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Using Community Drama Therapy to Support Adults with Crohn's Disease and Ulcerative Colitis

A Capstone Thesis

Lesley University

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Clinical Mental Health Counseling and Drama Therapy

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Abstract

This master's thesis explores a drama therapy community engagement project, conducted in February 2020, intended to serve a population of chronically ill adults. Specifically, it was implemented for those who have been diagnosed with inflammatory bowel disease (IBD). IBD is a combined term for Crohn's disease or ulcerative colitis, autoimmune diseases of the gastrointestinal tract. Crohn's and colitis can cause debilitating symptoms; some of which include pain, frequent diarrhea, and vomiting, while also affecting other organs in the body (Crohn's and Colitis Foundation, 2014, p. 9). The chaos of having a chronic illness can contribute to anxiety, depression, and other mental health conditions (Crohn's and Colitis Foundation, 2014). Community drama therapy offers an embodied, playful form of support to help bring humor, self-expression, and relationship-building to ease the isolation of having a personal and often embarrassing illness.

Keywords: crohn's disease, ulcerative colitis, chronic illness, drama therapy, expressive arts therapy, improvisation, therapeutic theater, drama, theater, play, games, humor, community, relationship building, workshop, therapeutic, embodied, mental health, role

This thesis is dedicated to all of the children, teenagers, and adults who wake up every morning and face the day living with a chronic illness. They continue to live their life in spite of pain, fear, sadness, frustration, and health circumstances beyond their control that affect them every day. You are an inspiration to me, and to us all.

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I thank Elaina Repucci and the Crohn's and Colitis Foundation for helping me to make this project a reality. With everything from marketing and distributing flyers, to first giving me backing about my thesis idea, their organization has been an essential resource for me in my research as well as execution of my idea. I thank all of my workshop participants who jumped heart first into this experience without knowing what to expect. They made this project a reality.

I am also eager to thank my drama therapy cohort, as well as the cohorts that came before me, who inspired me, gave suggestions, and bring their creativity, brilliance, and desire to spread drama therapy and expressive arts therapy to the world. I also thank my loving family, friends, and partner for believing in me and for motivating me. I will forever spread the power of art, drama, music, and joy to my future communities. Thank you for reading.

Introduction

Children and adults with chronic illness face a wide range of emotional and medical challenges (Crohn's and Colitis Foundation, 2014). The pervasiveness of chronic illness in the United States is continuing to develop, and it is anticipated that 157 million Americans will be living with at least one chronic condition by 2020 (Bodenheimer et al., as cited in Kaynan and Wade, 2018 p. 10). Individuals with inflammatory bowel disease (together known as IBD), which include Crohn's disease and ulcerative colitis, can experience debilitating symptoms of pain, diarrhea, bleeding, vomiting, weight loss, and extreme fatigue (Crohn's and Colitis Foundation, 2014, p. 4). Additionally, unpleasant side effects from medications such as corticosteroids can result in weight gain, bone loss, and mood swings, among others (Crohn's and Colitis Foundation, 2014, p.14). In 2017, there were 6.8 million cases of IBD globally (Alatab et al., 2019, p.17).

Crohn's can affect any part of the gastrointestinal tract while ulcerative colitis is restricted to the large intestine: the colon. (Crohn's and Colitis Foundation, 2014, p. 4). Additional complications can also exist outside of the gastrointestinal tract, affecting other organs of the body, like the liver (Crohn's and Colitis Foundation, 2014, p. 7). Crohn's and Colitis, while commonly lumped together under the umbrella term IBD, or confused with IBS (Irritable Bowel Syndrome), are quite different with their own unique pathologies.

The treatment process for Crohn's and colitis can fluctuate between cycles of active disease and periods of remission, with little or no symptoms. Flare ups more commonly referred to as "flares," mean the disease is active, while remission refers to when symptoms of the disease are inactive. "To date, there is no certain cure for IBD, and treatment is aimed at managing the inflammatory response during flares and maintaining remission with a focus on

adhering to therapy” (Sajadinejad et al., 2012, p.1). Some patients can be in remission for many years at a time, while others struggle to keep the condition under control (Crohn's and Colitis Foundation, 2014, p. 6). “Chronic IBD requires prolonged observation, periodic adjustments in therapy, and colonic and radiologic surveillance” (Kirsner, 1991, para 6). Patients often try countless prescriptions, experience hospitalizations, and sometimes are required to have multiple surgeries.

Medications and the trauma of having the disease can also cause depression and anxiety due to the personal, unpredictable nature of the condition (Crohn's and Colitis Foundation, 2014). The combination of medical symptoms can pose questions surrounding identity, relationships, body image, abilities, and one's sense of self. Having a chronic illness not only wreaks havoc on the body but can also affect one's self-esteem and confidence (Sajadinejad et al., 2012). “Throughout the adjustment process, patients may feel frustrated, sad, develop fears, miss work, and avoid social events and traveling due to the relapsing and remitting course of IBD” (Kiebles, Doerfler, and Keefer, 2010, p. 1685). Therefore, having IBD can certainly negatively impact one's quality of life.

