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## Evaluating Standardized Assessments' Ability to Capture Lived Experience of Cancer Patients and Survivors in Art Therapy Groups

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Evaluating Standardized Assessments' Ability to Capture Lived Experience of Cancer Patients  
and Survivors in Art Therapy Groups

by

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A research paper presented to the

Faculty of the Department of  
Marital and Family Therapy  
Loyola Marymount University

In partial fulfillment of the  
Requirements for the Degree  
Master of Arts in Marital Family Therapy

May 6, 2021

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### **Dedications**

To my loved ones for their support, and to anyone who has experienced the healing power of art—this is for you.

–Lara

To my dearest family and friends who have supported me throughout this venture, and to my research team for their dedication and hard work.

–Sarah

To my family, friends, partner, and loved ones who stood by me and supported me throughout this journey. To my dad who fuels my love and passion for education. Special thanks to my mom, sister, and all the powerful women in my life who have paved the way and shown me what we fierce Latinas can do—I love you deeply.

–Cecilia

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### **Abstract**

This paper explores the use of quantitative assessments typically used in research to evaluate experiences of cancer patients and survivors receiving group art therapy services. Literature exploring program evaluation as a methodology, how current research selects standardized measurement tools for the evaluation of art therapy interventions with adult cancer patients and survivors, and on the efficacy of art therapy with this population is reviewed.

Quantitative and qualitative data were collected from four participants, who were clients in two eight-week art therapy groups. Quantitative data were collected in the form of pre- and post-test measurements using six commonly used standardized quality of life assessment tools. Qualitative data were collected via focus groups and art responses. Quantitative data were analyzed to identify general trends in the pre- and post-test measures, demonstrating that no significant positive shifts in symptoms or well-being were documented in the tests. Qualitative data were then analyzed to identify six prominent themes, including the impact of the COVID-19 pandemic on the participants' experience of the tests, the participants' perceived personal value of the tests, pre- and post-test measures as containment of experience, art responses as accurate representations of the benefits of art therapy, participants' passion for art therapy, and participants' feelings that standardized tests did not accurately capture their experience in the group. These findings were then examined in the context of the literature reviewed, and it was concluded that while standardized assessments have a valuable place in research, they do not effectively capture the lived experience of participants in art therapy groups. Furthermore, future research should continue to explore the value of qualitative research, including that which uses art-making, in evaluating art therapy programs and effectiveness.

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## **Introduction**

### **The Study Topic**

This research project investigates the use of quantitative assessments to explore the experience of cancer patients and survivors receiving art therapy services. It adapts some of the theories of program evaluation to investigate efficacy of different assessment measures with art therapy interventions in terms of relevance to the participants' experience. The ultimate goal is to provide evidence that helps the field imagine stronger methodologies to support continued study of efficacy in the field of art therapy.

### **Significance of the Study**

There is a growing body of literature on art therapy with cancer patients. Most of these studies that have been conducted have used a small number of participants with inconsistencies in methodologies. Measurements have not been selected according to best practices in the past. The research aims to take an in-depth look at one aspect of the program by focusing on how to measure efficacy and assessment tools as an attempt to inspect program evaluation as a methodology. Much of the literature has mentioned the need for research to be led by specifically trained art therapists with a greater focus on specificity of design of trials and art interventions. There is a need for distinction within the usage of terminology and what is considered "art therapy," to identify proper categorization of studies to further allow for concrete outcomes. Implementing these factors can further support improved methodologies and application of research tools in the field of art therapy with cancer patients and survivors.

## **Background of Study**

Art therapy has been used in the care of cancer patients and survivors for several decades. It's important to establish best practices for evaluating efficacy of art therapy interventions with this population in order to provide the best treatment possible. While there is existing quantitative research on the efficacy of art therapy with this population, it appears further examination into the methods used in such evaluations is warranted. This literature review explores program evaluation methodology, standardized measurement tools used to evaluate efficacy of art therapy with cancer patients, and a general look at themes in the literature on art therapy with cancer patients.

Program evaluation methodology investigates both the implementation and outcomes of a program or intervention. Further, evaluation sciences provide researchers with a means to assess the results of these investigations. This methodology helps researchers answer important questions about programs or interventions, including an identification of how the program led to its effects, and guides researchers to potential next steps for improvement. Research on program evaluation in the field of art therapy is sparse, indicating a need for further study.

When evaluating efficacy of art therapy interventions, quantitative study comprises much of the literature. These studies utilize standardized measurement tools to assess efficacy. The existing literature indicates key themes in best practices for selecting these tools when designing research in this field, including a consideration of whether measurement tools have relevance to the study population or culture, the tools' reliability, circumstances in which tests are administered, and more. Additionally, the literature reveals a potential need to incorporate qualitative and arts-based evaluation of efficacy with quantitative tools; being discerning about which quantitative tools are paired with arts-based and qualitative approaches will allow

researchers to better capture study participants' experiences and, ultimately, create a more holistic picture of the impact of art therapy interventions.

Based on the existing literature, medical art therapy has already proven beneficial for cancer patients. For example, researchers have demonstrated that art therapy may help reduce physiological and psychological symptoms in this population. However, the literature reveals a need for further research with better-quality study design and increased specificity in order to improve both research quality and treatment outcomes for patients.

## **Review of Literature**

### **Introduction**

Over the past several decades, clinicians have increasingly been using art therapy to support cancer patients and survivors quality of life and reduce unwanted symptoms. This literature review aims to establish the need for evaluation of efficacy of remotely delivered art therapy groups with adult cancer patients and survivors and determine which measurement tools align best with the patients' lived experience.

The analysis in this literature review explores program evaluation as a methodology, particularly in the field of art therapy, and discerns how current research selects standardized measurement tools for the evaluation of art therapy interventions with adult cancer patients and survivors. Additionally, the researchers cover the existing research on the efficacy of art therapy with this population.

### **Program Evaluation as a Methodology**

This section examines the methodology of program evaluation including a review of the literature of program evaluation; program evaluation science and theory; and applications within the fields of art therapy and psychotherapy.

### ***Literature of Program Evaluation***

In discussing the literature of program evaluation, it is important to first explore and define the terms *evaluation* and *program evaluation*. The American Evaluation Association (AEA) states that how *evaluation* is defined can vary based upon the field of operation, background, education, and interest. *Evaluation*, when referring to organizational evaluation, is defined as a search for evidence to find out what is effective and not effective within an organization. According to Torres et al. (2018), evaluation by the AEA in 2014 was defined as “a

systematic process to determine merit, worth, value or significance” (p. 540). Rossi (2004) defined *program evaluation* as the use of scientific methods to evaluate a program’s design, implementation, improvement, and outcomes. Torres et al. (2018) expand on this definition as:

The use of social research methods to systematically investigate the effectiveness of social intervention programs in ways that are adapted to their political and organizational environments, and are designed to inform social actions in ways that improve social conditions. (p. 540).

Literature in this field notes the distinction between *evaluation* as an investigation of the process itself—looking at the implementation of the program—whereas *program evaluation* explores the outcome of a program or intervention. Torres et al. (2018) point to the interconnectedness of the two within program evaluation methodology. Program evaluation science and theory further explore these overlapping and interrelated areas and how they contribute to the practice of evaluation as research.

### ***Program Evaluation Science and Theory***

According to Sprenkle et al. (2005), evaluation science centers on the overlapping areas of program development and program research while actively examining the reasoning and efficacy of the program or intervention. Evaluation science provides researchers with analytical tools to understand the interventions used within programs while also providing a process by which researchers can assess, and address, evaluation results and the methods by which those results were acquired. Sprenkle et al. (2005) state that effective evaluation science uses measurable indicators throughout the evaluation process—from the initial assessment for the needs of the program through periodical monitoring and intervention results. Theory within program evaluation then plays an important role in “systematically clarifying an issue, planning

action to address it, and knowing how that action makes a difference” (Sprenkle et al., 2005, p. 274). The evaluation theory relays why a program or intervention should work. It specifies any assumptions made by the researchers or developers, explores how the program or intervention will make a difference, and how change will occur while also providing researchers with insight into the process and outcome of their intervention. The objective of evaluation research is then to “discern how resource use has supported particular program efforts and subsequent results” (Sprenkle et al., 2005, p. 282). Researchers must measure the effect of the program and determine whether the program or intervention made a difference—did anything improve as a result of the intervention? Literature in the field of program evaluation notes the important connection between evaluation theory, the design of the research, and the approach of the researchers. Torres et al. (2018) note a need to integrate the theory and practice with regard to evaluation research in an effort to close the gap. Deane et al. (2020) further support this need by calling for more methods or approaches to “enacting evaluation theory in the real world.” This then leads to the question of how program evaluation methodology has been or is being used in the real world, specifically within the fields of art therapy and psychotherapy.

### ***Application in Art Therapy***

Literature around program evaluation within the field of psychotherapy is sparse, with most reflecting on how evaluation theory can be used to further support the work of mental health practitioners. At the time of this review, one source of literature around program evaluation methodology and art therapy was found. A study by Feldman et al. (2014) looked at process and outcomes evaluations of an art therapy program for individuals living with AIDS. Their findings state that “although program evaluation provides opportunities to assess the outcomes of art therapy, evaluation studies have remained underrepresented in the art therapy

literature” (Feldman et al., 2014, p. 102). This study calls for more published work focusing on the evaluation of art therapy services and studies that evaluate the impact of art therapy programs. According to Sprenkle et al. (2005), the increasing need for mental health professionals to prove efficacy within their scope of practice calls for the systemic qualities of program evaluation research. Practitioners, through evaluation methodology, have the ability to assess the effectiveness of their services while demonstrating the credibility and validity of their practice, programs, and interventions through the production of meaningful and measurable outcomes. Again, according to Sprenkle et al. (2005):

Evaluation science and family therapy share the characteristics of being located in community settings, focusing on complex issues, instigating and examining change, and helping families and communities to improve their conditions. (p. 291)

These shared characteristics seem to further encourage the field to explore program evaluation methodology. Part of a successful program evaluation depends on the tools chosen to measure efficacy or the effectiveness of the services provided to the identified population, which is further discussed in the following section.

### **Standardized Measurement Tools in Art Therapy With Cancer Patients**

In designing an effective evaluation of efficacy of art therapy groups with cancer patients, it is important to consider the standardized measurement tools the researchers will use to assess for efficacy and their potential impact on the study and its participants. Betts (2006) states that in order to be most effective, assessment in art therapy should involve both objective measures like standardized assessments and subjective measures, which often involves the client’s artwork; but what are the best practices for incorporating those standardized measures? Here the researchers examine key themes the literature on past art therapy research with adult cancer patients reveals

regarding how quantitative measurement tools have been selected and implemented to explore the efficacy of art interventions.

