatment or prevention

What is the most interesting thing you learned from watching the video(s)?

If you could ask the artist(s) a question, what would you ask?

The video(s) has improved my understanding of the roles of art in overcoming an eating disorder. Circle one.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

The video(s) has improved my understanding of eating disorders. Circle one.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

Any additional comments:
APPENDIX D

PROJECT COORDINATOR RESUME
Sarah Pray
7664 Tumbledown Tr. • Verona, WI 53593 • (608)334-6057 • pray8587@gmail.com

Professional Profile

A highly-skilled, compassionate, client-centered art therapist in-training, with 4 years of clinical experience, and 9 years of creative arts facilitation and collaboration in the community. Multi-media artist, and multi-instrumental musician, with experience leading groups and individuals in expressive therapy directives and open studio processes. Bilingual, culturally competent, and dedicated advocate for eating disorder awareness. Effective in implementing treatment plans for adolescents and adults with eating disorders, anxiety disorders, and individuals with complex trauma through an attachment-based approach incorporating CBT, motivational interviewing, and mindfulness skills. Outdoor enthusiast. Strong interpersonal, organizational, and analytical skills.

Southern Illinois University-Edwardsville, Edwardsville, IL

Masters in Art Therapy Counseling
Thesis: A Pilot Project of Art and Eating Disorders: A Self-Advocacy Campaign through Video Narratives

Expected Graduation: May, 2016
Cumulative GPA: 3.8

St. Olaf College, Northfield MN
Bachelor of Arts in Spanish and Studio Art
Honors: Dean's List 4 semesters, Buntrock Dean’s Scholarship
Milton McPike Award Athletic Scholarship 2003

Graduation: Dec., 2007
Cumulative GPA: 3.6

Licensure
Eligible for LPC and ATR pending completion of 1000 contact hours of post-degree supervised experience in art therapy and board certification exam.

Clinical Experience

- Bilingual Art Therapy Intern at St. Francis Community Services in St. Louis, MO 2015-present
  Provided bilingual art therapy/mental health services to individuals; administered Psychosocial assessments; implemented treatment goals from a trauma-informed perspective; assisted with facilitation of Amigas Latinas Women's Support Group.

- Art Therapy Intern at McCallum Place Eating Disorder Centers in St. Louis, MO. 2014-2015
  Collaborated with a comprehensive treatment team while providing group and individual art therapy for adults and adolescents struggling with eating disorders

- Art Enrichment Intern at SIUE Head Start; East St. Louis, MO. 2013-2014
  Worked with teachers, parents, and the behavioral health team to provide therapeutic art experiences for children ages 3-5 aimed at specific social, emotional,
and behavioral goals.

- **Activity Coordinator** Ebenezer Adult Day Center; Minneapolis, MN 2008-2009
  Planned, assisted and lead creative and psychoeducation group activities for older adults; assisted clients with personal care; translated for Spanish speaking clients.

**Advocacy and Volunteer Work**

- **Volunteer at The Emily Program Foundation** St. Paul, MN 2011-2016
  Coordinated advocacy events including art and music events, lobbied in D.C, Collaborated on thesis project: 5 video narratives discussing the role of art in overcoming an eating disorder.

- **Volunteer at Casa de los Angeles in San Miguel de Allende, Mexico** 2013
  Provided daycare and art activities for 3-6-year-old children (360 hours).

- **St. Olaf College program in Mexico: Family Social Services** 2005
  Provided physical therapy support for disabled children of all ages in Puebla, MX

- **Mentor/tutor** Northfield, MN 2004-2006
  Mentored Latino youth through Reaching Our Goals program.

- **Spanish translator/assistant** HealthFinders Clinic; Northfield, MN 2006
  Assisted and translated for healthcare professionals at HealthFinders, a non-profit clinic for the medically uninsured.

**Music Experience**

- **Nationally Touring Musician** at www.sarahpraymusic.com; Minneapolis, MN. 2009-present
  Performed 200 + shows in 28 states and 11 countries; recorded 3 albums.

- **Creative Director** Essential Sessions Recording Studio; St. Paul, MN 2007-2010
  Designed graphics/websites, and produced music with clients and students.