In my experience, having chronic inflammatory bowel disease is a condition that is often kept hidden. People with access to mental health resources can learn to advocate for themselves and their disease, to articulate their needs in school, friendship, and dating. They can begin to feel more in control of their bodies and their selves, even when they are feeling emotionally obliterated and physically exhausted. In my experience, counseling and the arts were integral to my coping process. Furthermore, in my experience, when my bowels were out of control, that translated into me feeling out of control in my life. Casati and Toner (2000) studied IBD patients in relation to beliefs about personal control. Casati and Toner (2000) concluded that “Some

participants found that being unable to control and predict the course of their condition was distressing” (para 4). The concept of control in this disease can be a paramount factor in contributing to psychological anxiety.

I arrived at this community engagement project having lived with ulcerative colitis for twenty-one years. Navigating my journey with IBD gave me empathy to help others who were struggling with painful experiences. It ultimately led me on the path to pursue a license in mental health counseling and a credential as a registered drama therapist. In my own life, theater was my safe haven where I was surrounded by community, could express myself, and cope with my medical trials. In my experience, being diagnosed with a chronic illness led to feelings of powerlessness, resentment, sadness, confusion, and the mourning of not having a “normal” life. The Crohn’s and Colitis Foundation (2014), a resource that many patients depend on for essential advice, states:

Symptoms of IBD can flare up unexpectedly and can be...uncomfortable, inconvenient, and embarrassing...Some...patients react to the unpredictable and sometimes severe nature of IBD symptoms with feelings of anger, anxiety, or fear....Mental health counseling and support groups can be extremely helpful in dealing with the psychological impact of IBD. (p. 18)

In summary, the Crohn’s and Colitis Foundation advocates for mental health treatment as being part of a medical plan for patients.

I define medical trauma as trauma resulting from consistent exposure to medical experiences. In the field of trauma, medical trauma in our clinical scholarship is frequently overlooked. The physical and psychological impact of having IBD can lead to medical trauma in patients. For example, “Despite high levels of anxiety and depressive symptoms and poor quality

of life, psychiatric complaints in IBD patients were undertreated. Screening for and treatment of psychiatric symptoms should become an integral part of IBD medical care.” (Bennebroek Evertsz et al., 2012, p. 68). Medical doctors often focus on the biology of the disease and not the emotional impact, and often overlook counselling and psychological services as an intrinsic part of a patient's intervention plan.

My primary objective in creating this community engagement project was to witness firsthand as a facilitator how community drama therapy could support adults with Crohn's and colitis. I hoped to learn if my workshop would be authentic and engaging to patients. I was curious to see how an embodied form of creative expression like drama therapy might facilitate discussion, humor, and play for adults with IBD. As I suspected, the activities provided a lively and authentic group process. I witnessed people, who had not known each other before, able to connect and be honest about their shared experience.

Rationale for Drama Therapy

When considering what kind of therapeutic techniques might be most effective in addressing the need for mental health in the chronic illness population, drama therapy is a valuable choice. According to Emunah (1994), “Drama therapy is the intentional and systematic use of drama/theatre processes to achieve psychological growth and change. The tools are derived from theatre, the goals are rooted in psychotherapy” (p. 3). Drama therapy is a useful approach because, it is an active, embodied process that offers a way to combat distress by the simple act of engaging in play with others. While traditionally, “... a variety of studies suggest that IBD patients rely significantly on passive coping strategies” (Sainsbury and Heatley, and Casati et al. in Sajadinejad et al., 2012, p. 3), drama therapy offers an active form of support that

invites the body, as well as the mind, to experience drama and community building exercises in relation to treatment goals.

In drama therapy, Johnson (2009) defines the concept of the playspace, which is the experience where both client and therapist join together to process life and challenges. The playspace is referred to within a particular type of drama therapy intervention, called Developmental Transformations (DvT), in which therapist and client use improvisation together to process therapeutic content. Johnson (2009) explains that “The playspace is a mutual agreement among the participants that everything that goes on between them is a representation or portrayal of real or imagined being” (p. 93). Therapist and client play together during the session, to understand themselves and their feelings better. The playspace serves as a container for what will be taking place within the session. However, the concept of the playspace has permeated through drama therapy as a whole, signifying its importance as a space where activity is created.

In my drama therapy training experience, I observed the playspace as adaptable and constantly in flux, changing with each moment. It provides a release from the daily conventions of routine, and traditional talk therapy. For someone with a chronic illness, the playspace can be liberating. In my experience, IBD patients are tired of being labeled as “the patient.” They are in need of feeling strong, silly, and playful. Drama therapy provides a collaborative space where everyone in a group can be playful at the same time. We can situate this in what Emunah (1994) described as “the playing field.” The intention is that nobody is mocked if everyone is participating in the same goofy exercise (Emunah, 2009, p.51). In a game where everyone has to play the same way, there are no outsiders to the rules and standards.

Additionally, my community engagement project draws on sociodrama which encourages a group to work together to identify questions, topics, and common feelings. In the case of chronic illness, sociodrama can provide a container to help build similarities in group exercises. Themes of group activity are created through commonalities of a particular group, rather than focusing on the individual. The focus is what members of a group share, which can then lead to therapeutic exercises, self-discovered by the group. (Sternberg and Garcia, 2000).

Literature Review

The following review of literature is divided into six subsections that situate my thesis in theoretical and historical context. The review considers 1) the connection between inflammatory bowel disease and mental health, 2) drama therapy as a modality of intervention with a focus on Landy's role theory and method, 3) drama and expressive therapy in the medical and chronic illness setting, and 4) IBD arts-based research and performances.