### ***Relevance to Population and Culture***

In the literature on art therapy with cancer patients, standardized measurement tools are used that have some sort of specific relevance to the cancer population being studied. For example, many studies utilize measures specifically designed for use with cancer patients. Radl et al. (2018) choose some of their tools, including the Perceived Emotional Distress Inventory and the National Cancer Care Network Distress Thermometer and Problem List, in part because they were developed for use with cancer patients in order to assess for emotional distress and mood disturbance. Even when the measures are not designed to be cancer-specific, researchers consider their well-documented use with relevant populations. For example, Monti et al. (2006) include the Medical Outcomes Study Short-Form Health Survey as one of their tools to measure efficacy because the instrument has documented reliability and validity in several chronic illness populations.

Standardized measures are also selected due to their ability to measure symptoms that are relevant to cancer patients. For example, much of the literature uses measurement tools that assess for quality of life (QoL), such as the World Health Organization Quality of Life (WHOQOL) assessment. Svensk et al. (2009), who use this specific measure, state that QoL has become increasingly important when measuring treatment outcomes in cancer research because cancer treatment and the disease itself introduce stressors that directly affect QoL. Similarly, Svensk et al. (2009) also utilize the QLQ-BR23, an assessment tool designed specifically to assess QoL in breast cancer patients, tailoring the relevance of their measurement tools even further for their participants' specific cancer diagnosis.



The literature demonstrates that researchers also frequently select tools that measure for other physical and mental symptoms that are particularly common among cancer patients. For example, 12 studies analyzed in Jiang et al.'s (2020) systematic review on the effects of art therapy in cancer care identify QoL and symptoms of fatigue, anxiety, and depression as the main indicators measured when assessing efficacy. Studies not included in Jiang et al.'s (2020) review also follow this trend: for example, Bar-Sela et al. (2007) assesses efficacy of art interventions using the Hospital Anxiety and Depression Scale (HADS) and the Brief Fatigue Inventory (BFI).

Additionally, other aspects of the participants' culture are often taken into account when selecting measurement tools; for example, Ando et al. (2016) studies art therapy with Japanese cancer patients and therefore implements the Japanese language versions of the Profile of Mood States (POMS) and Functional Assessment of Chronic Illness Therapy Spiritual Well-Being (FACIT).

### ***Reliability of Tools***

In much of the literature, when the researchers list their chosen measurement tools, they make a point to state whether the instruments have demonstrated validity and reliability. For example, Radl et al. (2018) and Czamanski-Cohen et al. (2019) identify reliability and validity as key rationale for their chosen standardized measurement tools. Similarly, Svensk et al. (2009) note the meticulous nature of reliability and validity testing done with WHOQOL instruments. This theme is present across the literature, indicating the importance of choosing standardized measurement tools that will bolster the accuracy of study results.

### ***Circumstances of Administration***

Administration of standardized measures is a key consideration when designing a program evaluation. The literature demonstrates several common themes regarding circumstances of this administration. Firstly, who administers the tool and when can vary from study to study. For example, in Lee et al. (2017), researchers choose to have the same art therapist administer all of the tests throughout the study because they feel it encourages the development of emotional rapport and supports the patients' psychological well-being. In contrast, Svensk et al. (2009) decide to have an art therapist who did not lead the art therapy sessions administer questionnaires, with the rationale being that participants may feel more comfortable expressing both positive and negative experiences about their involvement in the study under these circumstances. Finally, some research utilizes measures that were self-administered, such as other assessments used in Svensk et al. (2009) and Radl et al. (2018).

As far as when measures are administered, most of the reviewed studies, such as Radl et al. (2018) and Lee et al. (2017), administer tests multiple times throughout treatment—for example, prior to the intervention to collect baseline data, at some point during the course of treatment, and then after treatment has ended in order to track change over time. Other tests simply gathered pre- and post-test measures to monitor this change, such as Bozcuk et al. (2017). Ease of administration also appears to be a factor considered in some of the studies when selecting standardized tools; for example, short or brief versions of questionnaire and scales are often utilized, such as in Ando et al. (2016), Radl et al. (2018), and Bar-Sela et al. (2007).

### ***Need for Supplementation With Non-Quantitative Measurement Tools***

As previously mentioned, much of the literature aims to measure art interventions' effects on cancer patients' emotional well-being—for example, utilizing measures that track symptoms of depression, anxiety, and distress. As Svensk et al. (2009) point out, these experiences common

in cancer patients aren't always easy to quantify or capture with words. With study participants already accustomed to art therapy, it may be appropriate and effective to supplement the use of quantitative data measures with the use of other, more subjective measures that allow for open-ended expression, such as qualitative interviews that may include art-making as part of the response. While some of the literature reviewed for this section utilized more subjective questionnaires in addition to quantitative measures when assessing efficacy of interventions (such as Wiswell et al. [2019] and Puig et al. [2006]), none of the studies appeared to utilize art-making as part of this process; this is something that may warrant consideration in further study with this population to best capture participants' experience in a holistic manner.

Current research that uses standardized measures chosen based on the criteria identified above, along with other research that uses qualitative or arts-based methodologies, demonstrates that art therapy shows promise with cancer populations; the following section explores themes of these results.

### **Medical Art Therapy with Cancer Patients**

Many studies have shown that the practice of medical art therapy with cancer patients has been beneficial with positive effects. According to the World Health Organization (WHO), statistics show that 1 out of 10 women and 1 out of 8 men are bound to develop cancer in their lifetime (Bray et. al., 2018). Art therapy has been used as a non-pharmacological form of treatment to reduce physiological and psychological symptoms in cancer patients. These symptoms negatively affect QoL along with clinical outcomes from disruption in the treatment process, as mentioned in Jiang et al. (2020). Art therapy can be used as a complementary treatment for cancer patients to alleviate such symptoms in a therapeutic setting led by a registered art therapist. Here the researchers examine art therapy literature and how it informs us

about the practice of medical art therapy with cancer patients along with the identification of themes and issues.

### ***Reduction in Psychological and Physiological Symptoms***

The most common symptoms of cancer patients consist of depression, anxiety, fatigue, and pain. Patients with a cancer diagnosis have difficulty coping with the physical side effects from medical interventions along with psychological symptoms of distress. Art therapy has been shown to reduce symptoms of depression, while increasing awareness and acceptance through emotional processing (Tang et al., 2019). Similar themes are present in the literature of Jiang et al. (2020), a meta-analysis, with the conclusion that art therapy has a positive effect on the QoL for cancer patients in both group and individual settings, along with the reduction in symptoms of anxiety. Through art making and expression, art therapy can aid in healing and coping by managing cancer-related issues and challenges. For example, in Buday (2019), the use of metaphor and imagery in expressing emotions and experiences are identified as a way to cope with trauma and a life-threatening illness. This process may allow cancer patients to feel empowered by using symbolism as a way to convey or express difficult emotions without words, while gaining insight from the process of reflection and from the final art piece produced.

### ***Need for Better-Quality Studies***

There are many ways in which research in the field of art therapy with cancer patients can be expanded upon. Future studies should be conducted by certified art therapists, with focus on greater specificity of design of trials and art inventions. Studies should be conducted over a continuous period of time, on a larger sample size, and with longer follow-up duration (Regev and Cohen-Yatzi, 2018). Many studies have been conducted where “art therapy” is used as a broad term that may involve visual arts, dance, music, drama, sculpture, and poetry (Tang et al.,

2018). The literature demonstrates that the usage of different terminology and what falls under the art therapy category may lead to improper categorization of studies (Kievisiene et al., 2020). There is a need for specificity in art therapy interventions in research to better allow concrete outcomes. Taking these factors into consideration can help elevate the level of research in the field of art therapy with cancer patients, contributing to improved methodologies and applications of research tools that may offer validity and reliability to better serve this population.

### **Conclusion**

This literature review explores the strategy of program evaluation research and investigates how current research uses standardized measurement tools to assess the efficacy of art therapy interventions with adult cancer patients and survivors. Further, it includes an in-depth review of general themes of art therapy with this population. This literature review is intended to support efforts for future research and evaluation of efficacy within the field.

### **Research Approach**

This research project uses an adaptation of program evaluation methodology. An extensive exploration of program evaluation literature and both quantitative and qualitative studies measuring the efficacy of art therapy with cancer patients was done in anticipation for using this approach within this research project. This project looks at measurements in research with this population using an adapted program evaluation methodology. It evaluates and measures cancer patients' experiences with art therapy using both quantitative and qualitative assessment tools and then evaluates which of these tools were the most useful and analyzes how meaningful they were to the participants themselves in terms of accurately capturing their experiences. This approach was chosen due to its ability to discern program interventions, and efforts, from results.

Sprenkle et al. (2005) supported our reasoning for using this methodology, stating, "A primary goal of program evaluation is to determine the effects of a prevention or intervention effort" (p. 285). Further, according to Feldman et al. (2014), evaluation plays an important role in understanding both the process and the impact of art therapy programs:

This dissemination of results from art therapy evaluations represents an important opportunity for promoting the potential of this discipline to significantly impact health and mental health outcomes. (Feldman et al., 2014, p. 108)

This study aims to identify indicators of efficacy of treatment with specific tools to measure the effectiveness of treatment and interventions with this population. By using more than one strategy to gather and examine data, the researchers aim to produce a more holistic picture of the results being measured. According to Sprenkle et al. (2005), "using both quantitative and

qualitative data to measure and process results... lends credibility to findings when there is consensus between the various data” (p. 287). Using a variety of research methods helps researchers be more discerning of the data gathered. According to Kapitan (2010):

Qualitative and quantitative data may yield evidence, obtained from such measures as client satisfaction surveys and focus group interviews... that may be sources for identifying the variables that point to program success as compared to where the program can make improvements. (Kapitan, 2010, p. 86)

This approach analyzes data that measures art therapy treatment outcomes in order to answer questions about the appropriateness of specific assessment tools in terms of accurately capturing the participants’ lived experiences.

## **Methods**

### **Definition of Terms**

**Program Evaluation:** Program evaluation is the use of scientific methods to evaluate a program's design, implementation, improvement, and outcomes (Rossi, 2004).

**Evaluation:** Per the American Evaluation Association (2020), evaluation involves assessing the strengths and weaknesses of programs, policies, personnel, products, and organizations to improve their effectiveness.

**Qualitative Methods:** Per the Centers for Disease Control and Prevention (CDC) (2010), qualitative methods are research methods that generate “descriptive information” and “add depth, detail, and meaning” to research (“Determine How the Information Will Be Gathered” section).

