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## Phototherapy and Empowerment for People Living with Chronic Conditions

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**Capstone Thesis: Phototherapy and Empowerment for People Living with Chronic  
Conditions**

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February 10, 2022

## Abstract

An exploration of combining empowerment theory, photo-based art interventions, and hope-based interventions in a group setting and whether this method can reduce feelings of depression and anxiety and increase feelings of hope, power, and empowerment for those living with chronic conditions and chronic pain. The reviewed literature showed that hope-based art interventions, photo-based art interventions, and empowerment can increase feelings of hope and empowerment and decrease levels of depression and anxiety in people living with chronic conditions. I created a method that combined all three interventions in a group therapy setting where the participants completed the artwork between sessions and shared their work and thoughts surrounding it in the following session. The group took place over zoom through a local creative university. The participants were between the ages of eighteen and twenty-six; all participants were female except for one male who attended one session and were Caucasian, Asian, Asian-American, and Indigenous. I learned that the combination of photo-based interventions, hope based interventions, and empowerment theory in a group setting for people with chronic conditions has the potential to lower feelings of depression and anxiety and with further research in a group with more consistent attendance, has the potential to increase feelings of hope, purpose, and empowerment. This research highlighted the need for more exploration into successful expressive therapy measures that support people with chronic conditions through empowerment, art, advocacy, and community.

*Keywords:* Art Therapy, Phototherapy, Hope-Based Interventions, Chronic Pain, Chronic Illness, Empowerment, Advocacy

*The author identifies as a large bodied, Caucasian, straight-passing lesbian woman from Georgia of mixed European ancestry.*

# **Capstone Thesis: Phototherapy and Empowerment for People Living with Chronic Conditions**

## **Introduction**

Empowerment theory focuses on strengths-based and outreach work. Chronic pain and chronic illness have devastating effects on the quality of life of individuals. Individuals' ability to function at work and home, care for themselves, have fun, and interact with others is impacted. Chronic health conditions are handled as if there is no hope for a cure which makes the impacts of the diagnosis more severe on the person living with chronic pain. Due to this, people living with chronic illness and chronic pain are forced to envision a future where their pain and disease are a constant in their lives. This can severely impact a person's ability to feel hopeful about the future and have life-threatening outcomes, such as suicide, which has twice the rate in the chronic pain population than in the general population (Varekamp et al., 2006). My focus was on the effect of empowerment theory combined with phototherapy and how it may reduce levels of depression and anxiety and increase levels of hope and empowerment in chronically ill young adults. I hoped to reduce anxiety, hopelessness, and depression and increase hope and purpose in clients with chronic conditions through my proposed method.

Multicultural issues and intersectionality played an essential role in my research. The medical care system often disenfranchises people with chronic illness, chronic pain, and disabilities. People with chronic illness, chronic pain, and disabilities can often feel invisible due to their conditions being undiagnosed or contested. Social institutions can exacerbate this feeling of invisibility by lack of adequate record keeping and tracking of health concerns and conditions (Dillaway et al., 2022). People over the age of 65, those with more severe disabilities, and people

who have at least one chronic condition can find themselves more isolated from adequate and quality healthcare when living in long-term care facilities. Those living with chronic conditions and chronic pain may experience poor or inadequate healthcare due to healthcare providers remaining unknowledgeable about proper care protocols (Dillaway et al., 2022). The authors Dillaway et al. (2022) add that this lack of education within the healthcare system on various chronic conditions can lead to negative attitudes toward people living with disabilities. Due to the healthcare system being designed with able bodies in mind, many offices are unable to accommodate those who live with chronic conditions and disabilities.

Patients who are women are substantially more likely to be passed over and mistreated by doctors; this inequality means being misdiagnosed, not being taken seriously, told their conditions are psychosomatic and ignored (Hoffman et al., 2016). The authors Hoffman et al. (2016) add that people of color, but especially women of color, are at even more risk for this treatment, with the addition of doctors not giving them adequate pain medication because of the still present racist idea that people of color feel less pain or suffer from drug abuse more frequently than white people.

Furthermore, if patients with chronic conditions are over the body mass index category of "overweight" they are often refused treatment and told that their symptoms are due to their weight which leads them to go misdiagnosed, untreated, and living in pain for years (Bacon & Aphramor, 2011). According to Cardoza (2019), people with chronic illness and pain who identify as LGBTQIA+ experience medical discrimination that includes refusal of treatment by doctors due to their sexuality or gender identity. The income status of individuals is one of the most significant indicators of quality medical treatment and life expectancy in the United States. Clark (2019) found that families with lower than average incomes more frequently experience

lapses in insurance coverage, barriers to accessing health specialists, and inadequate treatment for common illnesses, leading to poor health outcomes and substantially lower life expectancy. Intersectionality and systems of oppression play a substantial role in my clients' day-to-day lives, medical treatment, and quality of life (Talwar, 2010). These factors were considered when doing this research.

Due to the vast health inequities chronically ill people face, exploring how empowerment theory can help give them strength, improve mental health wellbeing and reduce feelings of depression and anxiety was essential when planning my research and method. Building on existing internal systems by focusing on strengths in the client, empowerment theory promotes health and advocacy and adaptation. Empowerment theory includes methods by which individuals look at their personal, community, and organizational systems and explore ways to empower themselves and others to create positive change—using a strengths-based approach. These processes make this possible to focus on enhancing mastery, promoting agency, and exerting control. Strengthening identity development, interactional skills, critical thinking, organizational involvement, and intrapersonal efficacy are psychological empowerment methods that increase clients' feelings of empowerment and strength (Zimmerman & Eisman, 2016).