Mental Health Issues in IBD

It is evident that scholars have extensively investigated the intersection between inflammatory bowel disease and psychological health, with the majority of studies being quantitative. One particularly noteworthy study by Sajadinejad et al., (2012) provided both quantitative and qualitative research that highlighted a variety of themes surrounding mental health issues in IBD. In the research the scholars identified multiple studies regarding the role stress plays in psychological health for those with IBD and the way stress can trigger symptoms. Sajadinejad et al., (2012) also discussed how those with IBD are using negative coping mechanisms (p. 1).

Sajadinejad et al. (2012) situate mental health factors in IBD within a historical context. Keefer et al., (as cited in Sajadinejad et al. 2012) clarify that the link between psychology and

IBD first began to be studied in the 1930s when “gastroenterologists and psychiatrists suggested that emotional life events and experiences are likely related to exacerbation of intestinal symptoms” (p. 1). However, other studies pointed to other factors like personality also being connected to development of the disease (Sajadinejad et al., 2012).

One noteworthy statistic according to Addolorato et al., (as cited in Sajadinejad et al., 2012), demonstrated that “The prevalence of anxiety and/or depression has been estimated to be as high as 29–35% during remission and 80% for anxiety and 60% for depression during relapse” (p. 4). There is no doubt that having a chronic illness such as IBD frequently connects to a patient’s mental health. In fact, Graff et al. (2012) (as cited in Sajadinejad et al.) claim that the triggers from the experience include fears surrounding procedures and surgery, cancer risks, and the fact that the illness is uncertain and lifelong, without a cure. IBD is unique in its remission and flare up nature which creates a true sense of impermanence.

Furthermore, there are a number of quantitative studies which sought to measure how IBD affects mental health, and more specifically, quality of life. Sewitch et al. (2001) used a cross-sectional study to analyze the mental health condition of patients in flare ups and remission of disease to consider how social support may help them cope (p. 1470). They measured 200 patients with an average age of 37 years old who all had long lasting severe IBD. (Sewitch et al., 2001, p. 1470). Results indicated that patients’ self-reported social support was helpful to their mental health. Furthermore, if a patient recognized moderate to high stress in their lives, then comfort from social supports were indicated. However, if the patient recognized low levels of stress, then social support was not a factor to increase mental health (Sewitch et al., 2001, p. 1470-1471).

Lix et al. (2008) took a holistic approach in creating a longitudinal study where they measured mental health for patients in flare ups, fluctuating disease, and in remission in regard to disease activity. The study assessed 388 recently diagnosed patients in Manitoba. Each patient sent in a survey by mail every 6 months each year, for two years (Lix et al., 2008). Results indicated that those with alternative patterns of disease showed substantial increase in quality of life as related to their IBD, contrasted with patients that were actively sick who did not see those benefits (Lix et al., 2008).

The conclusions of the study indicated that quality of life improvements are a result of the patterns of disease flare ups and remission. However, mental health more generally was not affected by the fluctuation of disease (Lix et al., 2008). This is noteworthy because it suggests that the permanent nature of chronic illness affects mental health even when not in active disease, because a patient may be anxious about getting a flare up (Lix et al., 2008).

There were numerous other studies found investigating the quality of life for patients with inflammatory bowel disease as it relates to psychological health. Guthrie et al. (2002) also considered whether disease severity influenced quality of life and psychological functioning, and if Crohn's disease is linked to more psychological issues than ulcerative colitis. Mikocka-Walus, et al. (2008) also studied quality of life and mental health comorbidity with IBD. They found that patients with "no functional gastrointestinal disorders had significantly better physical quality of life than those with more than two functional gastrointestinal disorders" (p.475).

In addition to quantitative studies which refer to the prevalence of mental health in IBD, there are also studies that consider how providing care relates to the larger economy and finances of health care systems. Lores et al. (2020) investigated the case for offering mental health treatment to the IBD population. There is a "high psychosocial burden and economic cost" in the

treatment of patients with IBD (Lores et al., 2020, para 1). The study revealed that providing mental health services into “routine management” in the health care setting could lead to smarter financial patterns and money saved (Lores et al., 2020, para 1).

Lores et al. (2020) conducted a two-year study with a sample size of 335 patients receiving medical care at an IBD department in a hospital in Australia. Patients completed screening instruments to assess well-being and psychological health (Lores et al., 2020). Additionally, “data on healthcare use and costs for the previous 12 months were also collected. Patients found to be at risk for mental health issues were offered psychological intervention and were followed up 12 months after screening” (Lores et al., 2020, para 2). Lores et al. (2020) indicated that the results showed emergency room visits decreased when psychological intervention increased for people with IBD in one-year periods. This quantitative study supported the essential need for mental health for the IBD population.

Drama Therapy and Role

When considering certain theories within drama therapy that can help guide practice with the IBD population, role theory is a strong fit. From a drama therapy perspective, Landy (2003) views the human experience as one filled with the various roles we play in our lives from day to day. Landy (2003) argues that through drama therapy and engaging with the taxonomy of roles, (his system for identifying various roles), we can begin to expand our role repertoire (p.151-152). Individuals can do this by participating in drama therapy exercises that invite them to pretend to be roles other than the ones they are used to; they can expand their sense of self. Landy (2005) suggests: “the aim of drama therapy treatment is to help people find a balance between their contradictory roles, such as that of the victim and the survivor, and to learn to live

with their role ambivalences” (p. 96). Therefore, we can start to see ourselves as a multitude of various roles, which is an essential part of being human.