- **2,11-week European Musical Tours** 2009, 2011
  Collaborated on solar-powered recordings in Spain, and played 25 + shows
Teaching & Clerical Experience

- **Women’s Studies Graduate Assistant;** SIUE, Edwardsville, IL
  2014-present
  Assisted in organizing and advertising events, designed newsletters, graded papers, wrote blog posts, and presented research on eating disorders.

- **College of Arts and Sciences Graduate Assistant;** SIUE, Edwardsville, IL
  2015-present
  Assisted Dean W. Shaw, composed donor letters and designed promotional material.

Special Skills

- **Art related:** Drawing (pen & ink, pastel), Painting (watercolor, acrylic), Ceramics, Digital media
- **Music related:** Voice (alto), piano, guitar, mandolin, saxophone, audio engineer basics
- **Computer related:** Microsoft Word, HTML/CSS, Adobe CS6, Final Cut Pro, Excel, PowerPoint
- **Language:** Fluent in Spanish

Professional Affiliations

- American Art Therapy Association, Student Member (2016)
- Wisconsin Art Therapy Association, Student Member (2016)
- National Association for Music Therapy, Student Member (2016)
- SIUE Student Art Therapy Association (2013-present)

Professional Development

- Motivational Interviewing Training (Jan. 2016)
- Illinois Association for Music Therapy and Illinois Art Therapy Association Joint Conference (2013)
- Student Art Therapy Association Workshop: Booking-making, Joanne Kuba (2013)
APPENDIX E

CALL FOR PARTICIPANTS
Art and Eating Disorders - Call for Participants

The Emily Program Foundation is proud to support the recovery and healing process of eating disorders through artwork. With the belief that artwork helps individuals find their voice, identity, and empowerment through creative expression, we share artwork inspired by eating disorder recovery with the public as a way to increase awareness and education of eating disorders.

With that, we launch a new audiovisual project under the scope of our Art and Eating Disorders program. Through an online video platform, the new project will create a space in which participants can give voice to their story of recovery through visual recording and other creative works. This project aims to document versions of the recovery narrative that acknowledge both the struggles and strengths to ultimately provide hope and increase public awareness of eating disorders.

We are calling for participants who are in recovery from an eating disorder to share their recovery story through audio and/or visual media. Participants are asked to share some form of creative work, such as artwork, poetry, music, lyrics that relates to their experience of recovery from an eating disorder. Participation in this project will involve audio or visual recording of your recovery story, and the final short films of your story will be hosted on The Emily Program Foundation website.

Filming will take place in August, 2015. Please contact Keri Clifton at 651-379-6134 or email at keri.clifton@emilyprogramfoundation.org.
APPENDIX F

IRB APPROVAL AND CONSENT FORMS
Sarah Pray  
3206 Magnolia Ave, 2E  
St. Louis, MO 63118

Dear Sarah:

Your proposal to conduct research involving human subjects, entitled, “A Program Evaluation of Short Videos on Recovery from an Eating Disorder,” was received by the Southern Illinois University Edwardsville (SIUE) Institutional Review Board (IRB), reviewed, and approved under the expedited review category 46.110 (6) (7) on May 6, 2015 with the following stipulations and/or comments as they apply:

That you use the SIUE IRB approved date stamped consent/assent/audio visual release form(s) included in your protocol filed with the IRB, as they apply. Completed informed consent forms, assent forms, and audio/visual release forms must be kept on file at this institution for 3 years following completion of the project. It is recommended that they be kept in a locked cabinet in your departmental office.

Please note that at the completion of the project, or on a continuing basis submitted annually for multi-year project with a maximum of 3 years you, you must submit a “Continuing Review Request/Notice of Study Completion” form. You will find this form by going to: http://www.siue.edu/orp/research-forms.shtml#irb_misce_forms

No further action is required unless you change your methods or duration dates, or alter your interactions with participants. In these cases you must contact the Graduate School’s Office of Research and Projects at lskelto@siue.edu to update your protocol and to determine whether further protections are warranted. You are also responsible for reporting any unanticipated events involving risk to participants or others. See http://www.siue.edu/orp/research-forms.shtml#irb_misce_forms for more information and to view our Federal Wide Assurance (FWA) Document.

