PEDIATRIC CARE & ART THERAPY (P-CAT)

A CONCEPTUAL FRAMEWORK FOR RESEARCH ON ART THERAPY WITH PATIENTS, FAMILIES, AND HEALTH CARE PROVIDERS IN PEDIATRIC HEMATOLOGY/ ONCOLOGY SETTINGS

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TABLE OF CONTENTS

Executive summary 3

Background literature on art therapy in pediatric hematology/oncology settings 5
- Introduction
- Literature relevant to art therapy and pediatric oncology 6

Collaborators 10

Description of Tracy's Kids Programming 12

Conceptual framework for research 14
- Aims of the research
- Overview
- Research questions 15

Logic Model 17

Research Approaches 18
- Short term approaches: 1-2 years
- Intermediate term approaches: 2-5 years 19
- Long term approaches: 5-10 years
- Data sources 20
- Data analysis 21
- Dissemination plans

References 22

List of Scales and measures 25

EXECUTIVE **SUMMARY**

BACKGROUND:

Childhood cancer affects 1 in 280 children every year. The illness affects biological and physical functioning and the treatment procedures can create significant psychosocial and spiritual/existential distress for children and families. Preliminary research indicates that art therapy can positively impact symptoms of psychosocial distress associated with pediatric cancer. Despite emergent evidence on the positive impact of art therapy, there are few systematic studies that track health outcomes for children, families and healthcare systems. There is also limited scholarship on apt clinical approaches for this population.

COLLABORATING ORGANIZATIONS:

A well-established clinical model developed over the past two decades is provided by Tracy's Kids, a non-profit organization that offers open studio clinical art therapy in eight pediatric oncology/ hematology settings around the nation. The proposed project will involve research on art therapy outcomes in sites served by the Tracy's Kids program. Funding for the research is provided at present by the National Endowment for the Arts Research Labs program with matching funds from Drexel University.*

CONCEPTUAL FRAMEWORK:

The purpose of the research collaboration is to systematically study the processes and outcomes (short and long term) of open studio art therapy on patients, families, and the associated healthcare systems. The conceptual framework for the research on art therapy in pediatric hematology/oncology settings is founded on the assumption that the clinical

services impact the biological, psychological, social and spiritual/ existential aspects of life of child, family and care providers.

RESEARCH QUESTIONS AND APPROACHES:

The guiding research question is: How and to what extent does art therapy impact the health and psychosocial outcomes of pediatric hematology/oncology patients, families and healthcare providers? The research studies in this framework propose to use a mixed methods design approach and will examine: the mechanisms of change and outcomes of art therapy for patients and families; the impact of art therapy on healthcare providers at the setting; viewer experiences of artwork by patients, families and care providers; as well as health systems outcomes including reduced health care costs and improved medical outcomes. Data sources will include standardized measures of psychosocial functioning, measures of medication usage and healthcare effectiveness, qualitative interviews and focus groups; and art-based measures of content and impact of art-making. Data analysis will include traditional statistical approaches as well as innovative mixed methods models. Findings will be disseminated in conferences and scholarly journals as well as in community-based settings and to clinical providers using journals, policy briefs and exhibition-based formats.

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BACKGROUND LITERATURE ON ART THERAPY IN PEDIATRIC HEMATOLOGY/ONCOLOGY SETTINGS

INTRODUCTION

Cancer is the leading cause of death by disease among children and adolescents ages 0 to 19 years, accounting for over 50% of childhood deaths (www.Curesearch.org). Though cancer in children continues to be rare compared to rates for adults, recent CDC reports (2018) indicate that each year approximately 14,500 children ages 19 and younger are diagnosed with some form of pediatric cancer. Children are most commonly diagnosed with leukemias, brain cancer and other cancers of the central nervous system as well as lymphoma. Though survivorship has improved to approximately 83% overall, there are long-lasting effects in addition to the short-term physical and psychosocial effects, including the anxiety of potential relapse and the real fear of experiencing a secondary cancer (www.cac2.org). Psychosocial supports for children, their siblings and their parents/caretakers are critical for the overall wellbeing and psychological health as well as for recovery. Treatment is aggressive and takes a physical toll on children and they are often out of school for weeks and months. Little normalcy occurs amidst this traumatic change in their lives.