Landy (2003) created role profile cards as an assessment tool, within his larger system of role theory to help explore the roles that each person plays in their everyday life. Clients in therapy that uses the role system may be given a list of roles, such as the worrier, the critic, the clown, the husband, the dreamer, the sister, average person, hero and so forth (p. 154)...As part of the assessment process, clients are invited to place these roles into four categories: “who I am, who I am not, not sure who I am, and who I want to be” (Landy, 2003, p. 154). Landy’s role sort helps us make sense of our current identity, and our hopes for the future into becoming who we strive to be.

In the case of clients with IBD, they have often been labeled “the sick one” which is one of Landy’s roles in the system. In a patient’s experience, going to doctor’s visits, procedures, and missing school, they may become used to being in this category and even become pigeonholed in it. From a perspective of role theory, Landy (2009) discusses concepts of health. He explains that: “The unhealthy person from a role perspective, is one who has given up the struggle to live with contradictory tendencies and has, instead, embraced one role or a cluster of related ones, at the exclusion of all others” (p.73). I argue that the institutions that the client is connected to, like school, work, or hobbies can also impose this role onto a person, and then they can begin to internalize it. Society may understand someone as the unhealthy role, and then they in turn may understand themselves as only that role. Role theory can help people with IBD to think of themselves as not only the unhealthy person, helping them to avoid being defined by their disease, and to embrace all of the identities within themselves that make them who they are and who they wish to be.

Expressive Therapy in Chronic Illness, Medical Settings, and Child Life

Among the research, I was only able to find one study about expressive arts with specifically IBD patients. However, there are multiple studies situating art therapy as a creative arts modality working with chronic illness patients, and arts-based research. Additionally, Omens (2014) and Sextou and Monk (2013) discuss using drama and drama therapy in hospital settings.

Vanger et al. (1995) conducted a music therapy case study involving a 22-year-old woman recently diagnosed with Crohn's disease. The client was struggling with family and relational issues, trying to gain her independence and autonomy while also suffering from Crohn's (p. 148).

The therapy included 25 sessions of helping the client process the chaos in her life and the client chose to play the xylophone and other instruments, once she became more comfortable, and participated in musical improvisations with the therapist (Vanger et al, 1995). "The experience of the self within an unstructured, threatening acoustic space reconstructed the patient's personal experience of her chaotic family situation. She was able to relate to the experience and through it recognize her own psychological condition" (Vanger et al., 1995, p 149). The musical improvisation sessions were recorded and examined through a factor analysis looking at confidence, decisiveness, active vs. passiveness, expressiveness vs. reservation, and lively vs. quiet characteristics (Vanger et al., 1995, p. 150-152). The clinical report summarized the findings indicating that, "The therapist felt that the musical expression of the patient in the sessions reflected her separation conflict. She reported that the patient had difficulty in initiating the playing and did not let herself go with the music in an associative manner" (Vanger et al., 1995, p. 152).

Malchiodi (2013) edited a comprehensive book on Art Therapy and Healthcare. The topics in the book include art therapy and children with chronic illness, art therapy in the medical setting and in child life, art therapy with children hospitalized, and art therapy with children with cancer, to name a few. Additionally, topics for adults include those with HIV/AIDS, chronic illness, and cancer. However, other modalities including drama are absent from the research. In terms of art therapy, Malchiodi (2013) identified several topics related to interventions in the medical arena. there are also many goals that are part of most patients' art therapy in medical settings; these include, but are not limited to the following: 1) psychosocial care, 2)rehabilitation, 3) health benefits, and 4) re-authoring the dominant narrative of illness” (Malchiodi, 2013, p. 5).

Additionally, Omens (2014) wrote about working firsthand with children experiencing medical trauma within the hospital setting. She worked as a child life specialist and creative arts therapist near the New York City area. She used DvT with a focus on using spontaneity and improvisation to address clinical goals. Omens (2014) used assessments and therapeutic intervention to help children and families navigate their hospital experience, get ready for procedures and surgeries, and try to reduce stress. Omens acknowledged the medical trauma for children and their families going through medical struggles and staying in the hospital. She highlighted that drama therapy can be done in the playspace even when the space itself is limited, working in a hospital bed (Omens, 2014, p. 270-271). The author considered “... the child is limited by sickness. The play occurs in a liminal space... where physicality can be transformed. Dramatic metaphors can arise... Drama therapy can be used to transcend the traumatic effect of illness... with what can only be imagined” (Omens, 2014, p.270). She concluded that drama therapy's possibility and potential is far reaching, and with imagination, limitless in many ways.

Similarly, Sextou and Monk (2013) focused their research on medically ill children and considered how therapeutic theater and drama therapy (what they call “applied drama”) can help to reduce negative experiences for hospitalized children. Sextou and Monk (2013) used “practice-based pilot research” at the Birmingham Children’s Hospital in England where they investigated the “impact of bedside theatre performance on hospitalised children’s well-being” (Sextou and Monk, 2013, p.81). The study took note of research supported by a questionnaire and interviews about how bedside theater can help patients and their families (Sextou and Mark, 2013, p.81).