Thank you for cooperating with the Institutional Review Board. If you have any questions about your research with human subjects, please contact Linda Skelton, IRB Administrator, Graduate School’s Office of Research and Projects. Complete contact information appears at the top of this memo.

Sincerely,

P. Ann Dirks-Linhorst  
P. Ann Dirks-Linhorst, Chair  
Institutional Review Board

Cc: Megan Robb
Acknowledgment of Informed Consent

Section I: Identification of Project and Responsible Investigator:

I hereby agree to participate in a research project entitled A Program Evaluation of "Art and Eating Disorders": Audiovisual Narratives of Recovery from an Eating Disorder to be conducted by Sarah Pray as principal investigator.

Section II: Participant Rights and Information:

1. Purpose of the Program Evaluation:
It is my understanding that this program evaluation will create short films about recovering from an eating disorder. The films will test the feasibility of procedures and to gather information prior to a larger advocacy campaign, designed to present hope and increase the awareness of eating disorders. It is my understanding that my participation in this program will involve recording (through audio and/or visual means) my story of recovery from an eating disorder. I will be asked to share any expressive work, such as poetry, music, journal entries, artwork, photographs, or other work that helps me express my recovery story. The recording will take place at Essential Sessions Studios, and/or in a location(s) of my choice. The recording process will take between two and four hours and take place between September 3-7th, 2015. I may choose to remain anonymous and off camera. If choose to participate, I understand that my recovery story will be edited into a 3 to 7 minute short film, that will be shared on the Emily Program website and social media sites beginning November 1st, 2015.

2. Description of Risks:
I understand that the recording and sharing process may bring up a lot of emotions. Almost all participants will feel some nervousness about having to talk in front of a microphone or camera, especially about very personal things. If you seem to be feeling more than a normal amount of nervousness, we will help you feel at ease, or take you out of the study if need be. It is important to assess the risks of self-disclosure on your personal wellbeing, such as the possibility of feeling exposed, vulnerable to judgment, and/or emotionally overwhelmed. It is imperative to stay focused on your own recovery before taking steps to help others. If you are currently working with a professional, or have worked with one in the past, please ask for their feedback regarding your decision to share your story.

3. Description of Benefits:
Participation in this program evaluation may benefit you by providing you an outlet of expression, the opportunity to grow as an advocate, and to develop a recovery narrative that is meaningful to you. Your participation may benefit others by decreasing the stigma associated with eating disorders, and by providing hope and support for those struggling with an eating disorder.

Disclosure of Alternative Procedures:
There are no alternative procedures for this program except for non-participation. However, if you complete the recording session and wish to at anytime withdraw from sharing your story publicly, your audiovisual narrative will be kept private and will still be valuable to the evaluation of the program.

5. Confidentiality of Records:

We will keep a record of your full recording session. The record will include your age, occupation, sex, and race. However, the record will NOT include your name, address, social security number, school ID number or any other personal information. While I am assessing the program, the recordings will be open to my committee board at SIUE, Brad Matale at Essential Sessions, and the Emily Program Foundation. If you consent to the final short film, it will then be shared on the Emily Program website and social media pages beginning November 1st, 2015.

6. Available Assistance:

There is a chance that you might be one of those few participants who discovers that he or she is unusually nervous about recording and/or publically sharing your recovery story. If you have any strong, negative emotional and/or physical reactions to the work we ask you to do, then we will: (a) take immediate steps to help you feel more at ease; (b) help you make contact with counseling services to discuss the situation; and (c) follow through to make sure you have received any help that you feel is needed.

7. Contact Information:

If you have any questions about our program evaluation or about your rights and activities as a participant, then please contact the project’s principal investigator, Sarah Pray or volunteer coordinator, Keri Clifton. You can call Sarah at (608) 334-6057, e-mail her at spray@siue.edu, or write her at Campus Box 1774, SIUE, Edwardsville, IL 62026-2999. You can contact Keri at (651) 379-6134 or at keri.clifton@emilyprogramfoundation.org. If you are a participant and become worried about your emotional and physical responses to the project’s activities, then we encourage you to immediately notify Sarah Pray or Keri Clifton. They will work with you to help identify the problem and solve it. If you have any questions about your rights or any other concerns, you may also contact Linda Skelton with the SIUE Institutional Review Board at (618) 650-2958 or lskelto@siue.edu.

