

Impact of an Art Therapy Program for Those with Thyroid Eye Disease and Care Partners

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As a low vision child I struggled in school art classes and was quick to tell people “I don’t do art.” Over the years I yearned to learn to throw on a wheel, and finally I put my “I don’t do art” attitude aside and enrolled in a pottery class in 2020. It has been a wonderful experience. I have pride that as a low vision person, I’ve had the confidence to ask for support from my instructors, adapt techniques as needed, and try something out of my comfort zone. Pottery has provided me with an emotional outlet and joy as I have created pieces for others.

In November 2023, Jeff Todd, the CEO of Prevent Blindness, invited me to evaluate the impact of their Art Therapy Program on past participants and cultivate recommendations from participants that can assist the organization as they continue to offer and, hopefully, expand the program. Launched in spring 2022, the Art Therapy Program was designed for those with thyroid eye disease (TED) and their care partners.

Art Therapy

On their website, the American Art Therapy Association (n.d.) explains:

Art therapy, facilitated by a professional art therapist, effectively supports personal and relational treatment goals as well as community concerns. Art therapy is used to improve cognitive and sensorimotor functions, foster self-esteem and self-awareness, cultivate emotional resilience, promote insight, enhance social skills, reduce and resolve conflicts and distress, and advance societal and ecological change. . . Through integrative methods, art therapy engages the mind, body, and spirit in ways that are distinct from verbal articulation alone.

Art therapy has benefited individuals from diverse groups including those isolated during COVID-19 quarantine (Ahn & Park, 2021), those experiencing depression

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(Blomdahl et al, 2021), refugees (Feen-Calligan et al, 2023), and those with Alzheimer's disease (Marco & Redolat, 2023). In studies, art therapy was found to provide a way for individuals to express themselves and cope with stress (Ahn & Park, 2021; Feen-Calligan et al, 2023; Marco, & Redolat, 2023). For those who experienced isolation, art therapy had a positive impact on participants' self-esteem (Ahn & Park, 2021; Feen-Calligan et al, 2023; Geréb Valachiné et al, 2023).

Art therapists provide participants directives that encourage them to think and reflect. The directives are designed to elicit emotions while building participants' emotional well-being (Ahn & Park, 2021; Becerra et al, 2021; Feen-Calligan et al, 2023; Geréb Valachiné et al, 2023; Marco & Redolat, 2023). Art therapy assists participants to gain skills that enable them to deepen relationships with others (Feen-Calligan et al, 2023). Art therapy sessions do not have to be conducted in person; there have been studies documenting positive outcomes when art therapy sessions are conducted using online web conferencing (e.g., Ahn & Park, 2021; Feen-Calligan et al, 2023; Geréb Valachiné et al, 2023).

Thyroid Eye Disease

TED is an autoimmune disease occurring in approximately 40% of people with Graves' Disease, which is an autoimmune disease (Burch et al, 2022). Symptoms of TED may include swelling of the eye, photophobia, diplopia, excessive tearing, dry eyes, and feeling as if something were in the eye (Burch et al, 2022; Smith et al, 2023). Those with TED are a heterogenous group with the impact of the disease on the individual's health and quality of life varying tremendously (Sharma et al, 2022; Smith et al, 2023). TED can impact an individual's ability to complete daily tasks, for example, reading, driving, and engaging in outdoor activities (Sharma et al, 2022). The change in appearance of one's eyes may cause the individual to withdraw from social opportunities (Sharma et al, 2022; Smith et al, 2023). TED symptoms can improve or worsen over time with each individual's symptom trajectory varying (Smith et al, 2023).

TED Art Therapy Group Hosted by Prevent Blindness

Prevent Blindness hosted an online eight-session art therapy series for those with TED and their care partners (e.g., spouses, children, close friends), Each session was divided into three segments as part of an open studio model for art therapy. The first portion, greetings and intentions, lasted approximately 30 minutes. During this time, participants were provided the opportunity to greet each other and share personal updates, the art therapist reviewed the materials to be used, and participants set a goal for the session. The next portion of the session was used for art making.

Participants spent an hour exploring the art materials and creating in whatever capacity felt right to them based on the directive provided by the art therapist. The last 30 minutes was devoted to the third segment, witnessing, which gave participants the opportunity to share their own artwork and observe and connect with the artwork of other members of the group.

For each session, the art therapist provided a directive to participants to help guide the art-making process. These directives focused on a variety of concepts designed to help participants express and process emotions and experiences resulting from TED. For example, one directive, titled “Letting Go,” encouraged participants to write about something they wanted to let go of or move on from. This could be done in the form of a letter “Dear TED,” or through words, phrases, a journal, entry, etc. Once the writing felt complete, the participants were encouraged to tear up their writing and use the pieces of it to create a work of art. In addition to the torn paper, participants could use any other materials they wished—other decorative papers, paints, pastels, etc.