The study focused on children between the ages of five and twelve in the inpatient departments of cardiology, oncology, and pathology (Sextou and Monk, 2013, p.81). The study did not only include patients, but also their caregivers and families. The research used two actors who volunteered their time to participate in rehearsals where they adapted a story through improvisation and storytelling (Sextou and Monk, 2013, p.82). Once at the hospital, the actors used clowning techniques in their warm-up and then transitioned into 20-minute play sessions with the child. Props and toys were used to help liven the performance, and the story used relaxation and mindfulness themes. A brief closure for processing was used after the performance (Sextou and Monk, 2013, p.83). Results indicated that bedside theater helped to serve as a “distraction from illness... help with taking medication,[and] help with preoperative stress” (Sextou and Monk, 2013, p. 86-87).

Additionally, Reynolds and Prior (2009) explored a study with thirty women who were living with chronic illness and how their art making impacted them. The women were all interviewed, and five women also sent in written narrative (Reynolds and Prior, 2009). The results indicated that the art making process was more than just therapeutic and emotionally

engaging. The art making process created a flexible way to take charge of one's life, and fight against the "restrictions imposed by illness on self and lifestyle, in many cases creating a more enriched lifestyle than before" (Reynolds and Prior, 2009, para 3). Overall, the literature points to that using the expressive arts in the population of people with chronic illness, no matter what their age is, can be beneficial to psychological health.

Theater Performances and Arts Based Research

Finally, I will draw upon three autobiographical theater pieces that highlight living with IBD to help inform my project. These pieces include actress Amy Brenneman's (2011) play titled *Mouth Wide Open* that ran in Boston at the American Repertory Theater, which was a depiction of herself with ulcerative colitis and enduring major surgeries. Additionally, Allison Brzezinski-Scorese (2018) created a performance called *Unraveling Chronophobia* which she performed in New York City at the Jamaica Center for Arts and Learning, using dance, theater/poetry, and music to share her personal experience and mental health coping with IBD. Finally, Kaynan and Wade (2018) situated chronic illness and IBD within the family system through a therapeutic theater piece surrounding family dynamics.

Brenneman (2011) created a performance about her life in Hollywood as well as her battle with ulcerative colitis called *Mouth Wide Open*. Brenneman (2011) stated: "I really wanted to do some performing that was not in front of the camera, and I wanted to do a sort of abstract play with some first-person storytelling," (Theatermania, para 3). Brenneman's piece helped to raise awareness about ulcerative colitis and bring her story to audiences. Using her popularity as an actress, she continued to speak about IBD to the media. *Mouth Wide Open* depicted hospital scenes, and the debilitating aspects of her disease, as well as trying to navigate life in the spotlight (Harvard Magazine, 2011).

Like Brenneman (2011), Brzezinski-Scorese (2018) also created an autobiographical piece which she starred in, titled *Unraveling Chronophobia*, about her experience living with Crohn's disease, which used recorded sound, live dance, and poetry/theater. For example, Brzezinski-Scorese (2018) performed:

I used to wish I could cut myself open, remove my organs and soak them.... drench them in hot soapy water, scrub them with a loofa until they shone...After they had been carefully massaged and cleansed I would place them back into my body and sew myself back together, like a repaired doll.....My body hates itself...It attacks itself, doesn't work like how it is supposed to....And I hate it right back. I think my body is incredibly petty, weak, inconsistent, shitty and a total bitch. (*Unraveling Chronophobia*)

Brzezinski-Scorese (2018) used comedy as well as poignant drama to situate her own feelings and mental health on stage for audiences to experience. Her boldness and honesty in her understanding of her illness may have helped people in the audience struggling with not only chronic illness, but other life challenges. Her candidness in talking about a subject like fecal matter also helped to normalize and challenge stigma regarding IBD:

The good thing about Crohn's Disease is that I have now become pretty comfortable talking about going to the bathroom with nearly everyone.....And then those who love and worry about me need to know the intimate details of my bowels. I've become quite the storyteller of my fecal matter (*Unraveling Chronophobia*)

Kaynan and Wade (2018) used therapeutic theater at the NYU drama therapy program, in the series *As Performance*, to create an autobiographical depiction of lived experience with ulcerative colitis and how that affected family dynamics. Kaynan and Wade's (2018) research is based on Landy's role theory and Satir's experiential family therapy theory (p. 11). Kaynan and

Wade's (2018) "research question manifested: how does the trauma of chronic illness perform within family systems and how can creating an original performance with family be healing?" (p. 10).

Kaynan's (2018) study took five months and was focused on how IBD impacted the roles within families. Kaynan (2018) created questions to ask each family member and "Each question was open-ended and focused on...memories, creative responses (i.e. choosing a song to describe a memory) and illuminating each individual's...roles...This was followed by...meetings with each family member during which [she] facilitated a role profile" (p. 12-13). The script was created from the responses to these questions, and drama therapy students and professors were cast to perform in the piece, to provide what Landy refers to as "aesthetic distance" (Kaynan and Wade, 2018, p. 13). Landy explains aesthetic distance being a manageable balance between not too close emotionally, but not too far either. The concept of "aesthetic distance" is also influenced by Kant's notion of the term, when applied to art. After the play was performed, there was also a post-show discussion. Kaynan and Wade (2018) highlight that "Given the dramatic symptom flares and dormant periods of remission, there is a theatrical nature to chronic illness that, we are proposing, lends itself to drama therapy treatment interventions" (p.19).

Brenneman (2011), Kaynan (2018), and Brzezinski-Scorese (2018) situate their own experiences with inflammatory bowel disease into the larger context of drama therapy, and performance art. Through performance they were able to explore the ways in which chronic illness disrupts life and career, everyday routines, family systems, and internal anxieties that can affect self-esteem, sense of purpose, and relationships. Through their candid storytelling and displays of vulnerability, they were able to use personal narrative as well as scholarship and

research to help ground their pieces. They pave the way for new artists and researchers to create autobiographical content related to chronic illness that audiences and readers can resonate with.