8. Statement of Voluntary Participation:

If you choose to join our program evaluation, your participation will be voluntary. You can ask to withdraw from the pilot project at any time. If you have been the process of recording, we will simply stop keeping records of your participation and destroy previous material. The changes will be made in a way that does not draw any special attention to you. You will not be penalized in any way if you decide to withdraw from the project.
Section III: Signatures

1. Participant: ___________________________ Date: ______________

2. Principal Investigator: ____Sarah Pray_______ Date: 2/1/2015__________

3. Principal Investigator’s address: 3206 Magnolia Ave 2E St. Louis, MO 63118

4. Principal Investigator’s phone number: 608-334-6057

5. E-Mail: spray@siue.edu

Updated 05/02/12 PGC
RECRUITMENT STATEMENT FOR RESEARCH PARTICIPATION

[Essential Sessions Studios, and various locations that are meaningful to you]

1. Sarah Pray, Art Therapy Counseling MA student, and the Emily Program Foundation 501(c)(3) are inviting you to participate in this program evaluation.

2. The title of this study is A Pilot Project of "Art and Eating Disorders": Audiovisual Narratives of Recovery from an Eating Disorder. The purpose of this study is to evaluate the project's ability to document, using film and art, personal recovery narratives that will increase the public awareness of eating disorders.

3. Your participation in this study will involve recording (through audio and/or visual means) your story of recovery from an eating disorder. You will be asked to share any expressive work, such as poetry, music, journals, artwork, that help you express your recovery story. The recording will take place at Essential Sessions Studios, and/or in a location(s) of your choice. The recording process will take between 2 and 4 hours. You may choose to remain anonymous and off camera. With your permission, the final short films of your story will be hosted on the Emily Program Foundation website.

4. There could be risks to you as a participant. You may experience the effects of self-disclosure on your personal wellbeing, such as feeling exposed, vulnerable to judgment, and/or emotionally overwhelmed. Understand that it may feel like a lot of pressure and will likely bring up emotions. It is imperative to stay focused on your own recovery before taking steps to help others. If you are currently working with a professional, or have worked with one in the past, please ask for their feedback regarding your decision to share your story.

5. The results of this study may be published in scientific research journals or presented at professional conferences. However, your name and identity will not be revealed and your record will remain confidential, if you choose. The recordings will be saved on a drive that is password protected. Any files or documents pertaining to you will be coded.

6. Participation in this study may benefit you by providing you an outlet of expression, the opportunity to grow as an advocate, and to develop a recovery narrative that is meaningful to you. Your participation may benefit others by decreasing the stigma associated with eating disorders, and by providing hope and support for those struggling with an eating disorder.

7. You can choose not to participate. If you decide not to participate, there will not be a penalty to you or loss of any benefits to which you are otherwise entitled. You may withdraw from this study at any time.

8. If you have questions about this research study, you can call Sarah Pray at 608-334-6057. If you have questions about your rights as a research participant, you can call the SIUE Institutional Review Board at 618-650-2958 or email at lskelto@siue.edu

APPROVED
MAY 06 2015
SIUE Institutional
Audio/Video/Digital Recording Release Consent Form
[Recordings include transcripts, study, and analysis]

"A Program Evaluation of Audiovisual Narratives from an Eating Disorder"

You will be audiotaped, videotaped, and/or digitally recorded as part of your participation in this research study. These recordings will be viewed and/or listened to by members of the research team to transcribe, code, and analyze data collected for the study. We may present findings from the study in classroom and professional settings if you consent below. Please indicate below any additional educational and professional uses of the recordings you consent to. Your consent in these areas is completely voluntary. Lack of consent will not affect your participation in this study. If recordings of you are used in any of these contexts, anonymity will be maintained. No identifying information (such as full names) will be used. In addition, if you agree to allow us to use the recordings for any of these purposes, we will keep the recordings for an indefinite period of time. If you do NOT consent to any of these uses of the recordings, they will be destroyed upon completion of the study.

I consent, by placing my initials next to any/each statement below, that:

1. The recordings or still pictures made from recordings can be used in scientific publications.
   Initials

2. The recordings can be used in classrooms.
   Initials

3. The recordings can be used in presentations at professional meetings/conferences.
   Initials

4. The recordings can be used in presentations about child development to non-scientific groups.
   Initials

I have read and understood this consent form and give my permission for the uses initialed above.