For some people, work gives them purpose, encourages them to leave their homes and connect with others, and gives them the means to support themselves. A portion of people with chronic illness cannot stay in the workplace due to debilitating pain, symptoms, and mental health deterioration. An article by Varekamp (2006) focused on using empowerment theory and strengths-based approaches to keep chronically ill people in the workplace longer within their life span. This study focuses on empowering clients to request accommodations at work, making

their ability to remain at their job more likely due to the accommodations which may ease their pain or symptoms while working.

In a 6-week group therapy program called Being Hopeful in the Face of Chronic Pain, the client's in-session experience of an arts-based hope intervention was the focus and better understanding of how to foster hope through art in this population. This program was meant to be helpful in addition to other chronic pain treatments. The study found that hope increased through several means, including coming together in hope, hope concerning the other, and internalizing hope. This intervention allowed clients to focus on aspects of their lives that were more positive and broader and go beyond their pain. Participants reported through the interviews that the collage and debriefing and connection to others increased their feelings of hope (Larsen et al., 2018). This intervention was similar to the photo collage work clients created during my group.

A study called “On Liveness: using art workshops as a research method” focused on using art workshops to explore pain communication. Participants developed images and metaphors that evoked their pain and sometimes provoked it (Tarr et al., 2017). One example would be a spoon rubbing against a grater, representing pain aurally. During these workshops, participants voiced their desire to protect others from their discomfort rather than sharing it. Due to many chronic pain sufferers repeatedly reporting feeling misunderstood or not believed about their pain and not relating to the typical number scale commonly used with pain sufferers, this study focused on nonverbal forms of communication. The “On Liveness: using art workshops as a research method” study used the arts as an expressive resource for people with pain. A review of current literature on art and health by Stuckey and Nobel (2010) noted a wide range of studies emerging in music engagement, visual arts, movement-based creative expression, and creative

writing, observing that art helps people express experiences that are too difficult to put into words (Tarr et al., 2017).

Different activities included making sounds, body movements, body scans, and drawings. These interventions are necessary because they gave people living with pain an opportunity to communicate their pain in a visual or auditory manner, not just based on an arbitrary, subjective number on a scale, which doctors frequently dismiss (Tarr et al., 2017). I incorporated a visual pain scale as one of the art directives in my group. Arts-based practices can be beneficial to those living with pain not only as a means of expression but as a means of communication and as a tool to foster hope and positive emotions (O'Neill & Moss, 2015). A visual pain scale can allow clients to draw or create an image depicting the location and severity of their pain, rather than identify it with a number, to aid in the communication and understanding between the client and their doctor.

My goal was to bring individuals who live with chronic illness and chronic pain together in a group therapy setting. Clients living with various long-term chronic pain and chronic health conditions were able to build community and peer support in the group setting. Through phototherapy, they expressed lived experiences, pain severity, location, symptoms, disenfranchisement, struggles, and triumphs. The focus was on reducing adverse mental health symptomatology and improving feelings of hope in the clients. Throughout the sessions, we explored coping skills and ways the clients can change policy and or accessibility on a personal, community, and systemic level. The goal of integrating empowerment theory, photo-based artwork, and coping skills for anxiety and depression was to improve the quality of life, reduce health inequities, increase self-advocacy and healing, and improve the client's ability to work and participate in life activities that can increase feelings of empowerment and purpose.

## **Literature Review**

Previous research showed that hope-based, photo-based, and empowerment-based interventions have been shown to increase hope levels and reduce anxiety or depression individually. Hope-based interventions focus on improving the levels of hope of participants through art. Photo-based interventions allow participants to use photography with or without college while exploring relevant topics to their treatment. Empowerment-based interventions focus on strengths-based work and advocacy and work toward building confidence and purpose while lowering levels of anxiety and depression.

### ***Hope Based Interventions***

In a six-week group therapy program called Being Hopeful in the Face of Chronic Pain (BHFCP), the client's in-session experience of an arts-based hope intervention was the focus and better understanding of how to foster hope through art in this population. This program was meant to be helpful in addition to other chronic pain treatments. It has been found that increasing hope and positive emotions can help disrupt the cycle of pain and negative emotions people with chronic pain typically experience. For this study, using one particular arts-based intervention, a hope collage, in-depth interpersonal process recall interviews were done with 11 members of the group to measure their experience of hope throughout this intervention. The study found that hope increased through several means, including coming together in hope, hope in relation to the other, and internalizing hope. Through a pre-post design, it also found that subjective levels of well-being, engagement in life, and hope increased, and there was also an increase in pain acceptance and a decrease in pain catastrophizing (Larsen et al., 2018).

In the second session of this group, participants created a hope collage, and they debriefed during the third session. The hope collage was beneficial as it is related to positive

psychology, intends to elicit positive emotions, allows participants to engage in the feeling of hope, and combines art and psychotherapy to bring healing and hope to the client through the creative process. When people have lived with chronic pain for a long time, they typically focus on their pain, and it is hard to concentrate on anything else related to their lives or identity. This intervention allowed clients to focus on aspects of their lives that were more positive, broad, and went beyond their pain (Larsen et al., 2018).

A case study methodology was used to design this study, which allows for exploring complex phenomena within real-world contexts. The research focused on the second and third sessions of the program. Using the case study method, no approach to data collection and analysis is specified, and it allows researchers to identify the best research design depending on the particular case. This study used intensity sampling procedures, which involved participants providing contextualized and rich experiences of the topics of interest. Participants were asked to create collages using construction paper and magazines while reflecting on hope and were explicitly told there is no expectation of having a beautiful collage, just meaningful. Participants were allowed to interact as little or as much as they wanted with other group participants. Many participants lost track of time during the activity, showing they were experiencing flow. They were reminded to move halfway through not to trigger a pain response. During debriefing in the next session, clients were asked to reflect on how the collage reflected hope to them. Both facilitators of the activity were registered counseling psychologists who have a background in hope-focused therapy and art therapy in medicine (Larsen et al., 2018).