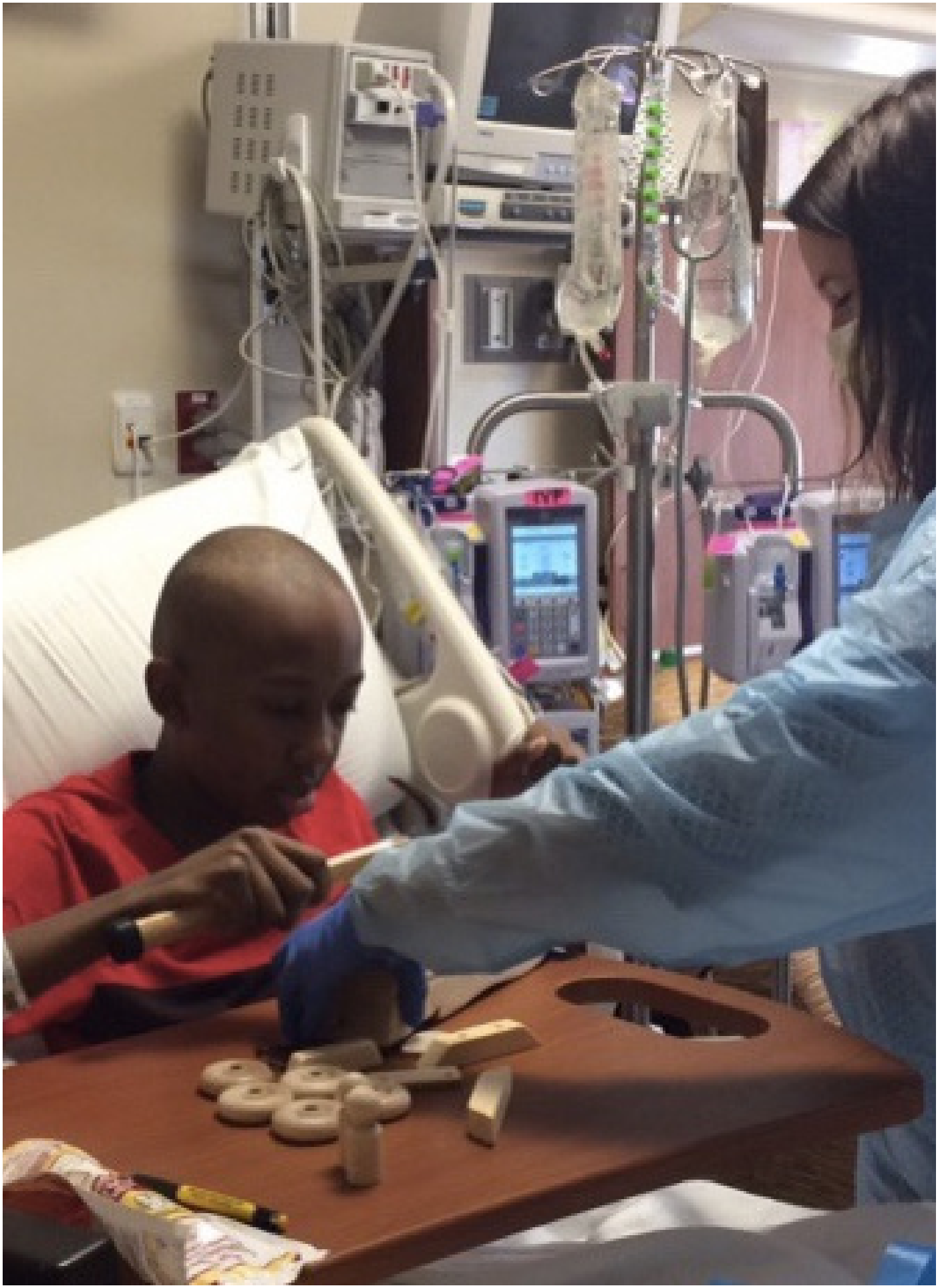
In 2015, standards of psychosocial practice and care for children with pediatric cancer and their families were released by a working group, the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) (Wiener, Kazak, Noll, Patenaude, & Kupst, 2015). In a multi-year, multi-step process to come to consensus on evidence and need, many experts and stakeholders worked together to outline 15 standards of care that they hope will be implemented in all pediatric cancer treatment centers. Out of this work, 5 critical areas of concern emerged: assessment of child and family well-being and emotional functioning, neurocognitive status, psychotherapeutic interventions, school functioning,

and communication, documentation, and training of psychosocial service providers. The aim now is for ongoing dialogue among professionals in pediatric oncology care to define recommendations, encourage implementation and evaluate ongoing work in this field (Wiener et al., 2015).

LITERATURE RELEVANT TO ART THERAPY AND PEDIATRIC ONCOLOGY

Art therapists have a long tradition of serving in medical settings (Aguilar, 2017). They work in adult and pediatric cancer treatment centers throughout the country, though there is no singular resource for finding practitioners, nor is there a standard of practice for work in pediatric oncology art therapy. Researchers and clinicians are beginning to study and document the clinical work, programs and efficacy of art therapy for pediatric oncology patients. Aguilar (2017) conducted a review of studies to look at the effectiveness of art therapy on children living with cancer. Their search revealed 7 studies that met criteria for inclusion for the review of qualitative and quantitative studies. Findings from this review suggest that art therapy, in the form of drawing interventions, improved communication with family members and providers, served as an expression of feelings, helped children develop effective coping skills and reduced the negative effects from treatment (Aguilar, 2017).

Some literature on pediatric care refers to art therapy as falling under a broad umbrella of Complementary and Alternative Medicine (CAM) where art therapy processes are either incorporated into other forms of treatment such as Mindfulness Based Stress Reduction (Ott, 2006; Peterson, 2015; Senser & Kelly, 2007; Tomlinson, Hesser, Etheir, & Sung, 2011) or is considered to be an complementary form of treatment, like yoga or hypnosis, designed to "restructure the recovery of health and quality of life in cancer patients promoting symptom reduction after invasive treatments" (Kaimal et al 2019; Kanitz, Caus, & Seifer, 2012). Jacobs (2014) looked at the vast use of Integrated Therapies (IT) in cancer treatment for the alleviation of specific symptoms in pediatric cancer care and included art and music therapy as being among the many ways that care teams help young patients manage the discomfort and improve their quality of life while undergoing difficult medical treatment.



Hyslop et al. (2018) conducted a study to look at drawings as an aid to symptom screening in young children (ages 4-7) for the treatment team to have more tools to have children express the symptoms that are most important to them in their care. They found that using drawings as a tool for such communication not only supported the team in understanding the emotional burden of the child's symptoms but also about the location of pain and the child's perception of their overall health, enhancing the care that nursing staff and others could provide. Similarly, Rollins (2005) found that drawing was a useful aid in getting direct information from pediatric patients about their illness and symptoms while undergoing cancer treatment. In a study of existential issues in pediatric cancer, Woodgate, West and Taylor (2014) explored the use of computerized drawings to gain insight into issues around anxiety and distress when facing cancer. Their interpretive, qualitative study found that children's drawings and interview data revealed existential themes of worry, longing, and, growth.