____________________________________________________________________________________

Names of Participants (Please Print)

____________________________________________________________________________________

Participant/Parent Signature                  Date

____________________________________________________________________________________

Principal Investigator                      Date
APPENDIX G

NEDA GUIDELINES FOR SHARING YOUR STORY
Guidelines for Sharing Stories of Recovery

As someone with a personal connection to the field of eating disorders, be it through your own experience or that of a loved one, you are in unique position to offer hope, understanding and vital information to others. At the same time, it is important to carefully consider the potential impact of your message on the public, as well the effects of self-disclosure on your personal well-being. Research and anecdotal evidence show that even with the best intentions, personal testimonies can provide dangerous ideas that may contribute to disordered eating behaviors. Furthermore, an individual sharing their story may be left feeling exposed, vulnerable to judgment, and/or emotionally overwhelmed. Below are strategies to help you present your story in a useful way while protecting your personal well-being. An effective recovery story helps others toward the direction of health, hope, and understanding.

How to Protect Your Personal Well-Being

Be committed to your own recovery. Before becoming an advocate for eating disorders awareness, be sure you are first and foremost an advocate for you! Sharing your story is a big responsibility. Understand that it may feel like a lot of pressure and will likely bring up a lot of emotions. It is imperative to stay focused on your own recovery before taking steps to help others. If you are currently working with a professional, or have worked with one in the past, please ask for their feedback regarding your decision to share your story.

Recognize your limits. While you are an expert of your own experience, remember that this experience is unique to you. It is important to not answer questions that you don’t: know the answer to or provide advice that suggests “this is what works for everyone.” Remember, since you are not an expert or professional in the field, you are not responsible for being someone’s therapist or for their recovery. You can, however, help to put individuals in contact with professionals specializing in eating disorders. You might even think about inviting a professional to participate in or be available for questions during your presentation if one is not already scheduled to be there.

Know what you are and are not willing to share. Just because you’ve taken this step to share your story does not mean you have to disclose every aspect of your experience. Keep a commitment to yourself not to disclose more than you are comfortable with. Be armed with phrases such as “That is more than I am willing to share” or “I believe you have enough understanding without talking about ______.” This will help protect you should questions arise that you are not comfortable answering.

Be prepared for assumptions/questions. Remember that the extent of eating disorders knowledge varies widely among the audience. Be prepared to address common myths about eating disorders and keep in mind what a valuable opportunity this is to clear up those all-too-prevalent misunderstandings. Refer to NEDA’s various handouts for more information (see next page for handout suggestions).

Always keep in mind ‘why’. Before sharing your story, carefully consider your motivations for doing so. While it may be personally rewarding to be honest and open about your experience, remember that you have an important obligation to your audience members. Make sure you leave your audience with the message that there is hope, that recovery and freedom from food and weight concerns is possible, and professional help is available.
How to Share a Story Responsibly

Eating disorders are serious illnesses that must be covered in a careful and responsible manner. Try not to inadvertently glamorize them or promote copycats who may experiment with life-threatening behaviors. Whether you are sharing your story during an interview, in a written piece, or in front of an audience, here are some suggestions to guide you in your coverage of eating disorders:

Don't focus on graphic images or physical descriptions of the body at its unhealthiest point. Research strongly suggests that testimonies which dramatize dangerous thinness can provoke a "race to the bottom" among those struggling with or susceptible to an eating disorder (i.e. "She is thinner than I am and she's still alive. I should lose more weight."). A focus on the physical descriptions of the body is not only dangerous, but can also be misleading. Individuals with eating disorders come in all shapes and sizes – just like in life!

Don't provide 'tips' or play the numbers game. "I ate only XXX calories a day" or "He took as many as XX laxatives at a time" can turn a well-intentioned story into 'how-to instructions' for someone to follow. You might instead highlight that our self-worth cannot be measured by the numbers on a scale or the size of our clothes. Stories can also effectively – and responsibly – be illustrated by focusing on the mental and physical consequences of the eating disorder (e.g. disrupted friendships and isolation, fear and depression, fatigue, decreased ability to concentrate, medical complications, etc.) rather than the specific behaviors or number counting that perpetuated the eating disorder.