Participants in this study were over 18 years old, had pain for at least three months, and were willing participants. The group was advertised at medical clinics, non-profit health organizations, and health newsletters. The study ended up with 11 participants between 25 and

68 years old who had a mean of 18.5 years of chronic pain. Data were collected 2-4 days after session three after research interviews were conducted with the participants. The interviews were done by two interviewers who had backgrounds in research methods and IPR training. During the interview process, participants were encouraged to take breaks so as not to exasperate their pain. Thematic analysis was used to research to allow for a more intuitive approach driven by the data. Participants reported through the interviews that the collage and debriefing and connection to others increased their feelings of hope (Larsen et al., 2018).

Another study titled “On Liveness: using art workshops as a research method” focuses on using art workshops to explore pain communication. This study was used as a methodological reflection on how the liveness of arts-based methods was significant and assisted in provoking novel forms of communication, produced unexpected outcomes during workshops, so much so that the authors theorized the art as “imprography.” A challenge in this study is

It constituted affective and collective experiences of “being there” as important but difficult-to-record parts of the data, which raises challenges to current understandings of what constitutes data, particularly in the context of team research and considering directives for archiving and reuse. (Tarr et al., 2017, p. 36)

There are several types of arts-based research, and one that continues to evolve is a performative approach which has led to the development of live and inventive methods. Research that involves active engagement with the changing world rather than investigating a nonchanging reality created the argument in favor of developing innovative methods that can reflect and explore what is happening in the social world, its ongoingness, relationality, and its contingency. This study took the idea of live methods and built upon them by exploring the use of liveness

across the research cycle and reflecting on art workshops that investigate new ways of communicating information about chronic pain(Tarr et al., 2017).

This study argued that it is essential to think beyond individual aspects of data collection, recording, and analysis and consider the broader themes of the research. The significance of this research lies in the experience of participation and the difficulty to record information related to affective engagement, ambiguity, and discomfort, all of which were recorded in knowledge, memory, or skill development. This study focused on the workshop as the research process instead of the arts-based methods as the research product. Participants developed images and metaphors that evoked their pain and sometimes provoked it (Tarr et al., 2017).

One example of this would be a spoon rubbing against a grater which can represent pain aurally. During these workshops, participants voiced their desire to protect others from their pain rather than sharing it. Instead of improving the representation of the experience of chronic pain, these workshops sought to rework chronic pain communication, which was done by changing the frame in which it occurred from a series of isolated and isolating interactions between a clinician and patient or a sufferer and non-sufferer to a communal space for discussing, sharing, and reinterpreting the experience of pain (Tarr et al., 2017). The art in the workshop was not the primary goal but rather, the focus was the reframing of pain through social interactions between people.

Due to many chronic pain sufferers repeatedly reporting feeling that they are misunderstood or not believed about their pain and not relating to the typical number scale commonly used with pain sufferers, as well as the fact that communication about pain often repeats binaries of real-imagined or mind-body which can delegitimize and stigmatize the experience of people who have pain, this research was created to explore different ways to

communicate pain that did not rely on standardized descriptors. This study focuses on nonverbal forms of communication and uses the arts as an expressive resource for people with pain. A review of current literature on art and health by Stuckey and Nobel (2010) notes a wide range of studies emerging in music engagement, visual arts, movement-based creative expression, and creative writing, observing that ‘art helps people express experiences that are too difficult to put into words (Tarr et al., 2017).

This arts-based research study is qualitative and built upon current literature on art workshops as research and aims to unpack the methodological benefits of workshops as live improvisational spaces. This study involved four workshops held bi-weekly on Saturdays for two months. Twenty-two participants were involved, of which 17 attended only one workshop while five participants attended multiple workshops. Of the 22 participants, most were people who lived with pain, two of them were caretakers, and five were pain clinicians. Professional artists ran the workshops in conjunction with professionals with complementary skills. The research process used resembled ethnography because, through the process, the researchers learned to frame pain collectively with participants, using materials rather than language frameworks. Data was collected through videos and field notes which included things said to the researchers during breaks or at the end of the workshops, observed encounters, affective relations, comments, and discussions held with participants outside the workshop (Tarr et al., 2017).

I did not include the different activities used in the workshops as they were extensive, but some included using tools to make sounds, body movements, body scans, and drawings. These interventions are necessary because they gave people living with pain an opportunity to communicate their pain in a visual or auditory manner and not just based on an arbitrary number on a scale that doctors don't take seriously (Tarr et al., 2017). I plan to incorporate both of these

studies in my thesis on how arts-based practices can be beneficial to those living with pain not only as a means of expression but as a means of communication and as a tool to foster hope and positive emotions.

The second resource was a study that “explores the value and potential impact of a YouTube film presenting qualitative evidence synthesis about chronic pain” (Toye et al., 2020). This study was funded by the UK National Institute of Health Research to examine qualitative research about the experiences of people living with chronic pain using resources such as a film that portrayed the findings. One thousand adults living with chronic pain worldwide were included in the study. The video used in the study was called “Struggling to Be Me with Chronic Pain,” and it was about a person's loss of sense of self, lack of adequate health care, and being taken seriously with an invisible illness. The study showed that when people in the health care field watched the movie in an educational setting, it encouraged them to see the patient as a person and helped spark a change in perspective. The study intended to determine whether there was a connection between the viewer's comments in response to the film and the potential value impact for people living with pain who watched it. A methodological approach evaluated the effect of arts-based health research on people living with pain. All comments on the video were copied for evaluation. There were challenges with confidentiality, as the video was in the public domain, but several measures were put in place to protect confidentiality. These measures were that overly identifying information was removed, narratives were deconstructed and reconstructed into a composite narrative, data was rephrased if it could be traced to the source data while keeping the original meaning, and googled every individual sentence to ensure it could not be traced back to the original narrative (Toye et al., 2020). After reviewing the data, themes were used from the qualitative research as an “a priori analytic framework” (Toye et al.,

2020). Inductive thematic analysis was used to eliminate the data that did not belong in the framework. This study presents a thematic analysis of online comments to evaluate how arts-based health research impacts those living with chronic pain.