Quality of Life is a construct that is often considered in cancer care generally and in pediatric oncology specifically as a term that seeks to address ways in which comfort and day-to-day experiences can be observed and supported under stressful circumstances. Though this construct is being studied fairly frequently in adult cancer treatment with regard to the use of creative arts therapies as a supportive therapy (Wiswell et al., 2019), fewer studies have looked at this in the pediatric oncology literature. Madden, Mowry, Gao, Cullen and Foreman (2010) conducted a pilot study comparing creative arts therapies to the attention of a volunteer to parse out the effects of the therapy on quality of life for children in treatment ages 2 to 18 years. The study found positive results using a creative arts therapy model (music, dance and art therapies) on a pediatric oncology unit to improve quality of life. Lastly, a study conducted in Iraq recently used Quality of Life as assessed using the KIDSCREEN-10 tool and a randomized control design showed that after a 20-session engagement with art therapy, children improved with respect to energy level, relationships, participation in social activities and perception of school performance.

Though art therapists work at many hospitals across the country, including leading pediatric hospitals, little has been reported regarding their work, including the work in pediatric

oncology. Of the literature that is available, much comes from pediatric nursing and other practitioners using the tools and techniques of art therapy without having an art therapist as part of the research or treatment team. Four articles were found that were written by art therapists practicing in medical oncology settings (Ciucci & Heffner-Solimeo, 2018; Councill & Ramsey, 2019; Kaimal et al, 2019; Peterson, 2015). These articles describe the programs and/or processes that these therapists engage in with their pediatric (Ciucci & Heffner-Solimeo, 2018; Councill & Ramsey, 2019) or adolescent/adult patients (Peterson, 2015; Kaimal et al. 2019). It is imperative currently to identify where art therapists are working within the pediatric hematology/oncology field and identify practices to begin to support the validity of psychosocial support through art therapy and advocate on behalf of this service.

COLLABORATORS

The collaborators at present for the proposed studies include Tracy's Kids sites (e.g. Medstar Georgetown University Hospital), NEA Research Labs, NEA Creative Forces and Drexel University. Additional sites and collaborators might be added in the future based on feasibility and research resources.

TRACY'S KIDS (TK):

Tracy's Kids is a nonprofit art therapy program providing services to children on Hematology/ Oncology units in 8 different hospitals in Washington D.C., Northern Virginia, Maryland, New York, and Texas. Their team of registered art therapists, under the leadership of founders Tracy Councill and Matt Gerson, and their Board of Directors have been serving these children, families, siblings and hospital staff since 1991. Tracy's Kids serves as a model for hospital-based, pediatric psychosocial support through art therapy.

NEA RESEARCH LABS AND ARCS LAB AT DREXEL UNIVERSITY:

With a focus on examining the value and impact of the arts, the NEA Research Labs program supports research in the areas of: The Arts, Health, and Social/Emotional Well-Being; The Arts, Creativity, Cognition, and Learning; and The Arts, Entrepreneurship, and Innovation. Drexel University's Arts Research on Chronic Stress (ARCS) Lab was one of the first recipients of funding support through a cooperative agreement from the National Endowment for the Arts to study the impact of the creative arts therapies on health and well-being.

MEDSTAR GEORGETOWN UNIVERSITY HOSPITAL:

Located in northwest Washington, DC, Medstar Georgetown hospital is a leading research and teaching hospital serving the greater DC area. The Jesuit principle of cura personalis- caring for the whole person is at the heart of what they do. Their pediatric hematology/ oncology center serves children, adolescents and young adults from birth through age 25 with all forms of cancer and blood disease and supports the whole child with comprehensive supportive care, including art therapy.

DESCRIPTION OF TRACY'S KIDS **PROGRAMMING**

Tracy's Kids began at the Lombardi Cancer Center of Georgetown University Hospital in 1991 and has grown from one art therapist at one hospital to ten art therapists at eight locations in five states. Tracy's Kids serves patients with cancer and blood disorders, and other chronic, life-threatening illnesses who receive treatment in Pediatric Hematology-Oncology Clinics. In 2018, the Tracy's Kids programs provided 11,885 art therapy sessions, 24,783 patient contacts, and 895 hours of consultation to medical teams.

Since Tracy's Kids patients come primarily for medical care, not for psychotherapy, the program developed a child-centered, open studio approach that provides support during all phases of treatment. The Tracy's Kids art therapists are integrated members of the medical care team. They educate patients and caregivers about how art therapy can help them cope with the challenges of treatment and develop personalized treatment plans. They also

provide opportunities for relaxation, confidence-building, and self-expression, and help young patients describe and work through the challenges they face. When patients endure traumatic experiences, such as painful or invasive medical procedures or devastating diagnoses, the therapists help them process their experiences and develop greater resilience as they move through treatment. The Tracy's Kids approach embodies many principles of trauma-informed care. The open art studios in outpatient infusion centers, where most young cancer and blood disorder patients receive much of their care, promote an atmosphere of safety and inclusion, maximize patients' choices, and provide non-verbal avenues to communicate feelings and needs to the medical team. Collaborative art-making projects in the clinics reflect the community of support patients experience in art therapy.

Art therapists staff the open studios during clinic hours and invite all patients and caregivers present to participate, normalizing the treatment experience and reducing the isolation imposed by cancer treatment. The therapists also provide continuity of care through individual and family support at bedside in the inpatient setting. In addition, annual art exhibitions of artwork created by patients. A range of art media are provided as part of the program and patients also often integrate medical supplies in their creations as seen in the images below.