This literature review drew upon the multitude of studies considering how inflammatory bowel disease affects mental health specifically analyzing stress, quality of life, identity, emotions, and coping mechanisms. The flare up and remission nature of having IBD is a factor that affects mental health, where even if a patient is feeling medically stable, the constant worry of when a flare may come contributes to overall stress and anxiety level. Additionally, a noteworthy study took a financial lens, analyzing how mental health treatment can help hospitals save money.

The review emphasized Landy's role theory in relation to patients with IBD, and how drama therapy can inspire them to acknowledge the various roles besides being a patient that one plays in their life. Additionally, this review considered how drama and expressive therapy are carried out in the medical and hospital setting, showing that the art-making process can be more about processing emotion, but can act as a behavior working to empower people with IBD to push back against the restrictions of their illness. Music, drama, and art therapy were highlighted as methods of working with people with chronic illness, with less studies being in drama. Finally, using performance demonstrates how to use a patient's own experience to raise awareness to IBD and show how it affects every aspect of a person's life, with mental health being an essential element to the disease. Overall lacking in the research canon is the overlap between IBD/chronic illness and drama therapy. However, Omens (2014) uses drama therapy in the medical setting with children experiencing severe illness. Art and music therapy have been researched more widely than drama therapy to fit people who have persistent medical conditions.

Method

In order to get a closer look at how mental health is impacted by a diagnosis and lived experience of Crohn's disease and ulcerative colitis, this thesis includes the description of a short one-time workshop based on community drama therapy for adults diagnosed with IBD. The following sections of this paper will outline my personal narrative and process surrounding creating this workshop and what results I anticipated. Additionally, this section describes the logistics of time, space, marketing, and population, as well as what the goals and project materials included. Also highlighted is the flyer (See Appendix) that was distributed to potential participants, as well as the outline of my workshop agenda, with added descriptions of what occurred.

Personal Narrative and Biases

My process for creating this community engagement project had multiple steps. First and foremost, I already had background knowledge regarding my lived experience of having ulcerative colitis for over twenty years. However, I had to be mindful to avoid letting my own experience and biases dictate my thesis and decisions. I tried to push myself to arrive from a place of curiosity, rather than all-knowing. At times this was challenging for me to do because I have a personal connection to this disease. However, this connection also created an unwavering passion and commitment to the project. I conducted many hours of research on IBD and mental health, as well as IBD and drama and expressive arts therapy that I included in my review of literature. After conducting this review, I am more informed than I have ever been about my topic and how it affects others.

I want to emphasize the fact that I had privilege and access to an IBD population already given my personal history with the disease, volunteer work with the Crohn's and Colitis

Foundation, and as a graduate student. I had access to a classroom space at Lesley University for no cost to me. Had I not had access to my population, or a space free of charge, it may have been more challenging for me to carry out my project. Other limitations included a lack of racial diversity in my participants. I was not aware of other identifying information, as I did not ask people to disclose any of this.

Population

I gained access to the population of IBD patients through the Crohn's and Colitis Foundation, as mentioned above. I am a member of their Young Professional organization here in Boston. We plan fundraising events and also participate in social discussions and support meetings. Nearly all of my participants appeared to be young adults, with one appearing to be older in age. All but one had a diagnosis of IBD. One person said she had stomach troubles, but not a formal diagnosis of IBD. There appeared to be three men and seven women in attendance. As this was not formal research, demographic data was not collected.

Logistics, Space and Materials

I gained access to a classroom at Lesley University for the workshop to take place, by coordinating it with my department's administrator. I ultimately decided on Lesley's room for convenience and financial reasons, as the room had no fee. I considered that the space was near public transit, as well as the fact that it had a parking lot. The space was also accessible to many restaurants and cafes in the area should anyone need food before or after the event. I chose to hold my event at 11:00 am to allow ample time for people to eat before the event. I encouraged people to bring a water bottle or snacks if they needed.

The only materials this project required included as large of a space as I could obtain, an uninterrupted hour and a half, at least 20 chairs, paper, a white board, and markers. Group members were asked to bring a notebook or paper and something to write with.

Marketing

I marketed the group at a few monthly Crohn's and Colitis Foundation meetings, making in-person announcements, emailed flyers to potential participants, and posted them on the social media pages. The director of the young professional organization agreed to help me email the invitation flyer, and she printed copies for me for the meetings. I created a detailed workshop plan that I brought with me to refer to as I conducted the group.

I also personally contacted specific group members that I thought would be interested in joining my presentation. I then collected the emails of interested participants at meetings and then communicated with them over email. I sent all participants a thank you email after the experience and asked if anyone might be interested in future groups. A few people said they would be interested in future groups. I think about how it would have been helpful for participants to fill out an exit survey but was discouraged from doing this since it was not actual therapy. In the Appendix, you will find the flyer that was hung on Lesley University's campus, distributed to the Young Professionals Crohn's and Colitis Foundation's meetings, social media pages, and through emails.

Project Goals

Because my project was community based, rather than therapy, the object was not treatment oriented, but therapeutically focused. I hoped for my workshop to include 1. using humor to facilitate a sense of community, 2. inspiring dialogue by empowering adults with IBD to feel more in control of their bodies, minds, and spirits even when their bodies might betray

them, and 3. using the concept of expanding roles to avoid being defined by disease.