**Quantitative Methods:** Per the CDC (2010), quantitative methods are those research methods that produce “numerical data such as frequencies, percentages or rates” and have traditionally been preferred as a means to establish efficacy (“Determine How the Information Will Be Gathered” section).

**Quality of Life (QoL):** Per the CDC (2018), “QoL is a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life” (para 3).

**Health Related Quality of Life (HRQoL):** Per the CDC (2018), HRQoL “on the individual level, HRQoL includes physical and mental health perceptions (e.g., energy level, mood) and their correlates—including health risks and conditions, functional status, social support, and socioeconomic status” (para 5).

### **Design of the Study**

#### ***Sampling***

For the purposes of this research project, researchers select participants of art therapy



groups for cancer patients at a major hospital's comprehensive cancer center via a program focused on wellness, survivorship, and resiliency of patients and their families. Specifically, a multidisciplinary professional team in this program will select the participants, all of whom will be adults (over age 18) who have been patients at the cancer center. Subjects will be contacted by the administrative assistant for this department and provided with a flyer about the groups. All participants signed the informed consent (see Appendix A). With two weekly groups running over 40 weeks and 10 participants per group, the researchers anticipate a potential of 100 participants.

### ***Gathering of Data***

For this research project, the researchers identified six assessments based on their frequent use in existing research on QoL in cancer patients:

- Edmonton Symptom Assessment System (revised version) (ESAS-R) (see Appendix B)
- Beck Hopelessness Scale (see Appendix C)
- UCLA Loneliness Scale (see Appendix D)
- PROMIS Global Health (see Appendix E)
- PROMIS – 29 Profile V.2.0 (see Appendix F)
- FACIT – Sp-Ex (Version 4) (see Appendix G)

Along with an accompanying letter of instructions (see Appendix H), each of these assessments are sent to participants of two 8-week modules of the art therapy group, one that starts in November 2020 and one that starts in January 2021. The participants take the assessments before starting the group and after finishing the eight weeks to provide pre- and post-test measures.

After these assessments are returned to the researchers, the researchers gather the participants in two focus groups (one per original module). In these focus groups, researchers verbally interview

the participants about their experiences using these measures. Additionally, there is an art-based response collected during the focus group.

### *Analysis of Data*

The quantitative data gathered via the pre- and post-test administration of the six standardized tools are not analyzed for the purpose of establishing efficacy; rather, these tests are given to participants only to provide insight into whether the standardized tools themselves were useful in accurately capturing participants' experiences. To analyze the data for this research project, researchers look mainly at the qualitative data gathered in the focus groups, including the interviews as well as participants' response art about their experiences of taking the pre- and post-tests. In this way, the research integrates both quantitative and qualitative data to identify strengths and weaknesses of the assessment tools in terms of establishing their usefulness for future research projects.

## Results

### Presentation of Data

The data collected for this research project can be divided into two categories:

1) Quantitative data: These data are presented in table 1, which reflects the results of the six standardized assessments participants were given as a pre- and post-test measure. The data presented in table 1 was collected from the two 8-week modules of the art therapy group.

2) Qualitative data: These data were collected during two Zoom focus groups in which a total of four participants shared their experiences regarding taking the six standardized tests and in what ways they felt each of the tests were relevant or irrelevant to their experience participating in the art therapy group, along with their suggestions for how to improve the relevance of such assessments. A narrative of key responses collected during the focus groups is reviewed, and common themes identified. Additionally, participants were invited during the focus group to create an art response about their experience of taking the pre- and post-tests as well as their experience of the art therapy groups in general. Screenshots of the art captured via Zoom are presented and further analyzed below to supplement discussion of themes in the research findings.

In the analysis, findings from the quantitative and qualitative data are further explored and integrated to identify strengths and weaknesses of the assessment tools in capturing the efficacy of art therapy groups for cancer patients and survivors.

### *Quantitative Data: Pre- and Post-Test Assessments*

The six assessments were sent to participants with instructions to complete them prior to beginning the art therapy group and after completion of the art therapy group to provide pre- and post-test measures. For the first 8-week module, which began in November 2020, participants

were sent physical packets with print-outs of each of the six assessments, along with a stamped and addressed envelope to increase convenience when participants mailed them back. In total, four assessments were completed and received from participants from this module however only one participant's data is reflected below due to their participation in the focus group.

For the second module, which began in January 2021, participants were again mailed physical packets containing the assessments. However, based on feedback from the first module participants and therapists facilitating the group, participants were also offered the option to complete the assessments electronically using PDFs they could send back via email. For this module, a total of three participants completed and mailed back the pre- and post-test assessments.

Pre- and post-test data is presented below in Table 1.

**Table 1**

***Summary of Quantitative Data From Pre- and Post-Test Assessments***

Assessment	Purpose	Results of pre- and post-assessments
<b>Edmonton Symptom Assessment System (revised version) (ESAS-R)</b>	Designed to rate the intensity of common symptoms experienced by cancer patients—pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath.	<ul style="list-style-type: none"> <li>● 2 of 4 participants experienced a negative shift overall with some symptoms staying the same.</li> <li>● 2 of 4 participants experienced a positive shift overall with the exception of two differing symptoms.</li> <li>● Well-being: 2 participants experienced a negative shift; 1 experienced a positive shift; 1 remained the same.</li> </ul>
<b>Beck Hopelessness Scale</b>	Measures three major aspects of hopelessness, including feelings about the future, loss of motivation, and future expectations.	<ul style="list-style-type: none"> <li>● 3 of 4 participants experienced little change with 1 to 2 shifts in responses.</li> <li>● 1 of 4 participants reported no change.</li> </ul>

<b>UCLA Loneliness Scale</b>	Designed to measure subjective feelings of loneliness and feelings of isolation.	<ul style="list-style-type: none"> <li>• 2 of 4 participants experienced an increase in overall loneliness.</li> <li>• 2 of 4 participants experienced a decrease in loneliness.</li> </ul>
<b>PROMIS Global Health</b>	Assesses general domains of health and functioning- physical health, mental health, social health, pain, fatigue, and perceived QoL.	<ul style="list-style-type: none"> <li>• 3 of 4 participants experienced an increase in QoL.</li> <li>• 2 of 4 participants experienced a positive shift in mental health.</li> <li>• Minimal or no shift in other areas.</li> <li>• 1 participant referenced impacts of COVID.</li> </ul>
<b>PROMIS – 29 Profile V.2.0</b>	Assesses pain intensity in seven health domains—physical function, anxiety, depression, fatigue, sleep disturbance, ability to participate in social roles, and pain interference.	<ul style="list-style-type: none"> <li>• 1 participant reported no changes and noted variables linked to COVID.</li> <li>• 2 participants experienced a decrease in anxiety.</li> <li>• 1 participant experienced an increase in pain.</li> </ul>
<b>FACIT – Sp-Ex (Version 4) Functional Assessment of Chronic Illness Therapy- Spiritual Well-Being Expanded Version</b>	Measures spiritual well-being.	<ul style="list-style-type: none"> <li>• 3 of 4 participants experienced a positive shift overall.</li> <li>• 1 of 4 participants experienced an increase in spirituality, thankfulness, and appreciation with a decrease in connection to others.</li> </ul>

### ***Qualitative Data: Focus Groups and Art Responses***

Participants who had completed and returned the pre- and post-tests were invited via email to a 1-hour focus group via Zoom with the purpose of learning more about the participants' experience of completing the standardized assessments and whether they felt the tests were relevant to their experience and able to accurately capture any change that may have occurred over the course of the 8-week therapy groups. The focus groups were held within two weeks of each module's completion. Following a period of discussion in which researchers inquired about the participants' experience of taking the pre- and post-tests, the researchers also invited the participants to create an art response. The prompt for the art response was: "Use your chosen art

materials to create a timeline split into three sections: 1) the pre-test experience, 2) the art therapy group experience, and 3) the post-test experience. In each of the three sections, add any imagery, words, or other marks that you connect with that time and the experience of either doing the assessments or being in the group.” Participants were given about 10 minutes to make art and were invited to share about their creations afterward. In the following sections, aliases are used for each of the participants due to confidentiality.

**Module 1 Focus Group.** For the first module focus group, the four participants who completed tests were invited. While three responded stating intent to participate, only one participant (Linda) ultimately attended the group. Linda appeared highly engaged and shared verbal responses as well as providing an art-based response. It’s important to note that due to the pandemic, Linda did not receive her pretest until the second week of the 8-week group. Overall, she reported enjoying taking the assessments.

When asked about her experience taking the assessments, Linda reported that the process of receiving the assessments in the mail and sending them back was “painless.” That said, she noted she would have preferred to complete them digitally, which the researchers took into account prior to the next module.

Linda shared that she felt some were more relevant to her lived experience as a cancer survivor in an art therapy group than others, and none of them perfectly captured her experience. As she spoke about each of the six assessments, she instinctively ranked them against one another. She reported that she found the assessments were more an accurate measure of where she was in that exact moment than an accurate reflection of the impact of the art therapy group on her symptoms. Below are Linda’s comments regarding each of the assessments she received, listed in the order of least to most relevance to her experience as she ranked them.

***Edmonton Symptom Assessment System (revised version) (ESAS-R).*** Linda made similar comments about this assessment. “Was I aware of my art therapy group impacting my level of pain? No, but, could there be benefit of focusing on the art and thinking through my experience? I assume so. I would say the Beck scale probably would be more directly relevant to the art therapy group than this one would be.”

***Beck Hopelessness Scale.*** This scale assesses the taker’s depression symptoms. Linda noted that the scale felt somewhat relevant, but she was aware that it was not fully capturing her experience of the art therapy group. “It’s not like the art therapy group was supposed to make it so I was supposed to look forward to the future—rather that just having the group in my life may have enhanced the experience of looking forward to the future.”

***PROMIS – 29 Profile V.2.0.*** Linda ranked this assessment as somewhat less relevant than the PROMIS Global Health and somewhat more relevant than the Edmonton assessment.

***PROMIS Global Health.*** Linda ranked this assessment as more relevant than the Edmonton scale but less relevant than the FACIT. “I identified some of the questions as more directly relevant.”

***UCLA Loneliness Scale.*** Linda stated that this assessment was the second-most relevant of all of the assessments she took.

***FACIT – Sp-Ex (Version 4).*** Linda stated that this assessment felt the most relevant to her experience of all six she received. “It felt most directly linked to the art therapy experience,” she stated. Further, she noted, “I understand the value of the wider perspective, so I see art therapy or my experience with the group as one tool to help broaden my perspective and increase my outlook. Is it the thing that directly makes me feel less nauseous? No, but it enhances and expands my outlook to improve some of these other factors.”