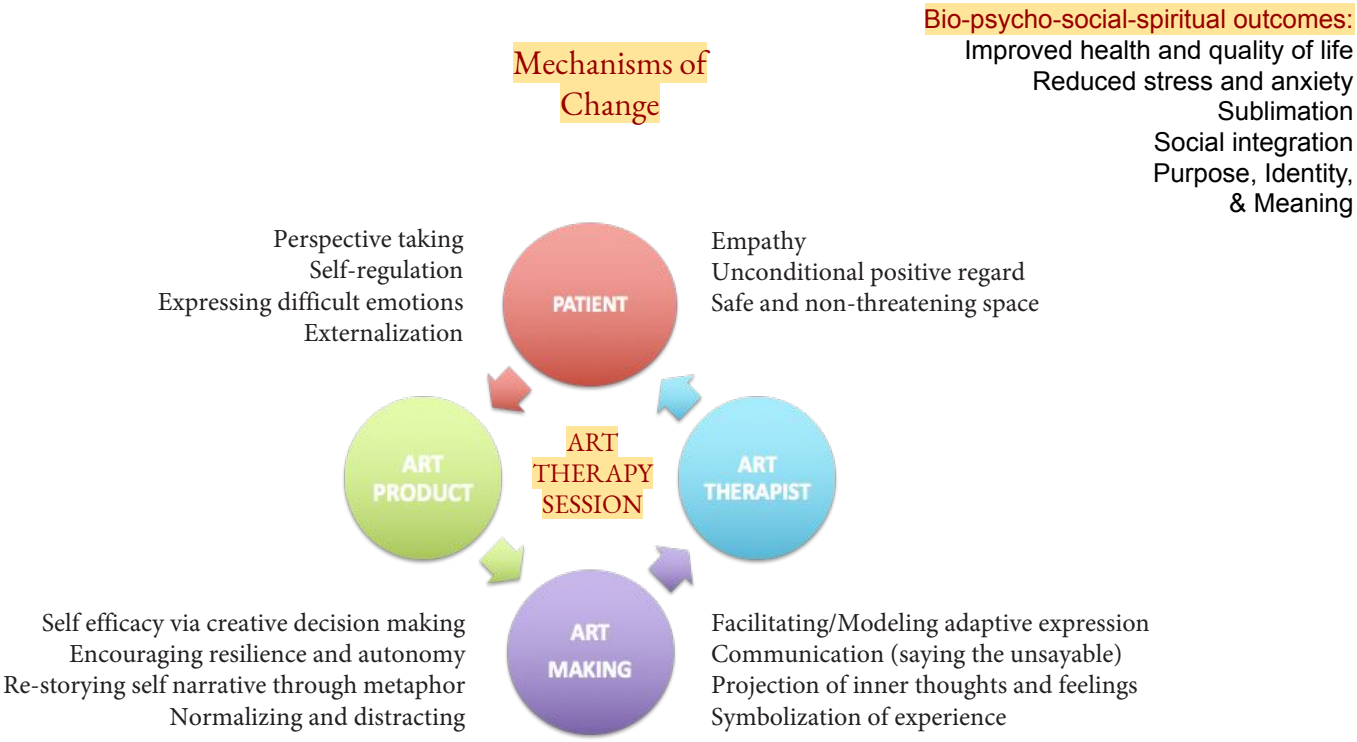
CONCEPTUAL FRAMEWORK **FOR RESEARCH**

OVERVIEW

This conceptual framework for research on art therapy in pediatric hematology/oncology settings is founded on the assumption that the clinical services impact the biological, psychological, social and spiritual/ existential aspects of the life of the child, family and care providers. The biological and physical aspects of the illness would include aspects like energy levels /fatigue, pain, nausea, lack of appetite, shortness of breath, and chronic stress. The psychosocial constructs associated with the illness include aspects like anxiety, depression, quality of life, self-image, socialization/ isolation, school performance, paranoid ideation, distraction/coping skills, communication, anger, confusion, hopelessness, and, adaptive boundaries. One of the unique aspects of the acute and chronic care trajectory of extended care oncological treatment, especially for pediatric patients, is the disruption of normal childhood development and the emergence of reflections on life, feeling different, and feelings of guilt about the stress the illness places on the family unit. This leads to specific existential and spiritual reflections and therefore tracking this meaning making, purpose, and approach to life and living becomes a salient construct to measure.