Watch out for ‘anorexia chic’. Eating disorders and those who have them should not be glamorized or, worse yet, presented as people with "astounding will-power" or "incredible self-control." This threatens to not only inaccurately portray eating disorders as "desirable," but can also give the false impression that if one only had enough will-power or self-control, they could overcome an eating disorder too. Eating disorders are not just a 'fad' or a 'phase,' and one doesn’t ‘catch’ an eating disorder for a period of time. Remind the audience that eating disorders are illnesses, not choices.

Be careful about providing testimony of how you "bravely fought this illness alone."
Perhaps you did, but most do not – the vast majority of those who recover from their illness do it only with the ongoing help of trained professionals. Make sure you reinforce that it is courageous and necessary to ask for support and help during the recovery process.

Emphasize the seriousness of eating disorders without portraying them as hopeless.
Always encourage people to seek help for themselves or loved ones who are suffering. Recovery is often a long and expensive process – but it is achievable and there are many options available.

Always provide a resource list. Include contact numbers, addresses or web links to information and local and national treatment resources. Otherwise you risk raising fears and concerns without providing an outlet for support and vital help. The NEDA website, www.NationalEatingDisorders.org, and toll-free Information and Referral Helpline, 1-800-931-2237, provide extensive resources nationwide.

If you need more information, ask! The National Eating Disorders Association has the latest recovery resources and can connect you to treatment professionals or educational outreach volunteers in your area. The NEDA website and informational handouts provide the most accurate and up-to-date information on eating disorders including statistics that can add relevance and importance to your stories. Some specific facts sheets that may assist in your coverage include “Statistics,” “What is an Eating Disorder,” “What Causes Eating Disorders,” “kNOw Dieting,” “Listen to Your Body,” “Sharing with EEEase” and “Treatment of Eating Disorders.”

Thank you for using your voice to highlight the seriousness of eating disorders and provide hope, understanding and resources to others!

© 2006 National Eating Disorders Association. Permission is granted to copy and reprint materials for educational purposes only. National Eating Disorders Association must be cited and web address listed.
www.NationalEatingDisorders.org Information and Referral Helpline: 800.931.2237
Recovery... it happens. And it happens in multiple ways.

Everyone who speaks of their recovery tells a different story. Your story will connect powerfully with some who come to hear it. For others, it won’t. And that’s ok.

Things to think about before you speak, and questions you might get...

• Be true to your story, it’s yours.
• How do you want to offer the audience hope?
• How did you do it?
  ◦ What offered you hope? What was the most helpful? What advice might you give to others?
• What is it like now?
  ◦ How do you cope with stress now?
• Imagine yourself when you were struggling, what would have been helpful to hear?
• What concerns do you have about sharing?
APPENDIX H

INTERVIEW QUESTIONS
Interview Questions

1. Why did you want to participate in this and share your story?
   • Why do people need to know more about eating disorders?
   • What do you wish the public could understand about eating disorders?

2. When did you first notice that you had issues with food?

3. What was the hardest thing about having an eating disorder?
   • What was your worst day?
   • Do you remember sharing your struggle with someone for the first time?
   • Why is it hard to talk about? Why is it so hard to beat an eating disorder?

4. What role has art played in your recovery?
   • How has it helped you when you have stressful moments or a relapse?
   • What does it do for you?
   • Do you have any stories or memories of how art has helped you?
   • In what situations do you turn to it?
   • How does it help you cope and what does it help you cope with?

5. Who was your support system through your recovery?
   • What did they do that was most helpful in your recovery?
APPENDIX I

DATA FROM ARTISTS FEEDBACK QUESTIONS
### Data from Artist Feedback Questions

<table>
<thead>
<tr>
<th>Artist Feedback Questions</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I felt comfortable sharing my story</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>I felt prepared for and informed about the recording process</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>My art enhanced my ability to tell my story</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>I was able to identify supportive factors in my recovery</td>
<td>4</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>My art enhanced my story/video</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>The film represents my experience accurately and effectively.</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Additional Questions</th>
<th>Very Positive</th>
<th>Positive</th>
<th>Neutral</th>
<th>Negative</th>
<th>Very Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>The recording process was a</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>__________experience</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My participation in Art and Eating Disorders was a __________experience</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Additional Question</th>
<th>Really helped me in</th>
<th>Helped me</th>
<th>Is not related to me</th>
<th>Made me feel somewhat further from</th>
<th>Made me feel very far from</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participating in this project ________ understanding my experiences or story.</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
APPENDIX J