*Additional Discussion.* In general, Linda stated that she understood the importance of the pre- and post-test assessments for the researchers' use, but felt they were not fully representative of her experience of the impact of the art therapy group. She did not assume that the tests were being given to determine whether the art therapy group directly impacted each item on each assessment.

Additionally, Linda noted that COVID-19 impacted her answers to some of the questions and her experience of the assessments overall. "I felt like some of [the questions] I had trouble answering because of COVID. There were questions about being able to do social activities and seeing friends. We are in strange times right now, so I'm not happy with my social interactions right now—but it's not because I had cancer, it's because we're in a pandemic. [...] If I were able to see my friends, would I be happier right now? Probably. The current times we are in affected my ability to fill out the assessments."

When asked about what she felt could have made the assessments more relevant to her experience of being in the art therapy group, Linda stated, "There wasn't anything that asked specifically about how the art therapy group contributed to any of this. It may not be necessary, but it could be sort of grounding."

While Linda felt the assessments overall did not fully capture the impact of the art therapy group, she did report finding the assessments useful on a more personal level. "Those assessments weren't just for you [the researchers]—they were for me too. While I was filling out the assessments, I was able to note how am I feeling about the future, about pain... The assessment tools were actually kind of useful check-ins for myself. In the moment, I was thinking I learned about myself more through the art and the group, but now I'm also realizing that the assessments are also useful from a personal perspective, but I think they're not as useful



if you are just given them on your own without any sort of support around them, because for example you may take them and find out you have a pretty dark outlook on life and feel like, ‘so great, now what?’” The groups provided the support she feels were needed surrounding the assessment experience.

**Module 2 Focus Group.** Although the researchers considered changing the format of the focus group, specifically to tailor the art response directive to try to focus more on the experience of taking the pre- and post-tests rather than the art therapy group experience, ultimately the researchers decided to keep the format and directive the same to ensure consistency from group to group.

For the second module focus group, all three invited participants attended (participants Rose, Maureen, and Lucille) and participated in providing verbal and art-based responses. All participants appeared highly engaged and eager to share their experiences. Notably, Rose had not yet completed or returned her post-tests at the time of the focus group.

Overall, the participants agreed that the six assessments did not fully capture the effect of the art therapy groups. Below are their comments regarding each of the assessments.

***Beck Hopelessness Scale.*** None of the three participants felt this assessment was relevant to their lived experience of the impact of the art therapy group.

Lucille: “I believe what the group is offering is not fully captured in these questionnaires. The questions are evaluating whether you have depression, how bad you are feeling, general blanket statements—but there is so much more refinement that goes into the [art therapy group]. These things also fluctuate from week to week—this is part of life. Some moments you are depressed, some moments you are hopeful. Does that really represent the value of the [group]? I don’t believe so. I don’t think the questions can really capture what the benefit of the class was

weekly/daily.”

Maureen: “Feelings fluctuate. [The questions] are just cookie-cutter.” She expressed that the art therapy group was “helpful in dealing with what at-the -moment feelings we had, and knowing other people are in the same category of mindset helps, but this questionnaire is just too straightforward.”

Rose: “I don’t know that this test is relevant. I think [my answers] just depend on the day that I took the exam. It kind of made me really look at the day where I was when I took the questionnaire. I felt [the tests] were helpful for those doing research, but personally, not really.”

*ESAS-R.* Maureen stated that she felt the questions did not relate to her experience of the art therapy group. That said, Lucille stated there was some level of relevance in this assessment: “It’s quantifying in a way that may give a better picture than the [Beck scale], but I still don’t believe it reflects the benefit of what the class gave on a weekly basis. Maybe you could be rewriting the question based on what we did gain from the class that we could maybe share with you.”

Rose agreed with Lucille and suggested more frequent testing, such as before and after each session rather than before and after the 8-week group, could better assess for the effects of the group itself. She stated that while the tests were somewhat helpful on a personal level to assess her symptoms at a specific point in time, she did not feel they captured the art therapy group’s effects. “These questions are good, but if I was to put it towards the therapy we’ve done, it’s not connecting. But if we were to use them for let’s say one session, for example one of the questions on pain, asking where was your pain before and after the therapy session that day... that could be annoying but maybe one or two questions before the session and after the session. That would probably make it more relevant to the session. I found that each session was different

for me, and I did see a lot of progress personally. If you were to ask me about pain, I do experience pain, but the group was a total distraction from that pain. I'm grateful for the program because it brought out a lot of things. There's a lot more to it than what I see here [in the tests]."

Lucille echoed this sentiment regarding more frequent testing as a more accurate way to capture the group's positive effects: "Maybe I went into class and was really tired that day, or had a headache, and through the activity and sharing I was giddy and the headache receded... so there really is a quantifiable way to see before and after, just in the two hours, that really makes a difference. I did [the art therapy group] because of that; I really enjoyed how I felt afterward."

Maureen agreed: "Some sessions I would be gloomy, cry, or extremely tired after session, drained of energy, but [the group] also helped me deal with some of that stuff, and helped bring up some of the pent-up sadness in art-making and talking about it." In this way, she felt assessing for levels of pain, sadness, or tiredness before and after the sessions would not accurately capture the therapeutic benefit of the groups. Additionally, she felt some of the questions were completely unrelated to her experience of the art therapy group, such as questions asking about her shortness of breath. "I'm not running around in the group—I'm just sitting down. These questions are kind of irrelevant."

*FACIT – Sp-Ex (Version 4)*. Lucille felt this assessment was also somewhat relevant to her experience in the art therapy group, although still too broad for her liking. "If you're taking [the questions] and connecting them more with what the [group] did instead of the general things, it would be better... Some of these questions are good, [such as those about] creativity, peace of mind, purpose—those are quantifiers that could be relating more to what the [group] is about, they just need to be rewritten in a way that makes sense contextually."

Maureen and Rose both agreed that the questions would have been better suited to

evaluate the group's efficacy had they been more customized to the art therapy group experience. Overall, however, the participants agreed that the FACIT held more "potential" to accurately capture the group's effects than the other assessments discussed so far.

***PROMIS Global Health.*** Overall, the participants agreed this assessment was not relevant to their experience in the art therapy group. Maureen stated, "It's way too general—this is what you get asked when you go to the doctor."

***PROMIS – 29 Profile V.2.0.*** Maureen reported feeling that this assessment was somewhat relevant to her experience in the art therapy group: "There is some relevance as far as social role because even though [the group] is via Zoom, we are still connecting with other people we don't know and sharing about having the same illness you're dealing with. and it might be that our feelings and thoughts and way we are is a little different from one another, but at the end of day, we all are very similar—the fear of [cancer] coming back, the fear of tiredness, loneliness, health, friends... so there is some connectivity that you can see in here, but it's still very general. It's important to see the dynamic of the people in the [groups] to see how their moods go up and down and how people come in to help others."

At this point, Rose asked the researchers whether they had ever participated in art therapy as clients. She stated she felt it would be a helpful experience if the researchers were designing standardized tests to accurately capture the effects of art therapy. This opened up the focus group to a more general discussion of the values of art therapy.

Maureen: "Art therapy is definitely helpful. I had never done it before, and when I went into it, I didn't expect anything, but it was really good and really deep."

Lucille: "The population that is going through the art therapy is important. The group has cancer, so there is another phenomenon going on with that, which is an additional layer... You

couple the therapy process with a support group, a sense of understanding what others are going through and sharing... there is a learning process that gives strength, which is more specific to what art therapy is about... You connect with other people with the same experience, all together talking about feeling, in a way that's pleasurable with the art... you gain knowledge, strength. You may not realize it consciously."

Rose: "I enjoyed it so much that I have to go back and look at the drawings I did, and I want to start journaling because there are things that came up during each session, so I want to go back and remember what happened during that experience.... Things come up unexpectedly [with the art]."

*UCLA Loneliness Scale (version 3).* Two of the three participants of focus group 2 received a different version of the UCLA Loneliness Scale than did the participant in focus group 1. The three participants reported that this assessment did in some ways feel relevant to their experience as group participants.

Maureen: "I remember in our [group] that we did talk about loneliness, and we did share that being with cancer, being in the COVID situation, and how being lonely has heightened the sadness. The loneliness has heightened what we went through." That said, she still felt the questionnaire did not fully capture her experience.

*Additional Discussion.* At this point, Lucille offered her ideas of what could make for a more appropriate and holistic assessment to capture the change the art therapy groups caused. For example, she suggested asking each client to share an adjective to describe how they felt at the beginning of a group session and the end of a group session to explore the effects of the therapy. She also suggested collecting testimonial statements or letters from the participants about their experiences in the group.

The other two participants reaffirmed their opinion that these assessments do not adequately capture the impact of the groups. The participants appeared eager to share about the power and benefit of the art therapy groups that they feel the tests did not fully capture, and it was difficult to get them to stay focused on sharing about the tests they took specifically. They felt some aspects of the six quantitative assessments could potentially be combined with assessments that were more specific to their experience (such as qualitative data from interviews with participants) to create a new assessment tool that truly reflects accurately the efficacy of the groups.

After completion of the art responses (explored in-depth in the next section of this paper), the participants expressed increased confidence in the researchers' abilities to understand their lived experience as part of the art therapy group and shared their final thoughts on the assessments and their experience below:

Maureen: "You guys get it now—you're going in the right direction. I highly recommend you attend one of those [art therapy groups]."

Lucille: "The [art therapy] is so valuable, and it drives me crazy to see questionnaires that do not relate or capture what the experience is, because oh my god, this is so important! So I appreciate you asking these questions because I think we could really capture it—it's the alchemy of the soul. [...] Because you come in with left-brain, logical doctor [questions], but we are talking about the soul, the human spirit—we are talking about what gives us resiliency. Those things are not normal language of the medical sector. [...] I feel like if you could spend more time really listening to what people are getting from the groups in terms of words and experience, you could transform it and find the right way to quantify it. That understanding is really crucial, and none of the [assessment] questions brought that level of understanding, and in

order to understand, you really have to listen in-depth to the experience to encapsulate and get it, and then you can transform it into whatever metrics you can.” She further expressed frustration that there were no assessment questions about the benefits of “commonality of the experience” in the art therapy group, stating, “That is a critical aspect that is missing that needs to be accounted for. I really believe it’s something that makes such a profound difference in the cancer community.”

Rose: “The whole pre-summary, post-summary, and therapy itself was all beneficial. I agree to what others say about customizing the questions because it is a very subjective practice, just like I could feel wonderful at the end of session, others could have totally different outcomes. To go back to the [assessments,] they were beneficial for me personally to reflect on what was going on in my life that day, because these are good questions to reflect on, so in that sense it helped me. But [the assessment questions] definitely [could use] more insight into the therapy itself, and hearing from the person who had the experience what they went through. I’ve been promoting [art therapy] to my support groups. I’d go back again in a heartbeat.”