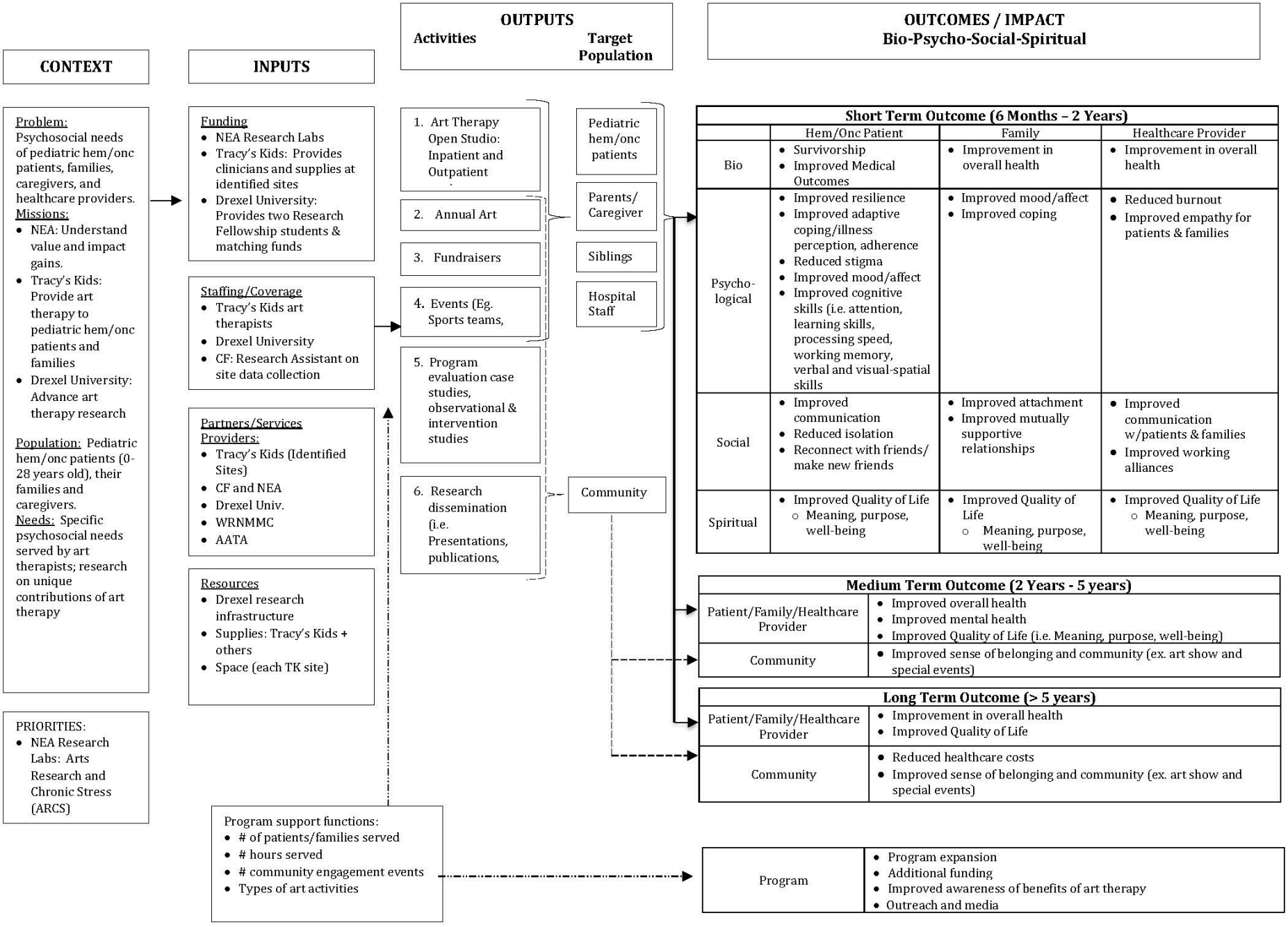
MECHANISMS OF CHANGE IN ART THERAPY

A key aspect of art therapy practice that requires articulation relates to components of a session and therefore mechanisms of change which form the basis of the proposed conceptual framework. The figure below is an illustration of how art therapy promotes adaptive responses (Kaimal, 2019) among patients and families undergoing the challenging and stressful experiences of cancer and/or other hematological conditions.



As can be seen from the figure above there are four components to art therapy practice including the art therapist, the patient, the artmaking process and the art product. The interaction between the therapist and patient promotes pro-social experiences, a sense of safety, and, empathy. The artmaking process helps practice problem solving, normalizes hospitalization and encourages self-efficacy through the acts of creative expression. The artwork itself helps provide perspective and externalizes what might be difficult, unsayable and/or complex inner emotional states. Together these components of the art therapy sessions facilitate changes in the patient based on goals of quality of life, mood, self-efficacy, perceived stress, relational development and adaptive choices in the face of adversity (such as the medical condition in this case). The session itself is led by the art therapist with an awareness and understanding of the context of the patient's life as a member of a family, community, healthcare system and society. Thus initial mechanisms of change and outcomes are represented at the individual level but these can go on to impact the family and communities associated with the patient. In addition, if patients and families are positively impacted, it might be expected to have effects on the quality and costs of healthcare.

Included next is a logic model that proposes how the studies can be connected to the research activities proposed as part of this framework.


CONTEXT
INPUTS
OUTPUTS
Activities
Target Population
OUTCOMES / IMPACT
Bio-Psycho-Social-Spiritual
Problem:
Psychosocial needs of pediatric hem/onc patients, families, caregivers, and healthcare providers.
Missions:
NEA: Understand value and impact gains.
Tracy's Kids: Provide art therapy to pediatric hem/onc patients and families
Drexel University: Advance art therapy research
Population: Pediatric hem/onc patients (0-28 years old), their families and caregivers.
Needs: Specific psychosocial needs served by art therapists; research on unique contributions of art therapy
PRIORITIES:
NEA Research Labs: Arts Research and Chronic Stress (ARCS)
Funding
NEA Research Labs
Tracy's Kids: Provides clinicians and supplies at identified sites
Drexel University: Provides two Research Fellowship students & matching funds
Staffing/Coverage
Tracy's Kids art therapists
Drexel University
CF: Research Assistant on site data collection
Partners/Services Providers:
Tracy's Kids (Identified Sites)
CF and NEA
Drexel Univ.
WRNMMC
AATA
Resources
Drexel research infrastructure
Supplies: Tracy's Kids + others
Space (each TK site)
1. Art Therapy Open Studio: Inpatient and Outpatient
2. Annual Art
3. Fundraisers
4. Events (Eg. Sports teams,
5. Program evaluation case studies, observational & intervention studies
6. Research dissemination (i.e. Presentations, publications,
Pediatric hem/onc patients
Parents/ Caregiver
Siblings
Hospital Staff
Community
Program support functions:
# of patients/families served
hours served
community engagement events
Types of art activities
Short Term Outcome (6 Months – 2 Years)
Hem/Onc Patient
Family
Healthcare Provider
Bio
Survivorship
Improved Medical Outcomes
Improvement in overall health
Improvement in overall health
Psycho-logical
Improved resilience
Improved adaptive coping/illness perception, adherence
Reduced stigma
Improved mood/affect
Improved cognitive skills (i.e. attention, learning skills, processing speed, working memory, verbal and visual-spatial skills
Improved mood/affect
Improved coping
Reduced burnout
Improved empathy for patients & families
Social
Improved communication
Reduced isolation
Reconnect with friends/ make new friends
Improved attachment
Improved mutually supportive relationships
Improved communication w/patients & families
Improved working alliances
Spiritual
Improved Quality of Life
Meaning, purpose, well-being
Improved Quality of Life
Meaning, purpose, well-being
Improved Quality of Life
Meaning, purpose, well-being
Medium Term Outcome (2 Years - 5 years)
Patient/Family/Healthcare Provider
Improved overall health
Improved mental health
Improved Quality of Life (i.e. Meaning, purpose, well-being)
Community
Improved sense of belonging and community (ex. art show and special events)
Long Term Outcome (> 5 years)
Patient/Family/Healthcare Provider
Improvement in overall health
Improved Quality of Life
Community
Reduced healthcare costs
Improved sense of belonging and community (ex. art show and special events)
Program
Program expansion
Additional funding
Improved awareness of benefits of art therapy
Outreach and media