Another popular directive, usually done toward the end of the series of sessions, asked participants to decorate a paper mask. On the inside of the mask, they were asked to depict how they felt at the beginning of the art therapy series and on the outside of the mask how they felt after completing the art therapy series, or how they saw themselves on the inside vs how they felt others saw them from the outside. They were encouraged to use lines, shapes, colors, and textures, along with a variety of mediums (paint, pencils, papers, craft supplies, etc.) to illustrate their thoughts and feelings based on the prompt.

Focus Groups

I met with Prevent Blindness staff and the coordinator of the art therapy program. I prepared focus group questions. An announcement about the study was sent to individuals who had completed at least one art therapy series. In January 2024, I conducted four focus groups with 11 individuals. Ten of the individuals had TED and one was the spouse of an individual with TED. The study was not approved by an Institutional Review Board; however, each participant completed a consent form prior to the focus group. Below I share some of the study findings. I end with a section on implications for practitioners.

Self-Reflection Is Powerful

All participants shared that taking part in the Prevent Blindness Art Therapy Program provided them the opportunity to engage in self-reflection. One participant, who had TED for many years, reported that until she was led by the art therapist through a scribbling exercise, she didn’t realize how much anger she had bottled up inside of her. Another participant shared that the mask activity previously described

was powerful for her. The inside of her mask was dark and had a person hiding all by herself while the outside was bright with flowers and birds. In reflecting on the mask, the participant came to recognize how much of herself she was hiding from others.

Sharing Common Experiences Provided Perspective

TED can be an isolating disease due to feelings of self-consciousness since one's face looks different and/or because of the severity of symptoms that make it difficult to be in varying lighting conditions. Participants found others in the Art Therapy Program understood what they were experiencing because they too had or were impacted by TED. During sessions one could empathize with others and also learn about their experiences; for example, potential side effects caused by medication or the recovery period from surgery. Several participants commented that talking with other members of the Art Therapy Program provided a different outlet for them than speaking with those in their personal network had provided. For some participants, by the completion of the series, they had changed how they viewed the disease.

Engaging in Art Improved Participants' Emotional Well-Being

Whether an individual had little or no experience with art or was themselves an artist, the Art Therapy Program had a positive impact on participants' emotional well-being. Several participants found that the time they engaged in art allowed them to let go of the day-to-day thoughts and feelings they were experiencing due to TED. They found that creating art allowed them to discover things about themselves. One participant shared that she had dressed in blacks, whites, and grays prior to taking part in the program. Through art she had discovered color and as a result now dressed in colorful clothing and even noticed the color and textures of foods in a different way. For some participants, the Art Therapy Program helped them shed the embarrassment they felt about having TED so that they were now able to talk more freely with others about the disease and its impact on them.

Some participants noted negative feelings that occasionally emerged from the hearing about the challenges others faced due to their TED symptoms or medical interventions. A few participants questioned if things would get worse for them. Sometimes the negativity of other group members' comments caused participants to feel anxious or depressed. These negative feelings, however, were balanced for them by the positive aspects of the Art Therapy Program.

Letting Others Know What You Are Experiencing Is Important

The Art Therapy Program helped some participants learn how to explain to others about TED and the symptoms they were experiencing. After hearing about others'

experiences with a TED medication, one participant recognized that the physical symptoms she was experiencing were side effects of the treatment. She then discussed these side effects with her physician. The husband and wife who took part in focus groups reported they now each had a deeper understanding of the other's experience with TED. After taking part in the Art Therapy Program together, they each reported they were better able to communicate with each other about the impact of TED on themselves and their family. Several parents of younger children reported they shared the materials and activities with their children. While engaging in art with them, they were able to discuss the feelings their children were experiencing about having a parent with TED.

Implications for Practitioners

Art therapy, therapeutic arts, and art making offer us the opportunity to express what we cannot say in words. This allows for a sense of relief, self-understanding, and the ability to accept that not everything is under our control, which in turn can relieve stress. (Helmick, 2023, p. 328)

Taking part in an art therapy program, or another creative therapeutic program such as music or dance, can benefit those with visual impairments and those in their personal networks who support them on their journey with low vision, blindness, or dual sensory loss. As professionals, we should seek out resources in our community that allow individuals to explore their feelings and improve their emotional well-being. We may also need to provide support to therapists who are unfamiliar with ways to adapt activities for those who are visually impaired.

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