**Art Responses.** Below, each participant’s art responses is presented, along with descriptions of their own explanations of their artwork and its meanings.

***Linda’s Art Response.*** Linda reported enjoying the process of making her art response (see Figure 1) during the focus group and appeared eager to share about her imagery, which she had created with colored pencils in a sketchbook. She described the top third of her paper as the pretest period, the middle as the period during the art therapy group, and the bottom third as the post-test period. Below are Linda’s comments about each section and her creative choices for each.

Pretest Experience: During this time period, there was “anticipation and excitement. I was fine to do the evaluations.” Linda stated she decided to draw a sunshine or sunrise, “kind of like starting the process, starting the day.”

Art therapy group experience: “Different things came up for me. The red circle in the middle is [to represent that] while I was going through the group, I was experiencing some stomach discomfort.” The basket represents feeling “really supported” by the therapist leading the art therapy group: “I felt like I could rest anything I needed to and feel supported.” She described drawing fireworks to express her

enjoyment of the art therapy group process. The heart is “representative of support I felt from [the therapist] but also from some of the other group members.” She reported adding a question mark because there was a sense of guilt around the small number of participants attending the group. Finally, she discussed her decision to add grass to this portion of her visual timeline because “I grew from it.”

Post-test experience: In describing the bottom third of her drawing, she stated, “It’s sort of a sun, but it’s gray, and I remember thinking when I was doing the posttests that I was worried that my perspective hadn’t improved, but it was less about [effects of] the group and more about where I was at the time. I was feeling down when I was doing the test, and I remember feeling like, ‘uh oh,’ but it wasn’t because of the group that I was feeling down. Whether it’s laid out in

**Figure 1**

*Participant Linda’s Art Response*





the assessment data or not, I found the groups very useful.”

**Rose’s Art Response.** Rose chose to use colored pencils on white paper for her art response (see Figure 2) during the focus group. She described the timeline as moving from left to right, with the left-most third representing the pre-test period, the center representing the art therapy groups, and the right-most third representing the post-test period. Rose’s comments about each section of her visual timeline are below.

**Pretest experience:** Rose reported that the question mark she drew was representative of “starting the unknown” with the art therapy group experience. “It’s black, because I have no idea what’s there.” She did not comment specifically on the experience of taking the assessments during the pre-test period.

**Art therapy group experience:** Rose described the middle portion of the timeline as representative of her emotional state during the course of the 8-week group. She described the change in colors from the bottom up, starting with red. “The red [represents] being a little bit excited from whatever I was doing [in the group]. The yellow is brightness and hope. Then I end up here in the blue, which is the peaceful, calm state.”

**Post-test experience:** The blue “calm state” from the center of the image carries over to the post-test portion of the visual timeline. Rose stated, “At the end of the calm state, it’s me feeling like a circle, whole, clear in the middle, with bright blue for the peacefulness; orange, my

**Figure 2**

*Participant Rose’s Art Response*



favorite color, is joyous and happy; and then green grounding me. I feel whole, not scattered or in an unknown place.”

**Maureen’s Art Response.** Maureen used markers on white paper for her art response (see Figure 3). She described the timeline as moving from top to bottom chronologically. Her comments about each section of her visual timeline are below.

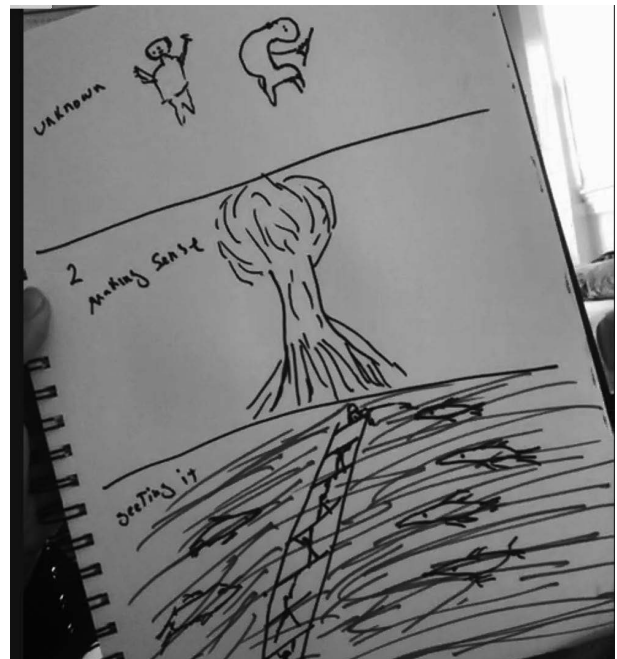
**Pretest experience:** In the pre-test portion of her timeline, Maureen drew two human figures with black marker, one standing and one sitting and drawing. She also wrote the word “unknown.” She stated, “This shows the confusion.”

**Art therapy group experience:** For the middle section of her visual timeline, Maureen drew a tree with visible roots in black marker, along with writing the words, “Making sense.” She stated, “In here, it feels like I’m grounded and grounding because of all these tentacles of the trees going down, and the tree is flourishing.”

**Post-test experience:** For the last portion of the timeline, Maureen wrote the words, “Geeting [sp] it” in black marker and drew a diagonal ladder-type shape down the middle of the section, with stick figures at different stages of the ladder. She drew several large fish on either side of the ladder, also in black. With blue marker, she drew horizontal lines across the entire image to represent water. She described it as follows: “In the last one, there is a little person who is just struggling to go up the ladder, and then they finally get up there and start

**Figure 3**

*Participant Rose’s Art Response*



fishing, so reaping the effort that you put in.”

***Lucille’s Art Response.*** Lucille used pastels on white paper to create her art response (see Figure 4) during the focus group. She described her visual timeline as moving from left to right chronologically. Her comments about each section are below.

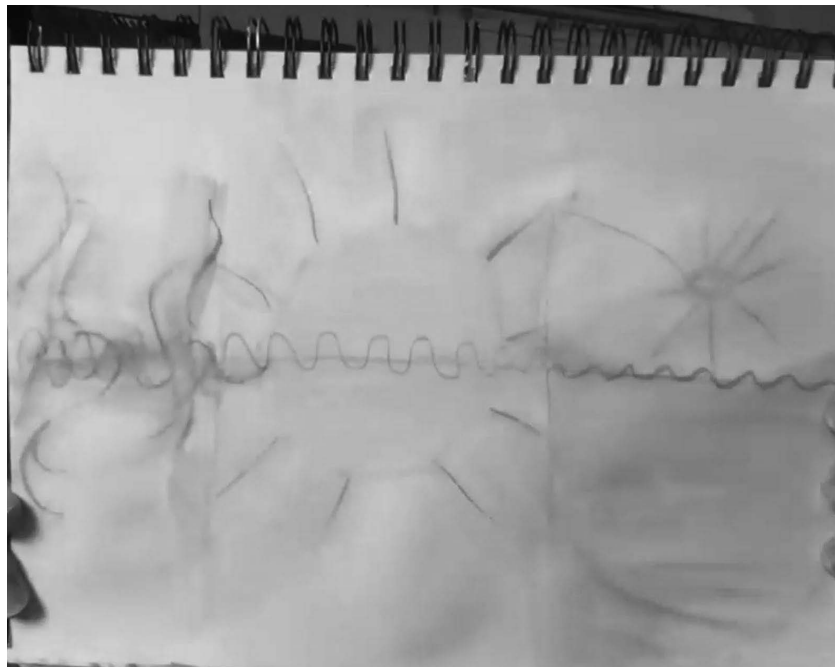
Pretest experience: On the left-most side of the page, Lucille used purple to create a wavy horizontal line that bisects the page. Other wavy purple and pink lines extend out from this line vertically, and they have a blurred appearance. She stated, “It’s a chaotic type of energy, you know, my life is going in every single direction, trying to catch all of the balls and trying to find peace and center.” Regarding the wavy line, she said, “It’s like the up and down of life. I believe we all have ups and downs, it’s like the beat of the heart that goes up and down, so we go through that emotion of life. Here, my emotion was chaotic.”

Art therapy group experience: In the middle section, the horizontal wavy line

continues in orange. Compared with the previous section, the wavy line is clear and crispy, which she described as the emotions “stabilizing.” A large yellow sun with orange rays encompasses this section, overlaying the wavy line in the middle. Lucille described this section as follows: “Here is the time during the art therapy, and I represented it as a sun, because it felt

**Figure 4**

*Participant Lucille’s Art Response*



warm and rich, and also because it's round [like] a round table and being together and being as a group and processing emotions.”

Post-test experience: In the final portion of the visual timeline, the horizontal line becomes even less wavy and becomes green. A smaller sun is depicted above this line in orange, and the horizontal line becomes the horizon line of a landscape. Below the line is a semicircle filled in with blue, representing a body of water, with green for grass below it. The horizontal line, she stated, becomes Describing the whole section, she said, “This is the result of that processing of emotion, and my landscape is becoming much more calm, my water has calmed down, and there is my sun into my life and I'm seeing my landscape all around.”

### **Analysis of Data**

In this section, the presented data is explored more deeply to uncover richer meaning. The data from the pre- and post-tests is explored first, followed by the qualitative data from the focus groups, including the artwork.

### ***Contextualization of Analysis: Research During a Global Pandemic***

This research project was conducted during unprecedented times due to the COVID-19 pandemic. The pandemic had several notable impacts on this research. For example, the art therapy groups were held remotely via Zoom, as were the focus groups. Due to public health directives to stay home and social distance from others, isolation, stress, and depression have increased throughout the population at large. Additionally, the increased time on Zoom has led to feelings of “Zoom fatigue,” technological challenges, and more. Further, as this research focuses on participants with cancer or histories of cancer, it’s important to consider the impact of living with a medical illness when the world is focused on another medical crisis that may eclipse the crisis of cancer. Overall, the combination of these factors may have resulted in the lower-than-anticipated number of participants who completed the pre- and post-tests and also attended the focus groups. These factors are further explored in the analysis and results sections of this paper.

### ***Quantitative Data Analysis***

Because the number of participants was small and the focus of the research is on the participants’ lived experience of the assessments and their relevance, the researchers completed only a broad analysis of the quantitative data from the pre- and post-assessments. To do this, the researchers compared the pre- and post- responses from each participant, noting any positive or negative shifts in the data. A review of the participant responses, as shown in the table above,

showed mixed results for each assessment, with some participants experiencing an increase or reduction in symptoms and some experiencing a positive shift, negative shift, or no shift in overall responses. In reviewing the general findings, researchers noted that only one assessment, the FACIT – Sp-Ex, reflected positive shifts and experiences for all participants.