Two inductive themes were developed to explore the value and impact of watching the video, which were “it has given voice to our suffering” and “it makes me feel that I am not alone” (Toye et al., 2020). From those themes, two subthemes were added which were “first, I have had enough of me, which added insight to the theme my life is impoverished and confined; second, I am treated like a criminal because I take opioids added insight to the theme lost personal credibility” (Toye et al., 2020, p. 70). The study's findings show that watching the video can impact people with chronic illness and give their suffering a voice and give a sense of community.

The third hope-based resource focused on using ecological and hope theories and their use in creating arts-based tools and interventions for use with refugee children in inner-city Canada. The interventions used in this study include a hope quilt, narrative work, photographs, the opportunity for children to share their work, and parents and family members to have open dialogues with the children about their work (Yohani, 2008). The children in the study were given cameras to capture images in their community that brought them hope and then asked to share their thoughts surrounding the photographs. This study integrates theory and method for arts-based and hope-focused program development. It focuses on the positive effects on hope levels in refugee children when they are exposed to interventions that combine human ecology theory and hope theory. The hope project done in the study used theoretically informed arts-based tools in two ways: (1) as a method to gather data for the research, and (2) as program activities that were used to enhance levels of hope among refugee children and their families (Yohani, 2008).

Yohani (2008) described the Hope project as an Early Intervention Program (EIP) in a mid-western Canadian city. This program was run through a non-profit organization's community strengthening program created for refugee children between the ages of 6 and 18 who were thought to be "high risk." The groups for the project were run by social workers, educators, counselors, and people trained in youth/child work. Yohani (2008) received ethical clearance and consent from the parents of the children and the program staff and worked in the program for six months. The children in the program were from Sierra Leone, Iraq, Sudan, Pakistan, the Philippines, and China. Psychosocial activities were done with the children to create a safe, comforting environment that could provide healing and growth while the children adjusted to Canada. The program ran for ten weeks with one staff member assisting in facilitation and included seventeen children between 8-and 18 and twelve families. All the children who participated in the program had lived in Canada for one to four years during the study and had basic English language skills. English interpreters were available for assistance if needed (Yohani, 2008).

Before beginning the study, children were asked to "describe what hope is for you" and "describe what makes you hopeful" to provide insight into what was relevant and meaningful about hope for the children participating. The children then began the Hope Project by learning about the arts-based parts of the project they would be doing. The children participating were told that hope looks different to many people and to form their own meanings of hope(Yohani, 2008). The children explored hope and how hope can be increased by using painting, drawing, photography, and collages while working in two groups (8-12 years and 13-18 years old). After completing the work, the children wrote or dictated explanations of their work and participated

in two group interviews and one photo-assisted individual interview where the explanations of the work and art were categorized thematically to generate descriptions of hope (Yohani, 2008).

Two group interviews and one individual photo-assisted interview were conducted with children, and transcripts of interviews and written descriptions of the art were analyzed thematically to generate descriptions of hope. The 24-exposure disposable cameras allowed children to explore hope in various areas of their lives. The photographs produced by the children show that hope was found in many settings. After the children completed their photo-based art directive, they began the Hope Quilt. The children were assisted by staff in transferring their artwork and explanations of hope onto the quilt. The stories of hope that emerged were survival and escape from war, hopeful experiences such as seeing a United Nations food truck in a refugee camp, memories of playing with new friends, and cultural metaphors (Yohani, 2008).

The photo-based work and story quilt acted as tools that allowed children to cross the boundaries of time and systems and reflect on hope in their lives in meaningful ways. Stories were essential in this program, as studies have shown that hope is most efficiently expressed through personal stories. This program demonstrated how an ecological framework could influence a therapeutic environment when synthesized with a hope perspective (Yohani, 2008).

Using this approach made it more apparent that a strengths-based approach does not “imply ignorance of vulnerabilities, but instead broadens our perception to include the positive attributes of children” (Yohani, 2008). The levels of hope in the children increased, and when their families saw this, they began using more hope-based language. The use of hope-based language in community work showed that hope is a word that can be re-accessed by all participants. Creating hope connections between children and adults shows potential for empowering various communities (Yohani, 2008).

The fourth hope-based study focused on the impact of hope on the health-related quality of life of chronically ill people who are uninsured or underinsured. There are several groups of unserved people in the United States (U.S.) who experience health disparities, one of which is uninsured and underinsured adults (Wippold & Roncoroni, 2019). When discussing this group of people, it is essential to note that the uninsured refers to people without health insurance. At the same time, underinsured relates to people who have some health insurance but are exposed to the risk of financial hardship when they use their insurance or need medical care (Wippold & Roncoroni, 2019). Uninsured and underinsured people have been found to experience high rates of chronic illness, including psychiatric needs that go unmet compared to insured people. Research shows the comparison mortality odds of uninsured vs. insured people are 0.97-0.71 even when adjusting for lifestyle factors (Wippold & Roncoroni, 2019).

While this study is based on hope-based strategies, it is also related to empowerment, as hope is an empowerment-based intervention. Empowerment has been recognized as a critical factor in promoting health as it has the potential to alleviate some health disparities. Empowerment is a developmental, group-based process with which oppressed people can increase the level of control over their personal lives and environment. This includes oppressed individuals making decisions and taking action that affects their health (Wippold & Roncoroni, 2019).

Hope-based interventions are considered mechanisms of psychological empowerment. Through pathways and agency, hope is defined as the ability to achieve the desired goal. Pathways refer to the number of ways a person identifies that can help them achieve their goals, and the agency is a person's view of their ability and motivation to achieve their goals. A person

with high levels of hope has a goal, the ability to identify ways to achieve their goal, and is someone who believes they can achieve it (Wippold & Roncoroni, 2019).