WORD CLOUD: SUPPORTIVE FACTORS IN RECOVERY
Supportive factors in recovery as quoted from the interviews and color-coded by artist. “ED” is eating disorder.
APPENDIX K

WORD CLOUD: ETIOLOGY OF THE EATING DISORDER
<table>
<thead>
<tr>
<th>SENSITIVE CHILD</th>
<th>DESIRE FOR STRUCTURE &amp; CONTROL</th>
</tr>
</thead>
<tbody>
<tr>
<td>LEARNING DISABILITY</td>
<td>ED WAS CONTROLLING ME</td>
</tr>
<tr>
<td>LEARNING DISABILITY</td>
<td>IT WAS THE ED, NOT ME</td>
</tr>
<tr>
<td>OCD WENT HAND IN HAND</td>
<td>TRAUMATIC EVENT CHANGED</td>
</tr>
<tr>
<td>ADD TRANSFORMED INTO ED</td>
<td>MINDSET THAT WORLD WAS</td>
</tr>
<tr>
<td></td>
<td>DANGEROUS</td>
</tr>
<tr>
<td>EXCLUDED FROM THE CROWD</td>
<td>IF I DIDN’T CONTROL IT BAD</td>
</tr>
<tr>
<td>NOT “NORMAL”</td>
<td>THINGS WOULD HAPPEN</td>
</tr>
<tr>
<td>LONELY</td>
<td>LACK OF CONTROL AND</td>
</tr>
<tr>
<td>BULLYING</td>
<td>TRYING TO GAIN IT THROUGH</td>
</tr>
<tr>
<td>ISOLATION</td>
<td>SYMPTOMS</td>
</tr>
<tr>
<td>TO FORGET MEAN THINGS</td>
<td>TRYING TO COPE THROUGH</td>
</tr>
<tr>
<td>KIDS SAID</td>
<td>SYMPTOMS</td>
</tr>
<tr>
<td>ASHAMED</td>
<td>NOT A CHOICE</td>
</tr>
<tr>
<td>CONFIDENCE NON-EXISTANT</td>
<td>TO MEET A PERFECTIONISTIC</td>
</tr>
<tr>
<td>FELT WEAK</td>
<td>IDEAL</td>
</tr>
<tr>
<td>HATED MYSELF</td>
<td>NOTHING TO DO WITH FOOD</td>
</tr>
<tr>
<td>SOMETHING WRONG WITH ME</td>
<td>NOT ABOUT FOOD AND</td>
</tr>
<tr>
<td>FELT BROKEN</td>
<td>EXCERCISE</td>
</tr>
<tr>
<td>WANTED TO HIDE</td>
<td>QUIET ABOUT IT</td>
</tr>
<tr>
<td>TO BE INVISIBLE</td>
<td>ED SAT WITHIN THOUGHTS</td>
</tr>
<tr>
<td>PUNISH MYSELF</td>
<td>RUMINATION</td>
</tr>
<tr>
<td>COULD NOT FIND COMFORT IN</td>
<td>ED RULES PROVIDED SECURITY</td>
</tr>
<tr>
<td>MYSELF</td>
<td>AND SAFETY</td>
</tr>
<tr>
<td>I DIDN’T LIKE MYSELF</td>
<td>PROTECTED ME</td>
</tr>
<tr>
<td></td>
<td>A WAY TO COMFORT</td>
</tr>
<tr>
<td></td>
<td>A WAY TO NUMB THE PAIN</td>
</tr>
</tbody>
</table>

**DEBORAH, KELLY, KRISTINE, MARSHA**

Etiology of the eating disorder as quoted from the interviews and color-coded by artist. “ED” is eating disorder.
APPENDIX L

WORD CLOUD: THE ROLES OF ART IN RECOVERY
The role of art in overcoming an eating disorder as quoted from the interviews and color-coded by artist. “ED” is eating disorder.