Additionally, researchers noted that one participant made comments in the margins, and included additional notes on various assessments, referencing the current COVID-19 pandemic and its link to QoL and social activities. Researchers found this important to note as it provided insight as to whether the assessments, and any of the responses, were accurately capturing participants' experiences and how the data may be impacted by the ongoing pandemic.

The value of analyzing the data, although smaller in numbers due to the reduced number of participants, was to examine whether the assessments could capture something similar to what the participants shared about their experience during the focus group and in their art response which are analyzed in the following section.

### *Qualitative Data Analysis*

For this analysis, researchers looked for emergent themes within individual experiences and those of the group as described in the focus groups and art responses. The researchers first began by identifying bullet points that described key moments or ideas expressed in the focus groups. Next, researchers clustered these bullet points into common themes that emerged in the analysis. Researchers then reviewed the art responses and the participants' explanations of their imagery, which revealed common themes in imagery and metaphor use that were added to the identified themes. Ultimately, six key themes were identified based on the qualitative data.

**Impact of COVID.** There was a low participation rate in the research, despite higher numbers the researchers anticipated based on the number of actual participants who signed up for

the art therapy group modules. This further demonstrated the COVID-related factors such as more “online data” or the feeling of overwhelm with all the questionnaires leading to lackadaisical interest. The participants from the focus groups expressed the inability to clarify which test answers were the result of COVID-related factors such as the feelings of loneliness or depression due to isolation from the pandemic. They also were not sure if these feelings were exacerbated because of the pandemic. Everything was conducted via Zoom and virtually, thus attributing to Zoom fatigue, low energy, and less enthusiasm for participation in this research.

**Personal Usefulness of Tests.** Participants expressed that the assessments were useful in terms of providing self-reflection and as a self-check-in when comparing their pre and posttest answers. Linda stated: “Those assessments weren’t just for you [the researchers]—they were for me too. While I was filling out the assessments, I was able to note how am I feeling about the future, about pain... The assessment tools were actually kind of useful check-ins for myself.” Another participant, Rose, stated that these assessments were “subjective” given the time the test was taken, and provided “more insight on [her] experience.” Participants all agreed that the answers to the tests were dependent on when the test was actually taken. For example, Lucille mentioned that maybe she was feeling pain that day, but noticed it less after group art therapy, which may have “distracted” her from feeling pain due to the enriching experience.

**Tests as Containment of Experience.** The data appear to show that the pre-and post-test assessments, along with participation in the focus groups, provided some level of containment of the art therapy group experience. This was illustrated by the three-part art directive given in the focus groups. Each participant conveyed the encapsulation of the beginning (pretest), middle (art group), and end (posttest). There was much similarity when describing the image drawn for the pretest and how participants came in with this unknown feeling of uncertainty as a precursor to

starting the group. For the posttest drawing, the imagery and themes resulted from processing emotions through group art therapy, with words such as “whole” and “stable” to describe the state of completion. The posttest was viewed as a way to conclude the entire experience and help participants continue to make meaning out of their time in the group; in this way, the assessments appeared to be useful bookends for the art therapy experience, with the focus group providing a safe holding environment in which clients could further process their participation verbally and via artmaking.

**Value of Art Responses in Assessing Experience.** The art directive given in the focus groups allowed participants to more fully express the beneficial effect they felt in the art therapy groups compared with the tests. Participants were eager to share about the power of the art therapy group through the art response, as they felt the standardized assessments could not fully capture or reflect this power. For example, as Lucille described, her experience was that the art therapy group led to a profound shift in her wellbeing, stating that after the group, she felt “much more at peace and attuned to my landscape.” Similarly, Maureen’s drawing depicted her as a figure who had “finally” climbed to the top of a ladder to begin fishing, “reaping the effort that you put in;” this appears to reflect her feelings that the art therapy experience, though at times hard emotional work, ultimately allowed her to gain new perspective at the top of the metaphorical ladder and see true benefits. The art response appeared to provide a way to encompass the participants’ lived emotional experience of the art therapy groups as a whole, showing common themes in the middle sections of the art response. For each participant, the art therapy group-related imagery focused on life, vibrancy, growth, stability, and hope, with drawings of trees, the sun, bright colors, and living things.

**Participants’ Passion for Art Therapy.** It was very difficult to get the participants to



stay focused on the topic of the assessments as it pertained to the research. Participants were reminded throughout the focus group what the purpose of the research was; however, they were more interested in sharing about the power of the groups and their art therapy experiences.

Lucille was extremely passionate about the art therapy group and stated, “in order to understand, you have to listen,” in response to how these tests were not able to capture the experience and what the main focus of researchers should be in this field. Participants shared how one thing they all experienced was cancer, but there was no commonality of the profound experience through art therapy and how the therapy process provided “strength” that could not be measured quantitatively.

**Inadequacy of Tests and Suggestions for Improvements.** The participants felt strongly about their experience in the art therapy groups and stated that the tests did not adequately capture the intensity of those feelings or ask questions that were relevant to their experience as cancer patients and survivors. For example, as participant Maureen noted, many of ERAS-S questions seemed fairly useless in terms of assessing efficacy of a psychotherapy group, such as questions about shortness of breath. She stated, “I’m not running around in the group—I’m just sitting down. These questions are kind of irrelevant.” The participants agreed that the experience of the art therapy group could not be assessed or “tied” to the tests; Maureen stated she was “trying to connect [to the questions], but not sure how it can be linked [to the experience].” The majority of participants agreed that the FACIT-Sp-Ex (Version 4) had the most potential of all six tests in terms of relating to the art therapy experience and the changes they experienced throughout; for example, Lucille said, “These questions are good—[asking about] creativity, peace of mind, purpose—those are quantifiers that are could be relating more to what the [group] is about.” However, the overall response was that even the FACIT-Sp-Ex was inadequate

overall. This indicates the insufficiency of these standardized tests to gather data since it cannot capture the participants' testimonials. Participants suggested changing the language used in these standardized tests and questioned if there were ways to create new tests that would be more applicable to their experience.

### ***Integration of Quantitative and Qualitative Data Analysis***

Researchers compared the broad analysis of quantitative data from the pre- and post-test assessments with the qualitative data from the focus groups, including metaphors and meanings that emerged in the art responses. Viewing these sets of data side by side, they observed connections and overlapping themes in the data. Through this process, the researchers gained a better understanding of the emerging themes. The quantitative and qualitative analysis served as a way to bridge the gap between the standardized assessment data and the actual lived experience of the art therapy group participants. Through the integration of quantitative and qualitative data analysis, researchers were able to discover the following findings as described below.

## **Findings**

This section summarizes the key findings from the analysis of the data and further integrates the qualitative and quantitative data results, adding in connections to the literature that grounded this project in a scholarly discussion.

### ***Disconnect Between Experience of Cancer Patients/Survivors and Assessment Questions***

Based on the data, it appears there is a notable disconnect between the true lived experience of the participants and the areas assessed in the quantitative assessments. Although several of the tests administered as part of this research were designed specifically for use with the population of cancer patients, the cancer patients and survivors in this research expressed feelings that they were not as relevant as they could have been to their experience. Overall, participants appeared to agree that the quantitative assessments did not ask the “right” questions if the goal was to assess the efficacy of this type of intervention. There was a mismatch in the types of benefits described by the participants—feelings of increased peace, wholeness, universality of experience, and community building, for example—and the symptoms and changes assessed for in many of the tests. This finding reaffirms the importance of selecting the right assessment tools in evaluating the impact of art therapy programs and how crucial it is that assessments are relevant to participants’ experience, as the literature review discusses. That said, because the standardized tests selected for this research were some of the most commonly used with cancer patients and survivors and for evaluating mental health symptoms, it stands to reason that researchers may need to create new assessment tools that are better suited to not only this population but also for specific use in an art therapy setting.

As explored in the literature review, factors including evaluation theory, the design of the research, and the approach of the researchers are all crucial aspects of effective program

evaluation (Torres et al., 2018); and per this research project's findings, commonly used standardized tests alone may not be adequate to achieve this goal.

### *The Potential Value of Art in the Assessment Process*

Based on the data collected in this research project, it appears that the art itself may be a more in-depth way to accurately capture the effect of art therapy groups for cancer patients and survivors. For example, the passionate reports of participants in this research project reflect their insistence that they gained great value from the art therapy groups, even though this may not be reflected on their pre- and post-test results measured in quantitative terms. In fact, the participants largely rejected the idea that the majority of the six tests could come close to accurately reflecting the impact of these groups on their symptoms and overall well-being.

Additionally, the art responses created in the focus groups also demonstrate the potential power of art-based assessments as a way to collect more accurate and holistic data on the lived experience of participants in such art therapy groups. For example, each participant was able to illustrate the change that occurred in their visual timeline throughout the course of the art therapy group experience, likely in part due to the unique power of art-making to make the unconscious conscious and allow the creator to explore their internal world via metaphor in a safe way. As Sprenkle et al. (2005) argues, there is a rising need for mental health professionals to prove efficacy—and it appears that art-based assessments as part of a systemic evaluation of efficacy of art therapy interventions could be a more accurate way to reach that goal. This finding also affirms Betts (2006) statements that the most effective art therapy assessments should include a combination of both standardized assessments and subjective assessments, such as those that incorporate client artwork. Again, this may be particularly appropriate with the population of cancer patients and survivors, whose symptoms and experiences are complex and often difficult

to quantify (Svensk et al., 2009).

The findings of this project affirm that it was beneficial to offer participants additional, more open-ended ways to express their experiences beyond just quantitative standardized tests, as was demonstrated through the use of focus groups and art responses. Overall, the participants' art response imagery and descriptions of that imagery during the focus groups appeared to reflect overwhelmingly positive effects of being in the art therapy groups. These findings are in stark contrast to the results of the quantitative assessments, which largely did not show significant positive shifts in symptoms or well-being. It is notable that the results of the qualitative data collected in the focus groups conflicts with the quantitative data; for if the participants themselves are verbally expressing these benefits, it is worth considering whether art-based assessments may be more accurate when assessing efficacy and change when evaluating art therapy interventions such as these groups for cancer patients and survivors. Not only did the participants in this research project report the art therapy interventions they engaged with were healing on a clinical level, but the art made about the experience of the tests and the groups in the focus group appeared to be a highly valuable tool in assessing efficacy in this research. While standardized art assessments do exist, they are largely discounted in the field of research and limited in scope; future art therapy research may focus on developing new and more useful standardized art-based assessments to capture participants' lived experience.

## Conclusions

This research project aimed to investigate the use of commonly used standardized quality of life assessments in assessing the experience of cancer patients and survivors in art therapy groups. The synthesis of quantitative data from six standardized tests and the qualitative data from the focus groups and art responses allowed the researchers to highlight common themes about cancer patients and survivors' lived experiences. The approach allowed for not only the collection of baseline quantitative data but also invited participants to share their detailed personal responses about their experience of taking these assessments and whether they were relevant in capturing their lived experience of the art therapy group.