The method used for this study was a survey on Amazon Mechanical Turk. The participants included 197 uninsured or underinsured adults who had at least one chronic health condition. There was diversity in age, race, and gender identity, and most participants had at least a two-year college degree. The chronic illnesses reported by participants were diabetes (type 1 and 2), arthritis, asthma, chronic kidney disease, chronic obstructive pulmonary disease, depression, anxiety, alcohol abuse, obesity, hypertension, tobacco use, and “Other” where “Other” includes chronic illnesses that were entered by participants and appeared once. The data gathered was reliable. The institutional review board approved the study of a large southeastern university in the United States. Participants completed a battery of assessments on MTurk after completing an informed consent. This study showed that a person's number of health conditions was a negative predictor, and pathways were not a significant predictor. At the same time, their level of the agency was a high predictor of health-related quality of life (Wippold & Roncoroni, 2019).

While this study had many strengths, it did have some limitations. The first was that the MTurk sample used may not represent the health of the overall population of the United States. The second limitation is that the study relied on self-reporting, and there is a chance that the participants answered questions in a way that would portray themselves more favorably. The third limitation is that the State Hope Scale has not yet been validated for use with diverse populations (Wippold & Roncoroni, 2019). Despite its limitations, the study showed that using empowerment strategies that are specific to people rather than using a "one size fits all" approach may provide the opportunity to address empowerment effectively and lower the adverse effects

of chronic health conditions among racial and ethnic minority communities (Wippold & Roncoroni, 2019).

This study showed the benefits of using an empowerment-based approach with underserved populations as historically, a deficits approach was taken with this population. Two important factors of this study explored how uninsured and underinsured people can take control of their health even when they face obstacles and the multidimensionality of health (Wippold & Roncoroni, 2019).

### **Photo-based Interventions**

Haaga's study focuses on evaluating and illustrating art therapy's effects on people with chronic pain and psychosocial comorbidities. The studies' goal is to answer three main questions, which are

1. Is there a statistically significant change in depression, stress, anxiety, self-efficacy, and physical pain after participating in an art therapy intervention for chronic pain? 2

How do participant responses help to explain the processes involved, and the types of art therapy approaches and techniques that are effective in addressing multiple dimensions of the chronic pain experience? and 3. To what extent is intervention fidelity maintained across treatment settings? (O'Neill Haaga, 2015)

An embedded mixed methods design, which included quantitative and qualitative data collected and analyzed simultaneously, was used for this study. The focus of this study was more heavily on the quantitative strand of data, which included the use of t-test analysis and measures of effect size to measure what impact the use of art therapy intervention had on the participants (O'Neill Haaga, 2015). The quantitative data showed significant decreases in self-reported pain, pain interference, depression, stress, and anxiety, with substantial increases in self-efficacy after the

art therapy interventions, were completed (O'Neill Haaga, 2015). To ensure consistency across various settings, measures of manipulation fidelity were used. The “analysis of fidelity-checklist data showed strong adherence to study directives, supporting internal validity and reliability of the intervention” (O'Neill Haaga, 2015). Client-participant artwork and comments from 109 people were gathered and analyzed for qualitative data to show and improve the understanding of the client experience. Using interpretative phenomenological analysis of client feedback, four central themes were produced: an opportunity for the visual expression of chronic pain, creating connections, relaxation and calming, and enjoyment in the artistic process (O'Neill Haaga, 2015). Manipulation fidelity was an essential part of the study, which intended to identify specific methods and techniques that could benefit people with chronic pain and give greater insight into mechanisms that drive the art therapy process. Qualitative analysis data were gathered from client artwork and provided a better understanding of the quantitative results (O'Neill Haaga, 2015). Fidelity criteria in this study were researcher-designed, so there is no information regarding validity. However, measures of manipulation fidelity showed a high rate of adherence to study directives, which enhanced the internal validity and reliability of the intervention used. There were limitations in the participant sample, which included nonrandom sampling and a lack of available volunteer art therapists. Despite these limitations, the researcher was able to build upon research previously done and create and put to use art therapy interventions for chronic pain. Measuring domains of functioning relevant to people with chronic pain and improving chronic pain assessments and treatment practices were included in the evaluation of the intervention. Clients saw an improvement in depression, anxiety, stress, self-efficacy, and perceptions of pain (O'Neill Haaga, 2015).

The second photo-based intervention study examines visual illness narratives focusing on narratives of depression. This study examined images on the internet site Tumblr. The study consisted of fourteen patients recruited from a counseling center with moderately severe depression with a mean age of twenty-seven, twelve of whom were female. The participants viewed 72 depression-related images from Tumblr during a semi-structured interview. Participants were asked to sort the images into three piles based on how much they felt each image related to them (Hussain, 2020). They were then asked to discuss each image. Six themes were identified during this process that provided insight into participants' depressive states, suicidal ideation, lifestyle changes, help-seeking, dysfunctional thoughts, and social struggles. This study provided insight into improving care for people experiencing depression using visuals of depression on social media (Hussain, 2020).

While this study did have limitations which included its use of a qualitative research method and researcher interpretations and conclusions, which may not have been without some bias, the small sample size, and its need for further research which would assess visual narratives of depression for clinically severe depressed individuals (Hussain, 2020).

Despite its limitations, this study contributes to research on visual narratives by examining how patients with moderately severe depression might use images to express their illness. The study found that visual images can allow doctors to see the world through their patients who have chronic illnesses and or disabilities eyes. This research can also help improve the clinical practice of psychiatrists and psychologists by providing them with an additional method with which to develop treatment plans relevant to a patient's daily activities and environment (Hussain, 2020). Two other outcomes of this study were that it increased understanding of what patients communicate about their mental health and helped initiate

dialogue between patients, families, and caregivers that could improve healthcare by growing support networks and increasing public awareness and knowledge about depression. The outcome of this study was the suggestion of a new mechanism for patients to use to communicate their lived experiences that can help care providers understand their perspective in a more profound way, which could improve care through policymaking (Hussain, 2020).