Additionally, I hoped to help participants express emotions, how they coped with their disease, and to provide a space to speak about a disease that is often hidden from others due to its personal and embarrassing nature.

Workshop Outline

I used the following agenda during my workshop for reference. I have added descriptions of what occurred during each activity:

1. Warm up:

A. Introductions (5 minutes): I played calming instrumental music for participants as they walked into the classroom. In this section I thanked everyone for being at the workshop and explained that I was a graduate student, that this workshop was community drama therapy, and not actual therapy. I explained that there would be no identifying information about participants in my thesis. I discussed the logistics of the building and explained that this project was part of a larger vision for my future career goals to work with those with IBD and chronic illness. I thanked my participants for having an enthusiasm to jump in, to listen to their bodies, and to make any adaptations that were needed for them. I discussed how this workshop was based on interventions I had learned at Lesley University. I emphasized that the goal of my workshop was to empower participants, to use humor, to build community, and to express themselves in what we all had in common, Crohn's or colitis. I disclosed that I also had the disease, though most participants already knew this through my involvement with the Crohn's and Colitis Foundation.

B. Name/Movement/Sound (5 minutes): In this activity, all participants stood in a circle and introduced themselves sharing their name, a movement, and a sound that went along with that name in tandem. Group members repeated back each person's short introduction.

C. About You (10 minutes): I asked participants to share a brief segment about who they are, why they came to this group, and how they found out about it. Many had found out about it through knowing me at the Crohn's and Colitis Foundation.

D. Spectrogram (20 minutes): A spectrogram is an activity that invites participants to arrange themselves on an imaginary line, with one end of the line being a certain category, and another end of the line being the opposite category. In the middle of the line is usually a more neutral category, or one that can't easily fit along the line. People can line up anywhere that they fall on this spectrum. The questions listed below were topics that I asked participants. For example, I asked do you like chocolate or vanilla better? Do you like cats or dogs? The questions began more neutral and increased in personal content. This activity offered a space for long discussions, much laughter, and connection. This is the game that I truly felt started to build community during this workshop. It was challenging to have to end people's discussions as they were talking, however I had to be mindful of the time. If I had more time, I would have allowed this section to continue longer.

Spectrogram Questions:

- Chocolate/Vanilla
- Cat/Dog
- Cold/Warm Seasons
- Love Boston/Dislike Boston
- Introvert/Extrovert
- Love Taylor Swift/Dislike Taylor Swift
- Diagnosed as a Child/Teen/Adult/Recently
- Tell Boss About Disease/Prefer Not to
- Tell Friends About Disease/Prefer Not to
- Tell Romantic Partner Earlier in Relationship/Tell Them Later in Relationship
- Like to Share Feeling About IBD/Prefer to Cope More Alone

- Specialized Diet/No Specialized Diet
- IBD Effects Daily Life/I Forget I Have It

Additional Questions If I Had More Time

- Pleased with my Doctor/Looking for Someone New
- Had Surgery/Thinking about it/Have Not

2. Short 10 Minute Break

3. Main Activity:

A. Making a Machine (5 minutes): In this exercise, participants, one at a time, entered the circle and created a sound and movement resembling a machine. As many people who would like to can participate. The whole group can join this activity. Everyone kept their sounds and movements going, so the group has created an imagined working machine together. This helped people prepare for the next phases of activity.

B. Group Sculpture: IBD Makes Me Feel (10 minutes): I asked the prompt, “how does IBD make you feel? How does having the disease make you feel?” I asked participants to create a pose with their bodies, what we call in drama therapy, a sculpture. At first, participants were asked to just use movements, and then to add sounds. I asked participants to give a word or phrase out loud from how they were feeling in their pose, when I pointed at them. Examples could include “I feel so alone” or “I feel hopeless.” I was pleased with how willing the participants were to display vulnerability during this activity.

C. My Inner Strength Poem/Sculpt Sharing (20 minutes): In my plan, I was going to distribute small papers with the prompts highlighted below, for this creative writing exercise. However, I decided to write the following prompts on the white board in the classroom, so people could complete them in their own notebooks. This was an exercise that I co-developed

with fellow Lesley drama therapy student, Manu A. Carpenter in a previous class exercise. This exercise can work with a number of different populations. After group members wrote this on their own, they were then asked to share their poems, and we created more group sculptures of them with one narrator, and a few actors to bring the piece to life. The narrator got to witness their story as they were telling it. A common theme that emerged were stories focused around physical and action-oriented activities or being outside.

Reflection Poem: My Inner Strength [drama therapy exercise] (2018)

Reflection Poem: My Inner Strength	
Name: _____	
I feel strong/brave when I am in/at _____	(setting/place)
I feel strong/brave when I'm doing _____	(activity/action)
I feel strong when I feel _____	(emotion/feeling)
One final word that represents your poem. _____	

D. Social Atom (5-10 minutes): The social atom exercise is based on theories of Psychodrama, and it asks a participant to think about themselves and who their social supports are. In traditional social atom practices, a client would draw themselves in the middle of a piece of paper, or write their name, and then write or draw the people around them that are closest to them in support. Then, on the outer sides of the circle would be, who still supports them, but in a further way. Because we did not have time for participants to complete this exercise on their own, I proposed the question of who and what supports you with your IBD? I asked, “how do

people cope? Many answers included hobbies, pets, spending time with loved ones, and using music and the arts.