RESEARCH APPROACHES

The framework offers several levels of research and analysis from case studies and evaluations to observational studies of patient, family and health systems outcomes to controlled studies of the impact of art therapy interventions. Specific research designs and approaches to be used are listed below along with a timeline for analysis based on whether these address short term, intermediate, or long-term outcomes.

AIMS OF THE RESEARCH

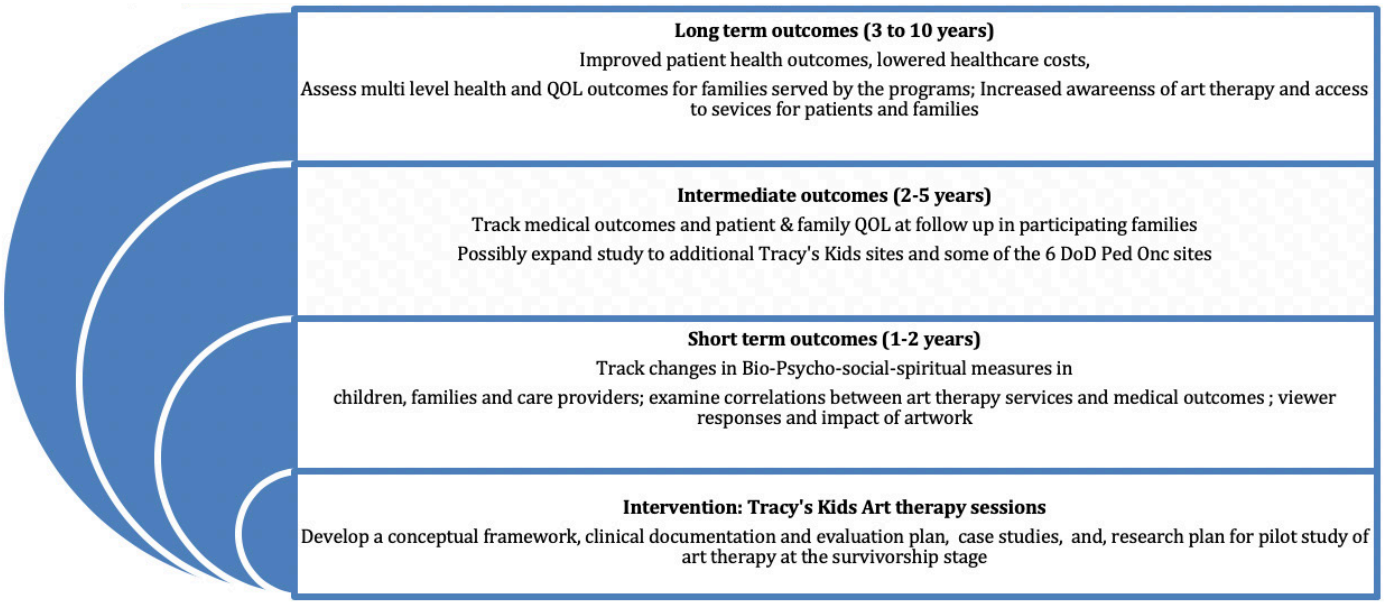
The purpose of the research collaboration is to systematically study the processes, mechanisms, and outcomes (short and long term) of open studio art therapy with patients who have oncological or hematological conditions, their families, and the associated healthcare systems.

RESEARCH QUESTIONS

The main guiding research question for the studies is: How and to what extent does art therapy impact the health and psychosocial outcomes of pediatric hematology/oncology patients, families and healthcare providers? Within this umbrella question additional examples of sub-questions might include the following

- How and to what extent does art therapy impact patients' and families' health, psychosocial functioning and quality of life through the active treatment process and in the survivorship stage?
- How and to what extent does art therapy improve communication, adherence to medical care, and working alliance in the medical setting?
- How and to what extent does art therapy at a site improve healthcare provider well-being, reduce burnout and healthcare utilization costs?
- How and to what extent does viewing artwork created by pediatric hematology/ oncology patients engender empathy, community engagement and sustainability?