The third photo-based intervention studies the significant improvements to the quality of life of chronically ill patients and how it motivates them socially to communicate their thoughts and feelings through art and allows them to use creativity as a tool for social action. While the visual arts being used to assist in healing is common for those with chronic illness, it has been found to be underutilized with people with HIV (Kabel et al., 2016).

This study included eight men and 20 women living with HIV in urban areas of the Midwest, United States, as participants. The participants stated that the project gave them a "muse" and allowed them to unleash their inner artists. This helped the participants reframe their thoughts about living with HIV. This project allowed participants to express resilience through photographs, identify challenges and articulate their strengths in relation to living with HIV. The themes identified through the participant's photographs were health and wellness, overcoming fear and stigma, and personal growth and restoration (Kabel et al., 2016).

The participants in this study expressed how participating in the Photovoice project allowed them to express themselves and identify their strengths while living and coping with HIV. The participants' responses provided the researchers with better insight into arts-based public health interventions (Kabel et al., 2016). The researchers found that photography as a form of expression can be an easily accessible way to improve strength and quality of life among people living with HIV. While the study points to the benefit of creative therapies for chronically

ill patients, it specifically found that Photovoice and photography may be particularly accessible for vulnerable populations who may have a minimal amount of art experience (Kabel et al., 2016). For patients to engage in this process, the only thing they needed to learn was to use a camera if they did not know how already. This allowed Photovoice to be used as a method for artistic expression and healing. One of the researchers' themes in the participant's work was striving for health and wellness that goes beyond physical fitness and includes medication adherence, coping with the loss of memory, and struggling with paperwork for medical insurance and medical bills (Kabel et al., 2016).

This study did not have many limitations other than its need for further research. This study focused on resilience; however, the researchers state that photovoice is flexible, and each participant's response to it was varied. The researchers noted it would be beneficial to study possible additional outcomes such as the impact on mental and psychological health. This study was based on small sample size and would benefit from future research with a more significant number of male participants (Kabel et al., 2016).

Photovoice in this study provided an anonymous and easily accessible way for people living with HIV, an extremely stigmatized illness, to express themselves in daily-life settings by creating art. Through photographs, participants were able to discuss different issues and experiences that may not have otherwise been discussed (Kabel et al., 2016). The themes that emerged from their work were restoring a threatening identity, fear, shock, stigma, and health and wellness. The researchers suggested that health professionals and health interventions should include Photovoice to gain more insight into the lived experience and resilience amount vulnerable populations such as people living with HIV. While the sample size was small for this study, despite that limitation, this study was able to show the benefits of using Photovoice

interventions to assist vulnerable populations in empowering themselves, increasing their resilience, and improving their quality of life (Kabel et al., 2016).

### **Empowerment Based Interventions**

The first empowerment-based intervention study was focused on keeping people with a chronic condition in the workplace using vocational rehabilitation and the characteristics, effectiveness, and feasibility of these interventions to find which are most helpful. This study was conducted by looking at previous studies where the criteria for inclusion were if the study was experimental, if it included an intervention that's purpose was to maintain employment through solving problems in the workplace, used an empowerment framework, and included employees with chronic illnesses such as diabetes, rheumatic diseases, hearing disorders, inflammatory bowel disease, multiple sclerosis, epilepsy, COPD, asthma, and or kidney failure (Varekamp et al., 2006).

The researchers identified nine relevant studies where the goal of the interventions was to implement work accommodations or improve psychosocial skills. The studies included individual and group programs and focused on methods that included assessment, counseling, training, role-playing, and education (Varekamp et al., 2006).

The limitations of this study were that while the studies included showed effectiveness, the evidence was considered weak due to the short time frame of follow-up and the lack of control groups, and the need for more evaluation. Despite the limitations, they found that the most critical outcome measures were the actions taken to arrange work accommodations, self-efficacy, social competence, and employment status and that there is some evidence that vocational rehabilitation interventions that focus on training in how to request work

accommodations, feeling of self-confidence, self-efficacy, and solving work-related problems are effective in keeping people with chronic illnesses in the workplace (Varekamp et al., 2006).

The second empowerment-based study focuses on how to empower patients with chronic illness. This study mentions previous studies that have found the factors contributing to communication between patients and their health care providers. These factors are patient impact, meaning, information provision, emotional support and active listening from healthcare professionals, and trust and patient collaboration (Suárez Vázquez et al., 2016).

This study found that some patients may need to be empowered differently. It proposed a model that could detect the type of patients who may live their empowering experiences differently. In a study of 181 patients with hemophilia, the researchers found two types of patients, some who had an inner locus of empowerment and some with an outer locus of empowerment. Due to these findings, they found that different strategies for fostering empowerment within these patients may be more effective than the size fits all approach (Suárez Vázquez et al., 2016).

For the patients with an inner locus of empowerment, the study's findings showed that their self-perception of their empowerment was improved with increased levels of illness involvement. Illness involvement includes participation in the patient's treatment and advocacy in the communities of people who have the same illness. However, the study showed that the patients who held higher trust in their physicians showed lower empowerment self-perception. Patients with an inner locus of empowerment believe their ability to manage their illness is controlled by themselves (Suárez Vázquez et al., 2016).

Patients with an outer locus of control are aware of the importance of their involvement in their illness treatment but do not attempt to impact other patients with the same illness. The

trust these patients have in their health care providers and their collaboration with them improved their empowerment self-perception. They were found to trust their providers and collaborate with them, which helped them want to take control of their health but did not want further information about their condition and would distance themselves from providers if they believed they were being spoken to with condescension (Suárez Vázquez et al., 2016).