The research process aimed to gather evidence to help the field envision improved ways to study the efficacy of art therapy. Challenges of the project included a low number of participants and limitations of virtual focus groups, likely due to the ongoing COVID-19 pandemic.

One of the key findings that emerged from the research was the inadequacy of commonly used standardized tests in assessing the efficacy of art therapy. While the participants vehemently asserted positive experiences of connection, growth, and healing as a result of the art therapy groups, which was reflected in the focus group and art response data, these positive shifts were starkly lacking in the quantitative data collected from the assessments. While existing assessments may be beneficial when assessing for specific symptoms or in other research settings, the results demonstrate these assessments' inability to accurately reflect the full benefits of participating in an art therapy group, likely due to the tests' lack of specificity and the limitations they place on participants' responses.

This research may serve as rationale for art therapists and researchers in the field to

continue the work of developing and standardizing effective art-based assessments for use in research as well as in clinical settings. The findings demonstrate the potential value in increasing the use of art in standardized assessments, particularly when the goal is to accurately capture the efficacy of art-based interventions.

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## Appendix A: Informed Consent Form

### Loyola Marymount University Informed Consent Form

- TITLE:** Evaluating Art Therapy Assessments with Cancer Survivors
- INVESTIGATOR:** Debra Linesch, Ph.D., Professor  
Graduate Department of Marital and Family Therapy,  
College of Communication and Fine Arts  
310-338-7674 [dlinesch@lmu.edu](mailto:dlinesch@lmu.edu)
- PURPOSE:** You are being asked to participate in a research project that seeks to investigate which kinds of standardized measures best evaluate the experiences of cancer patients who participate in group art therapy. You will be asked to complete questionnaires that compare your feelings before and after group art therapy. You will also be asked to discuss whether these tools accurately assessed the impact of the group experience. **Occurring at the end of your eight-week group, these program evaluation procedures will take about one hour.**
- RISKS:** Risks associated with this study include possible distress over the identification of feelings associated with having or surviving cancer. The group art therapists and hospital staff will be available to discuss any anxieties or concerns that emerge.
- BENEFITS:** Benefits associated with this study are the potential clarity you will experience about your own understandings of the mental health aspects of the lived experience of cancer. Additionally, there is possible satisfaction from participating in an effort to understand and augment funding for a new treatment approach.
- INCENTIVES:** Participation in the project will require no monetary cost to you.
- CONFIDENTIALITY:** This research will not collect participants' names or any identifiers. Your name will never be used in any public dissemination of these data (publications, presentations, etc.). All research materials and consent forms will be stored in password protected digital Boxes at LMU. When the research study ends, any identifying information will be removed from the data, or it will be destroyed. All of the information you provide will be kept confidential.
- RIGHT TO WITHDRAW:** Your participation in this study is *voluntary*. You may withdraw your consent to participate at any time without penalty. Your withdrawal will not influence any other services to which you may be otherwise entitled, your class standing or relationship with Loyola Marymount University or with Cedars Sinai Medical Center.

**SUMMARY OF RESULTS:** A summary of the results of this research will be supplied to you, at no cost, upon request to [debra.linesch@lmu.edu](mailto:debra.linesch@lmu.edu)/ 310-338-7674

**VOLUNTARY CONSENT:** I have read the above statements and understand what is being asked of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason, without penalty. If the study design or use of the information is changed I will be informed and my consent reobtained. On these terms, I certify that I am willing to participate in this research project.

I understand that if I have any further questions, comments or concerns about the study or the informed consent process, I may contact Dr. David Moffet, Chair, Institutional Review Board, Loyola Marymount University, 1 LMU Drive, Los Angeles, CA 90045-2659 or by email at [David.Moffet@lmu.edu](mailto:David.Moffet@lmu.edu).

---

Participant's Signature

---

Date

**Appendix B: Edmonton Symptom Assessment System**

**Edmonton Symptom Assessment System:(revised version) (ESAS-R)**

**Please circle the number that best describes how you feel NOW:**

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
<hr/>												
No Tiredness <i>(Tiredness = lack of energy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
<hr/>												
No Drowsiness <i>(Drowsiness = feeling sleepy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
<hr/>												
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
<hr/>												
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
<hr/>												
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
<hr/>												
No Depression <i>(Depression = feeling sad)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
<hr/>												
No Anxiety <i>(Anxiety = feeling nervous)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
<hr/>												
Best Wellbeing <i>(Wellbeing = how you feel overall)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
<hr/>												
No _____ Other Problem <i>(for example constipation)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____

Patient's Name \_\_\_\_\_

Date \_\_\_\_\_ Time \_\_\_\_\_

Completed by (check one):

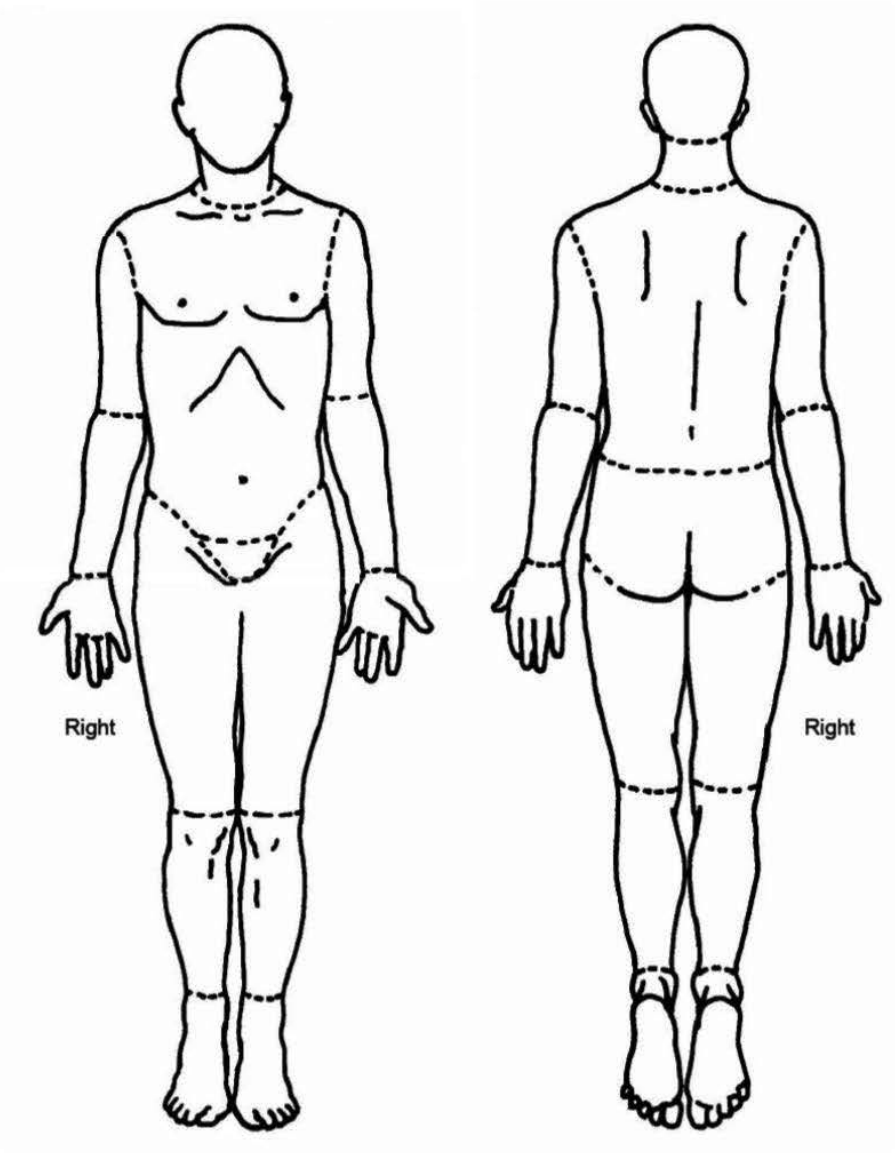
- Patient
- Family caregiver
- Health care professional caregiver
- Caregiver-assisted

**BODY DIAGRAM ON REVERSE SIDE**

**ESAS-r**

Revised: November 2010

Please mark on these pictures where it is that you hurt:



## Appendix C: Beck Hopelessness Scale

### A-6

#### Beck Hopelessness Scale

**Instructions:**

This questionnaire consists of 20 statements. Please read the statements carefully one by one. If the statement describes your attitude for the past week including today, darken the circle with a 'T' indicating TRUE in the column next to the statement. If the statement does not describe your attitude, darken the circle with an 'F' indicating FALSE in the column next to this statement. Please be sure to read each statement carefully.

I look forward to the future with hope and enthusiasm	(T)	(F)
I might as well give up because there is nothing I can do about making things better for myself	(T)	(F)
When things are going badly, I am helped by knowing that they cannot stay that way forever	(T)	(F)
I can't imagine what my life would be in 10 years	(T)	(F)
I have enough time to accomplish the things I want to do	(T)	(F)
In the future, I expect to succeed in what concerns me most	(T)	(F)
My future seems dark to me	(T)	(F)
I happen to be particularly lucky, and I expect to get more of the good things in life than the average person	(T)	(F)
I just can't get the breaks, and there's no reason I will in the future	(T)	(F)
My past experiences have prepared me well for the future	(T)	(F)
All I can see ahead of me is unpleasantness, rather than pleasantness	(T)	(F)
I don't expect to get what I really want	(T)	(F)
When I look ahead in the future, I expect to be happier than I am now	(T)	(F)
Things just don't work out the way I want them to	(T)	(F)
I have great faith in the future	(T)	(F)
I never get what I want, so its foolish to want anything	(T)	(F)
Its very unlikely that I will get any real satisfaction in the future	(T)	(F)
The future seems vague and uncertain to me	(T)	(F)
I can look forward to more good times than bad times	(T)	(F)
There's no use in really trying to get anything I want, because I probably won't get it	(T)	(F)



**Appendix D: UCLA Loneliness Scale****Scale:**

INSTRUCTIONS: Indicate how often each of the statements below is descriptive of you.