A summary of the timeline for the studies is included in the figure below:



SHORT TERM APPROACHES: 1-2 YEARS

Description of clinical approach at all sites: Research conducted as part of P-CAT could begin with clinical case papers describing the range of ways in which art therapy (as implemented as part of Tracy's Kids) is practiced in pediatric hematology/oncology sites. These can help provide insight on key mechanisms of change and identify relevant clinical information to track for further research.

Case series/ Single Subject Designs: Clinical cases series and single subject designs could include illustrative examples that provide comprehensive information on outcomes of the clinical model on children and families. These can then serve as foundation to develop more formal research designs, assessing clinical outcomes across a spectrum of factors. Single subject small smple designs and case series in particular can help identify changes that occur as a result of art therapy and appropriate variables to track with a larger sample of participants.

Program evaluation: Using practice improvement as the rationale, program evaluation research can incorporate customized forms and standardized measures to evaluate and improve programming in pediatric hematology/oncology units. As a first step at a new site, the team will gather data related to clinical support prior to commencing an art therapy offering and then gather data on participant experiences and outcomes as a result of the art therapy services. This approach will also be done at existing sites without the preliminary data to continue to assess and improve the programs. The team will consider using focus groups of caregivers, parents/families, health care providers and patients to assess benefits, strengths and challenges of providing art therapy in oncological and hematological care.

INTERMEDIATE TERM APPROACHES: 2-5 YEARS

Observational/cohort study: A review of clinical documentation will be part of this intermediate research protocol with a plan to integrate a systematic clinical documentation plan for the participating sites. These clinical data and existing electronic health records will be used for retrospective observational analyses. Analysis of quantitative, qualitative

have not will be compared. This will be done with the integration of clinical documentation protocols at selected Tracy's Kids' sites as well electronic health records collected as part of medical care,

Targeted intervention study: The targeted interventions may focus on a specific diagnosis or time period of treatment (e.g. survivorship). For example, this could be a research protocol for a family-centered 4-week art therapy intervention to be offered in the survivorship stage. This will be ideally be submitted to the IRBs at all participating sites. This study design is expected to include a mixed methods approach that includes quantitative, qualitative and arts-based data (use art assessment before and after, standardize the sessions, compare with psychoeducation).

LONG TERM APPROACHES: 5-10 YEARS

Health systems studies: These clinical data and existing electronic health records will be used for retrospective analyses to assess impacts on healthcare costs when programs such as Tracy's Kids are introduced in medical sites. Outcomes of interest in these analyses would be reduced costs of medical procedures, treatment time, and improved health outcomes.

Multi-site studies: Once preliminary studies are completed; larger fully powered multi-site clinical trials could be initiated to assess the effectiveness of art therapy as a part of the integrative care for pediatric cancer patients.

Sustainability and community engagement: The sustained investment in the art therapy programs can be tracked through resources generated for the programs including funding as well as additional program expansion support over time. The impact of responses to viewing artwork and the resulting level of community engagement can also help gauge the unique role and contributions of artwork created by patients. This will include systematic examination of viewer responses to artwork in physical and online spaces and role of the artwork in the therapeutic experience. Responses and feedback can be gathered during annual exhibitions as well as from patients, family members, and healthcare providers on-

DATA SOURCES

Data sources for the studies could be qualitative, quantitative and/or arts based. Quantitative measures could include standardized and validated measures of psychosocial well-being (mood, affect, self-efficacy, quality of life, etc.) as well as physical health (documentation of medications, medical procedures) as well as demographic features, treatment dosage and illness characteristics. DeWalt et al. (2015) have validated the PROMIS scales for a variety of pediatric chronic health conditions and White (2014) has studied the *Perceived Stress Scale for Children* for its content validity and reliability. As it pertains to general assessments of Quality of Life, three general scales are recommended for use, namely, DISABKIDS, KIDSCREEN 52 and PedsQL 3.0 (Janssens, Gorter, Ketelaar, Kramer & Holtslag, 2008, Varni et al 2002). The cancer module of the PedsQL is one of the most comprehensive and validated measure for our purposes. In addition, we have identified several validated scales and measures related to physical, psychological and spiritual health. Quantitative measures could also include biomarker data (as apt) that could track levels of neuroinflammation and stress in the body as well as functional and structural impacts of artmaking. Qualitative measures will include interviews, focus groups, and narrative clinical notes. Arts based data will include visual documentation and descriptions of artwork along with tracking of responses to the artwork and art spaces. A listing of measures is included in the appendices.

DATA ANALYSIS

The data will be analyzed using a range of methods. The quantitative data will first be summarized using descriptive statistics including patient demographics, illness conditions, treatment course and outcomes. Further inferential statistics will be used to determine relationships between patient characteristics and family responses in the domains of bio-physical, psychological, social and spiritual dimensions. Analysis of long term change including healthcare costs are expected to be conducted with access to the medical records and healthcare datasets. Qualitative data from interviews, focus groups, feedback and art work descriptions will be summarized using case study, grounded theory and thematic analysis methods.

DISSEMINATION PLANS

Findings from the studies will be disseminated in academic, community and practitioner forums to enable widespread access to research on the impacts of art therapy on patient outcomes. We expect the results to be published in scholarly journals as well as in accessible digital media outlets including websites of the collaborating institutions, blog posts and social media outlets.