These findings were significant because they showed that the level of trust between providers and patients only shows a positive effect on empowerment self-perception in those with an outer locus of empowerment. This study had several limitations, including the fact that only psychological empowerment was considered, cultural factors were not considered, individual temperament was not considered, and how patients' perceptions change throughout the life cycle of their illness were not considered (Suárez Vázquez et al., 2016).

Even when considering the study's limitations, the results show that when assessing patients' self-perceptions surrounding empowerment rather than preferences, only patients with better health conditions showed that trust in their health providers had a negative influence. In the outer locus of the empowerment group, confidence in their provider positively affected their empowerment self-perception. With that considered, they found that reinforcing the importance of the motivational dimension of their jobs should be the focus of health providers and professionals rather than the focus on information provision (Suárez Vázquez et al., 2016)

The third empowerment-based study focuses on using a person-centered intervention to empower self-management and health for people living with chronic conditions. The researchers looked at implementing an empowerment-focused person-centered intervention called the Bodyknowledging Program by healthcare providers. They evaluated its impact on people living with chronic conditions, focusing on their health and well-being (Heggdal et al., 2021). The

study found through healthcare professional interviews that the intervention supported health-related patient outcomes in four ways, by addressing the whole person, through hope and affirmation, through social support and revitalized relationships and through expanding recovery (Heggdal et al., 2021). In addition, they found that the person-centered, empowerment-focused intervention assisted patients with understanding the social, emotional, and physical impact of their illness through new tools. Through this understanding, health care providers gained insight into increasing patient engagement and promoting health for their patients (Heggdal et al., 2021). This study was valuable as it showed that the Bodyknowledging Program increased patient engagement by using patient-centered care while improving the patients' ability to use their resources to manage their health better while living with a chronic illness (Heggdal et al., 2021). When looking at the findings within all of these articles about the use of hope-based, photo-based, and empowerment-based interventions, it is evident that there is substantial research on how different art interventions can benefit chronically ill people therapeutically. This pertains to my research as I am exploring the effects of combining all three as a method on levels of hope, anxiety, depression, and purpose. The gap in research my method fills is in using hope-based, photo-based, and empowerment-based interventions together to empower and support those with chronic illness. Additionally, research and method making by others could potentially benefit various populations.

### **Methods**

I facilitated a photo-based empowerment art therapy group called “Empowerment for Chronic Conditions” for six weeks with students who live with chronic illness and or chronic pain and worked with them using empowerment theory and phototherapy interventions. The students who participated attended the university at which I interned. Clients at the site had

access to information regarding which groups were running each quarter and could choose to sign up. During the 6-week program, I used evaluations at the beginning of each session to measure the effectiveness of the interventions on this population. I later realized that this assessment would be more effective if given a pre-and post-assessment during each session due to outside factors that could influence the results between sessions. The clients rated their depression, anxiety, hope, a sense of purpose, and feelings of empowerment in each assessment. The data was collected on Google forms and was separated by each week.

When I was running my group, I maintained a Word document throughout this process, where I added notes about each session, what was successful, what could be improved in the future, any ideas clients suggested, things I learned, and any other relevant information I gathered. I had a section for each week in this document where I wrote about what I experienced and felt each week throughout the process, and I updated this document after each group session. I completed the art directive for each week and added my artwork to this document to use as examples. Before beginning the group, I had a hunch that the students would get along well and would be able to form a greater sense of community on campus after meeting each other. I had some speculation about attendance as attendance was low across all groups due to Covid. I was hopeful, however, that the attendance of my group would be sufficient due to it taking place on zoom. After the group began, I gained insight into the accommodations process on campus. The struggles this particular population of students experienced and the gaps that need to be filled for these students on this campus.

Each of the six sessions were formatted similarly to produce a feeling of stability and set expectations among the participants. Each session began with a brief meditation, then moved into a short tutorial on Pixlr, the online photo editing program the clients used to create their

artwork between sessions. During several of the sessions, all participants voiced having a thorough understanding of Photoshop and not needing a tutorial on Pixlr, so we did not do the tutorial during those sessions. In all but week one, after the tutorial or when we would have done one, clients shared the artwork they created that week, and we discussed what came up for them as they discussed their artwork. During week one, the clients did not receive their art directive until the end, so therefore, they did not share art during that session; instead, they shared their histories and experiences. Afterward, they discussed one or two relevant coping skills that they could add to their coping skill toolbox if they felt they fit their needs. We then moved into a short group discussion on ways it could be possible to change policy or increase accessibility in their personal lives, communities, and organizations. One example would be clients forming a club or advocacy group at the university for people living with chronic conditions. We ended each session with a grounding exercise and information about the following art directive. The clients worked on the art directives at home during the week between sessions and brought their work to the next session each week.