4. Closure (5 minutes):

Making a Soup: Drawing on the drama therapy method of DvT, I asked group members to add ingredients to a “soup” that we pantomimed mixing together. Ingredients could be real, like hot sauce or spices, or imaginary, like courage and confidence. I asked people what they wanted to add to our soup. This acted as a reflective exercise while also bringing fun, spontaneity, and improvisation to closure. Participants were joyful and energized during this exercise. We all said cheers and drank the “soup” together. At the end of the workshop, people had questions about drama therapy and thanked me for offering this space to come together in community.

Results

After I conducted my workshop, I journaled about what I heard, felt, experienced, and explored. I later created a poem about my experience leading the group, and how it felt to join with others with IBD, as well as offer a space for community. I thought about the concept of togetherness, having a shared experience, even with variations. Writing this poem helped me to process the strength, inspiration, and empowerment that I felt when reflecting upon the experience:

Together

Together, we share, fight, laugh, and dream
 Together, we face the uncertainty and continue to rise
 Together, we swallow pills, inject meds, and are cut open
 Together, we have laid awake in hospital beds
 Have looked in the mirror to see
 A puffy face
 Together, we find comfort in each other's faces
 Together, we are often invisible in our sickness
 But together, we continue to rise, to speak, to hope

The workshop was lively and engaging. Participants were talkative and expressed a joy and relief for being able to converse with other people going through similar experiences. There was laughter and smiling, and also intense listening. When I witnessed the communication between participants, this informed me of workshop session ideas and research I might lead within my career in the future. Once I fostered a sense of rapport through fun and even goofy exercises, people were more likely to be vulnerable and share intimate details from their life. People asked questions about drama therapy at the end of the workshop, and they seemed eager to learn more.

What I took away from this the most, was that having a space for people to share and create together was positive and needed. Now that I have established this need, like my literature review also states, many of my thoughts moving forward are surrounding format. How would people commit to a group? For what length of time? How long would it be for? The workshop could have lasted for more time. I could see a four-hour workshop being easily carried out. One hour and a half honestly felt short. What would attendance cost? As a facilitator, I felt proud to bring people together, in a disease that was so personal to me.

Discussion

Using drama therapy-based activities in a support group is an active and embodied form of community building to stimulate discussion and playfulness. This 1.5-hour workshop conducted at Lesley University for ten adults drew on methods of Developmental Transformations, psychodrama, role, and other drama therapy interventions. In the review of literature, it was identified that there is an urgent need for mental health treatment to work in tandem with medical treatment. I argue that it should not be solely up to an individual patient to find their own therapist, but gastroenterology departments and medical settings where IBD

patients are treated should use a holistic approach to offer therapeutic services in combination with medical services. Many of the themes from this thesis can also be applied to other chronic illnesses. With there still being much research that is continuing to be uncovered about the mind and body connection, and stress response, mental health treatment is essential. According to Johns Hopkins Medicine (2020), one of many institutions that have been promoting these claims, there is new evidence to suggest that anxiety and the gastrointestinal system are more connected than we have considered.

My workshop showed that an active form of group experiences can help to ease isolation and promote self-expression through drama-based interventions. We are on the cusp of many new discoveries considering how drama therapy/ expressive arts can continue to support patients with chronic illness, and it is imperative to continue to advocate for these mediums to be part of the clinical conversation.

It was my hope that my group model could be applied to other medical settings including hospital groups, or outpatient support groups, for patients with IBD. It can also be adapted to fit the needs of any type of chronic illness or medical condition. I hope that my project can help expand what doctors and psychologists consider providing as treatment for mental health using the arts, and specifically drama therapy. This workshop can also be used as arts as social action, providing a community for people that may feel isolated in their disease.

Though this Lesley thesis cannot contribute to strictly clinical research in the field since it was not therapy, it can show how community engagement using therapeutic processes and interventions can help people experiencing uncertainty from illness. I hope my thesis can show how people with IBD can receive emotional support through creativity and self-expression. It is my hope that participants felt more connected and seen, since IBD can be an invisible illness.

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Appendix

Marketing Workshop Flyer

Therapeutic Drama & Music Community Workshop

For Adults with Crohn's Disease and Ulcerative Colitis

February 8th, 2020

11am-12:30pm



Lesley University
1815 Massachusetts Ave, Cambridge, MA 02140
University Hall, Porter Square Campus
Third Floor, Room 3-100



As part of a master's level thesis project, join the facilitator in a short workshop designed to help support those with a diagnosis of Crohn's or Colitis. Whether you have been coping with the illness for many years, or are brand new to your experience, all are welcome. We will join together to use play, humor, improvisation, sound, movement, and writing to express our journeys with IBD. No music or drama experience required. Please bring paper or notebook and something to write with.

To register, or for questions, please email Molly at (email address).

THESIS APPROVAL FORM

**Lesley University
Graduate School of Arts & Social Sciences
Expressive Therapies Division
Master of Arts in Clinical Mental Health Counseling: Drama Therapy, MA**

Student's Name: Molly Weinberg

Type of Project: Thesis

Title: Using Community Drama Therapy to Support Adults with Crohn's Disease and Ulcerative Colitis

Date of Graduation: May 16, 2020

In the judgment of the following signatory this thesis meets the academic standards that have been established for the above degree.

Thesis Advisor: Dr. Laura Wood