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LISTING OF SCALES AND MEASURES

QUANTITATIVE STANDARDIZED MEASURES

MEASURES OF PHYSICAL AND MENTAL HEALTH

- The PedsQL 3.0 Cancer Module (child): measures the dimensions of physical, mental, and social health as defined by the World Health Organization, as well as role (school) functioning in this population
- The Coping Resources Inventory (CRI): measures how people handle stress, conceived in five basic ways: cognitive, social, emotional, spiritual/philosophical, and physical
- Mental Adjustment to Cancer Scale (MACS): was designed to measure Fighting Spirit (FS), Anxious Preoccupation (AP), Helpless-hopelessness (HH) and Fatalism
- The Brief Fatigue Inventory (BFI): used to rapidly assess the severity and impact of cancer-related fatigue
- The Symptom Checklist-90-R (SCL-90-R): a relatively brief self-report psychometric questionnaire designed to evaluate a broad range of psychological problems and symptoms
- Profile of Mood States (POMS): psychological rating scale used to assess transient, distinct mood states
- Pediatric PROMIS tool scales: a variety of scales to assess anxiety, depression, social relations with peers, fatigue, & a visual analogue pain scale
- Visual Analogue Pain Scale: a visual tool for allowing children to assess perceived pain
- Child Behavior Checklist (CBCL): parent-report questionnaire to rate a child's various behavioral and emotional symptoms
- PANAS (Parent & child versions): Positive and Negative Affect as rated by a parent of their child
- General Self-Efficacy Scale (GSE): measures the personal perspective of being able to reach goals, problem-solve and succeed in dealing with difficulties

QUALITY OF LIFE MEASURES:

- The PedsQL 3.0 Cancer Module (parent): measure the dimensions of physical, mental, and social health as defined by the World Health Organization, as well as role (school)

functioning in this population

- SF-36 Health-Related Quality of Life (HRQOL): measures an individual's or a group's perceived physical and mental health over time.
- WHO Quality of Life-BREF (WHOQOL-BREF): The World Health Organization's project questionnaire designed to measure general quality of life cross-culturally, including perceptions of such within the context of culture and value systems.
- Perceived Stress Scale (PSS): measures a person's appraisal of stress
- Posttraumatic Growth Inventory (PTGI): assesses outcomes reported by persons who have experienced traumatic events including factors such as New Possibilities, Relating to Others, Personal Strength, Spiritual Change, and Appreciation of Life
- Core Beliefs Inventory (CBI): a brief measure of disruption in the assumptive world that predicts posttraumatic growth and predictions about the effects of stressful experiences
- Impact of Events Inventory (IEI): measures the aftereffects of event-specific distress such as intrusive thoughts and avoidant behaviors

EMPATHY AND PERSPECTIVE TAKING MEASURES:

- Interpersonal Reactivity Index (IRI): a multidimensional approach to individual differences in empathy
- Perspective Taking & Empathic Concern Scale (EC +PT-Ohio state): measure of global empathy tapping into four aspects: perspective-taking, fantasy, chronic emotional reactions, and negative experiences of other

HOSPITAL EXPERIENCES MEASURES:

- Maslach Burnout Inventory: a survey for healthcare professionals that measures areas of emotional exhaustion, depersonalization and low sense of personal accomplishment to assess for burnout
- Working Alliance Inventory (WAI): 36-item measure of relationship with therapist, assessing agreement on the tasks of therapy, agreement on the goals of therapy and, development of an affective bond

QUALITATIVE STANDARDIZED MEASURES

- Clinical documentation form: Based on standard hospital-based psycho-social service clinical documentation. Includes art-therapy language.
- Child interview protocol: for use in focus-groups as a method to understand their perceptions of the art therapy experience
- Parent interview protocol: for use in focus-groups to focus on the parents' perceptions of their child's experiences in art therapy and their own use of the studio and art therapy.
- Family Focus Group protocol: for use in focus groups to assess the perceptions of art

therapy experiences for siblings and families.

o Healthcare provider group interview protocol: for use in focus groups to assess the perceptions of healthcare providers on the usefulness and impact of art therapy services for the children, families and care providers on the unit.

o Pediatric Cancer Art Therapy Study (PCATS) Program Assessment of Services: a questionnaire used to elicit responses from healthcare providers both prior to establishing an art therapy studio support service as well as once established.

PROGRAM EVALUATION FORMS

o Tracy's Kids Art Therapy Program Evaluation Patient Form 5 years old and under: standardized questionnaire for different ages 5 and under, designed to assess the overall experience of the Tracy's Kids program.

o Tracy's Kids Art Therapy Program Evaluation Patient Form ages 6 years and older: standardized questionnaire for children ages 6 and up, designed to assess the overall experience of the Tracy's Kids program.

o Tracy's Kids Art Therapy Program Evaluation Parent/Guardian Form: standardized questionnaire for parents/guardians of pediatric hematology/oncology patients, designed to assess the overall experience of the Tracy's Kids program.

o Tracy's Kids Healthcare Professional Provider Feedback Survey: a questionnaire designed to elicit feedback regarding their perceptions of Tracy's Kids programming

ARTS-BASED TOOLS

o Bridge Drawing (Hays & Lyons, 1981): Designed by art therapists Ron Hays and Sherry Lyons to look at a person's perceptions of their past, present and future.

o The Cancer Bridge Drawing (Councill, 2012): a modified version of the Bridge Drawing by Hays and Lyons (1981) that Tracy Councill developed for Tracy's Kids and childhood cancer survivors to look at the way they perceive their progress in treatment and envision their future.

o Road to Recovery Drawing (Hanes, 1995, 2017): The metaphor of a road in art therapy is often used to allow people to reference life events and movements in symbolic ways.

o Person Picking an Apple from a Tree (Gantt, 1990): This drawing directive is designed to see how children problem solve when facing obstacles. It is said to be a representation of general coping strategies.

o Draw a Story (DAS) Stimulus Task (Silver, 1991): this art therapy directive may be used to show a person's attitudes and emotional states and assess cognitive functioning by prompting them with provided images that they use as stimuli.