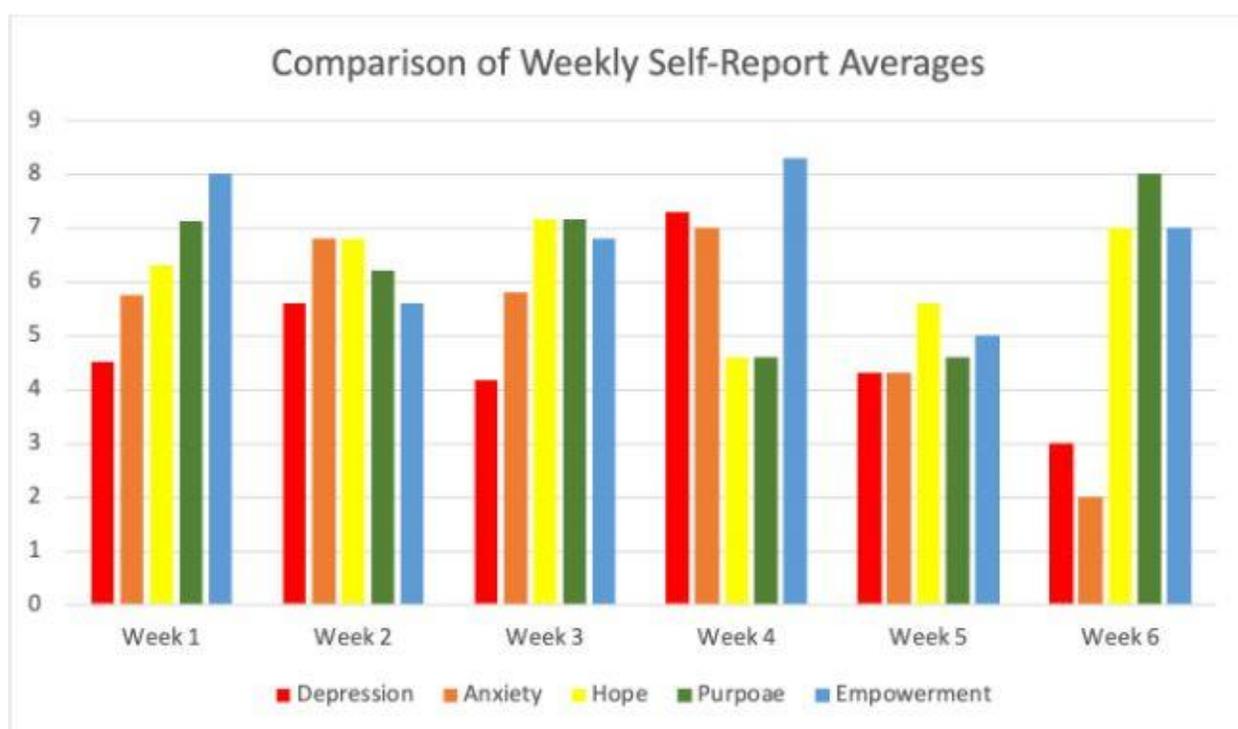
## **Results**

The results for this group were collected in Google forms and later entered into a spreadsheet. When the group ran, attendance varied greatly from session to session. Due to the quarter system at the site and the timing of finals for the students, the group could only meet for six weeks rather than the planned eight weeks. Upon viewing the average of the participant survey results, a reduction in depression and anxiety levels can be seen over the six weeks. Levels of hope were relatively high toward the beginning of the group meetings, then levels dropped for two weeks, then rose again on the last week of the group. A similar trend can be seen in the participants' feelings of purpose and empowerment ranks. The participants used their

own photographs and stock photos to create photo collages as responses to weekly prompts given at the end of each session. Due to confidentiality the work of the participants is not shown here. Overall, the group appeared to help reduce feelings of anxiety and depression among the participants and showed potential for helping to increase feelings of hope, purpose, and empowerment, but further research will be needed.

### Figure 1

*A graph showing the weekly average of participant assessment results*



### Discussion

Empowerment for Chronic Conditions is the title of the group I created and ran for six weeks at a local creative arts university. The group focused on the use of empowerment and photo-based interventions with students living with chronic illness and chronic pain. To be accessible to all participants, the group took place on zoom. A self-assessment was given at the start of each session upon which students reported their current levels of anxiety, depression,

hope, purpose, and empowerment. The purpose of this group was to create a supportive space for students living with chronic conditions where they could feel seen, heard, and empowered. At the end of the six-week period, students showed lower levels of anxiety and depression.

Despite the challenge of students adjusting to life on campus post Covid, which led to lower group attendance, I was able to successfully run the group for six weeks. My goals and desired outcomes were to provide an inclusive environment where clients felt seen, heard, and safe to share their artwork, experiences, feelings, and symptoms with other group members. Through the experience of being with others who are also living with chronic conditions, my hope was to enable clients to build community and resources that would better help them navigate daily challenges they may face in the future. The environment of the group was supportive, validating and promoted self-advocacy and empowerment.

My anticipated outcome was that clients would experience lower feelings of anxiety, depression, and hopelessness and increased feelings of hope, purposefulness, validation, and empowerment using phototherapy. Like O'Neill Haaga's (2015) study that showed an improvement in stress, anxiety, self-efficacy, perception of pain, and depression in participants, my study resulted in participants experiencing decreased levels of depression and anxiety.

While I realized the assessment I created needs to be given pre-and post-session to fully measure the effects of the group on clients each week, based on the results I did have as well as participant feedback, the group was helpful to clients in reducing anxiety and depression, increasing advocacy and empowerment, and giving clients a space where they felt seen, heard, and supported. The authors Heggdal et al (2021) mentioned in their study that using the Bodyknowledging program, increased patient engagement by using patient-centered care while also improving the ability of patients to use their own resources to better manage their health

while living with a chronic illness. I found that including conversations surrounding advocacy, empowerment, and using a systemic and person-centered approach, increased participant engagement and improved the participants ability to use their own resources to better manage their health as well. Participants in my group shared various tools, resources, and treatments with each other. During one of the sessions, the participants made their own Discord for students on campus living with chronic conditions, which they went on to use once the group was complete. This Discord gave them a place to support each other, vent, share referrals, resources, tools, self-care ideas, and help each other advocate for one another and themselves.

I hoped that this group would provide additional insight into the first-hand experiences of people living with chronic conditions. As a future counselor, I plan to provide a space for this population to express the feelings, pain, disenfranchisement, loneliness, depression, anxiety, and hopelessness, that often comes with living with a chronic condition.

My outcome showed that using hope-based, empowerment-based, and photo-based interventions may be a helpful and healing component to add to the treatment plan of people living with chronic illness. For others thinking about researching this topic, I would suggest examining if this method is as effective for seniors living with chronic conditions. After running this group, I have a better understanding of which resources, interventions, and types of advocacy would work best for providing practical, validating, and empowering future treatment plans.

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