C indicates "I often feel this way"

S indicates "I sometimes feel this way"

R indicates "I rarely feel this way"

N indicates "I never feel this way"

- |   |   |   |   |   |
|---|---|---|---|---|
| 1. I am unhappy doing so many things alone                        | O | S | R | N |
| 2. I have nobody to talk to                                       | O | S | R | N |
| 3. I cannot tolerate being so alone                               | O | S | R | N |
| 4. I lack companionship   | O | S | R | N |
| 5. I feel as if nobody really understands me                      | O | S | R | N |
| 6. I find myself waiting for people to call or write              | O | S | R | N |
| 7. There is no one I can turn to                                  | O | S | R | N |
| 8. I am no longer close to anyone                                 | O | S | R | N |
| 9. My interests and ideas are not shared by those around me       | O | S | R | N |
| 10. I feel left out   | O | S | R | N |
| 11. I feel completely alone                                       | O | S | R | N |
| 12. I am unable to reach out and communicate with those around me | O | S | R | N |
| 13. My social relationships are superficial                       | O | S | R | N |
| 14. I feel starved for company                                    | O | S | R | N |
| 15. No one really knows me well                                   | O | S | R | N |
| 16. I feel isolated from others                                   | O | S | R | N |
| 17. I am unhappy being so withdrawn                               | O | S | R | N |
| 18. It is difficult for me to make friends                        | O | S | R | N |
| 19. I feel shut out and excluded by others                        | O | S | R | N |
| 20. People are around me but not with me                          | O | S | R | N |

**Scoring:**

Make all O's =3, all S's =2, all R's =1, and all N's =0. Keep scoring continuous.

**UCLA Version 3 Loneliness Scale**

*Instructions:* The following statements describe how people sometimes feel. For each statement, please indicate how often you feel the way described by placing a check in the space provided. Here is an example: How often do you feel happy? If you never felt happy, you would check “never”; if you always feel happy, you would check “always.”

	NEVER 1	RARELY 2	SOMETIMES 3	ALWAYS 4
*1. How often do you feel that you are “in tune” with the people around you?				
2. How often do you feel that you lack companionship?				
3. How often do you feel that there is no one you can turn to?				
4. How often do you feel alone?				
*5. How often do you feel part of a group of friends?				
*6. How often do you feel that you have a lot in common with the people around you?				
7. How often do you feel that you are no longer close to anyone?				
8. How often do you feel that your interests and ideas are not shared by those around you?				
*9. How often do you feel outgoing and friendly?				
*10. How often do you feel close to people?				
11. How often do you feel left out?				
12. How often do you feel that your relationships with others are not meaningful?				
13. How often do you feel that no one really knows you well?				
14. How often do you feel isolated from others?				
*15. How often do you feel you can find companionship when you want it?				
*16. How often do you feel that there are people who really understand you?				
17. How often do you feel shy?				
18. How often do you feel that people are around you but not with you?				
*19. How often do you feel that there are people you can talk to?				
*20. How often do you feel that there are people you can turn to?				

*Scoring:* Items that are asterisked should be reversed (i.e., 1 4, 2 3, 3 2, 4 1), and the scores for each item then summed together. Higher scores indicate greater degrees of loneliness. From Russell DW: UCLA Loneliness Scale (Version 3): reliability, validity, and factor structure, *J Pers Assess* 66:20-40, 1996.

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### Appendix E: PROMIS Global Health

PROMIS® Scale v1.2 – Global Health

#### Global Health

Please respond to each question or statement by marking one box per row.

		Excellent	Very good	Good	Fair	Poor
Global01	In general, would you say your health is: .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global02	In general, would you say your quality of life is: .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global03	In general, how would you rate your physical health? .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global04	In general, how would you rate your mental health, including your mood and your ability to think? .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global05	In general, how would you rate your satisfaction with your social activities and relationships? .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global09r	In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.).....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
		<b>Completely</b>	<b>Mostly</b>	<b>Moderately</b>	<b>A little</b>	<b>Not at all</b>
Global06	To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair? .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

PROMIS® Scale v1.2 – Global Health

**In the past 7 days...**

		Never	Rarely	Sometimes	Often	Always										
Global10r	How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable? .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1										
		<table border="1"> <thead> <tr> <th>None</th> <th>Mild</th> <th>Moderate</th> <th>Severe</th> <th>Very severe</th> </tr> </thead> <tbody> <tr> <td><input type="checkbox"/> 5</td> <td><input type="checkbox"/> 4</td> <td><input type="checkbox"/> 3</td> <td><input type="checkbox"/> 2</td> <td><input type="checkbox"/> 1</td> </tr> </tbody> </table>					None	Mild	Moderate	Severe	Very severe	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
None	Mild	Moderate	Severe	Very severe												
<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1												
Global08r	How would you rate your fatigue on average? .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1										
Global07r	How would you rate your pain on average? .....	<input type="checkbox"/> 0 No pain	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10 Worst pain imaginable				

**Appendix F: PROMIS – 29 Profile V.2.0**

**PROMIS–29 Profile v1.0**

Please respond to each question or statement by marking one box per row.

<b><u>Physical Function</u></b>		<b>Without any difficulty</b>	<b>With a little difficulty</b>	<b>With some difficulty</b>	<b>With much difficulty</b>	<b>Unable to do</b>
PFA11 1	Are you able to do chores such as vacuuming or yard work? .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
PFA21 2	Are you able to go up and down stairs at a normal pace? .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
PFA23 3	Are you able to go for a walk of at least 15 minutes? .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
PFA53 4	Are you able to run errands and shop? .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
<b><u>Anxiety</u></b> <b>In the past 7 days...</b>		<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
EDANX01 5	I felt fearful.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX40 6	I found it hard to focus on anything other than my anxiety .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX41 7	My worries overwhelmed me .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX53 8	I felt uneasy .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b><u>Depression</u></b> <b>In the past 7 days...</b>		<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
EDDEP04 9	I felt worthless .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP06 10	I felt helpless .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP29 11	I felt depressed .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP41 12	I felt hopeless .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b><u>Fatigue</u></b> <b>During the past 7 days...</b>		<b>Not at all</b>	<b>A little bit</b>	<b>Somewhat</b>	<b>Quite a bit</b>	<b>Very much</b>
HI7 13	I feel fatigued .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
A3 14	I have trouble <u>starting</u> things because I am tired.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b>In the past 7 days...</b>						
FATEXP41 15	How run-down did you feel on average? ...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**PROMIS-29 Profile v1.0**

**Fatigue**

**In the past 7 days...**

		Not at all	A little bit	Somewhat	Quite a bit	Very much
FATEXP40 16	How fatigued were you on average?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**Sleep Disturbance**

**In the past 7 days...**

		Very poor	Poor	Fair	Good	Very good
Sleep109 17	My sleep quality was.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

**In the past 7 days...**

		Not at all	A little bit	Somewhat	Quite a bit	Very much
Sleep116 18	My sleep was refreshing.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

Sleep20 19	I had a problem with my sleep .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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Sleep44 20	I had difficulty falling asleep .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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**Satisfaction with Social Role**

**In the past 7 days...**

		Not at all	A little bit	Somewhat	Quite a bit	Very much
SRPSAT07 21	I am satisfied with how much work I can do (include work at home) .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

SRPSAT24 22	I am satisfied with my ability to work (include work at home).....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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SRPSAT47 23	I am satisfied with my ability to do regular personal and household responsibilities .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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SRPSAT49 24	I am satisfied with my ability to perform my daily routines.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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**Pain Interference**

**In the past 7 days...**

		Not at all	A little bit	Somewhat	Quite a bit	Very much
PAINI9 25	How much did pain interfere with your day to day activities?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

PAINI22 26	How much did pain interfere with work around the home? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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PAINI31 27	How much did pain interfere with your ability to participate in social activities?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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PAINI34 28	How much did pain interfere with your household chores? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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**Pain Intensity**

**In the past 7 days...**

Global07 29	How would you rate your pain on average?.....	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
		No pain										Worst imaginable pain

**Appendix G: FACIT – Sp-Ex (Version 4)**

**FACIT-Sp-Ex (Version 4)**

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

		Not at all	A little bit	Some- what	Quite a bit	Very much
Sp1	I feel peaceful .....	0	1	2	3	4
Sp2	I have a reason for living.....	0	1	2	3	4
Sp3	My life has been productive .....	0	1	2	3	4
Sp4	I have trouble feeling peace of mind.....	0	1	2	3	4
Sp5	I feel a sense of purpose in my life .....	0	1	2	3	4
Sp6	I am able to reach down deep into myself for comfort .....	0	1	2	3	4
Sp7	I feel a sense of harmony within myself .....	0	1	2	3	4
Sp8	My life lacks meaning and purpose.....	0	1	2	3	4
Sp9	I find comfort in my faith or spiritual beliefs.....	0	1	2	3	4
Sp10	I find strength in my faith or spiritual beliefs .....	0	1	2	3	4
Sp11	My illness has strengthened my faith or spiritual beliefs....	0	1	2	3	4
Sp12	I know that whatever happens with my illness, things will be okay .....	0	1	2	3	4
Sp13	I feel connected to a higher power (or God) .....	0	1	2	3	4
Sp14	I feel connected to other people .....	0	1	2	3	4
Sp15	I feel loved.....	0	1	2	3	4
Sp16	I feel love for others .....	0	1	2	3	4
Sp17	I am able to forgive others for any harm they have ever caused me .....	0	1	2	3	4
Sp18	I feel forgiven for any harm I may have ever caused.....	0	1	2	3	4
Sp19	Throughout the course of my day, I feel a sense of thankfulness for my life .....	0	1	2	3	4
Sp20	Throughout the course of my day, I feel a sense of thankfulness for what others bring to my life .....	0	1	2	3	4
Sp21	I feel hopeful .....	0	1	2	3	4
Sp22	I feel a sense of appreciation for the beauty of nature .....	0	1	2	3	4
Sp23	I feel compassion for others in the difficulties they are facing.....	0	1	2	3	4

## Appendix H: Letter to Participants

Dear Art Therapy Group Participant,

We are delighted that you have participated in the Cedars Sinai art therapy program and are inviting you to be part of the assessment of this project.

We are trying to assess if and how the group is useful by simply exploring different measurement tools. We are interested in learning if these questionnaires are meaningful.

Please fill out the six questionnaires that are in this packet and mail them back to us in the stamped, addressed envelope we have included. At the end of the eight-week group we will mail you another packet with the same questionnaires.

Our research team will invite you to discuss the value of the questionnaires, to help us learn which of the measurement tools make sense to utilize in future research.

Your contributions to our discussion will help us develop more art therapy programs at Cedars Sinai.

Wishing you good health and peace in these uncertain times,

Debra Linesch Ph.D.  
Professor  
Graduate Department of Marital and Family Therapy  
With Specialization in Art Therapy  
College of Communication and Fine Arts  
Loyola Marymount University

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Steps to follow:

1. Read and sign included Consent Form.
2. Complete all six questionnaires.
3. Place signed consent form and completed questionnaires in stamped envelope.
4. Mail envelope back to Cedars Sinai