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I Just Want to be a Normal Teenager: A Literature Review of Impacts of Adolescent-onset Chronic Illness on Identity Development and Proposed Benefits of Drama Therapy

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I Just Want to be a Normal Teenager:

A Literature Review of Impacts of Adolescent-onset Chronic Illness on Identity Development and Proposed Benefits of Drama Therapy

Capstone Thesis

Lesley University

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Drama Therapy

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Abstract

Adolescence is a crucial moment in life for establishing our personal identity, internal values, and social autonomy (Christie & Viner, 2005); however, this already-tumultuous time can be further complicated by the addition of a chronic illness diagnosis which can lead to feelings of isolation, uncertainty, and an inconsistent sense of self (Chisholm, 2018; Wicks et al., 2019). This literature review investigates the current research regarding the impacts of chronic illness on identity development as well as the landscape of available expressive therapies interventions. Based on personal experience and available literature, I argue that drama therapy can provide much needed support to chronically ill adolescents and propose a curriculum structure for a drama therapy group designed to support participants' unique identity development needs.

Keywords: chronic illness, drama therapy, role theory, performance theory, autobiographical therapeutic theatre, adolescents, identity, mental health, group therapy

Author Identity Statement: The author identifies as a queer, dis/abled and chronically ill, cisgender, white woman. The author has been diagnosed with Dysautonomia and Hypermobile Ehlers-Danlos Syndrome, which impact every element of her life.

I Just Want to be a Normal Teenager: A Literature Review of Impacts of Adolescent-onset Chronic Illness on Identity Development and Proposed Benefits of Drama Therapy

Prologue - Present Day…

Who am I?

Who do I want to be?

With my illness, outside of my illness, because of my illness, in spite of my illness…

The questions tumble around in my brain, but I never seem to land on satisfying answers. My illness is part of my identity. I have been sick for as long as I can remember. Many of my formative memories—for better or worse—are tinged with that sickness.

Throughout this academic exploration, I will also tell you fragments of my story, so that we both might understand a little more what it means to grow up and find yourself in a body like mine.

Introduction

Our teenage years remain a crucial time for understanding who we are and how we fit into the larger world around us as we strive to establish our personal identity, internal values, and social autonomy (Christie & Viner, 2005). Living with chronic illness during this already-tumultuous time significantly impacts our relationships with ourselves and others, leading to feelings of isolation, uncertainty, and an inconsistent sense of self (Chisholm, 2018; Wicks et al., 2019). This literature review seeks to establish the theoretical foundation for how an intentionally designed drama therapy group can mitigate these impacts and support chronically ill adolescents with their unique identity development needs.

Having navigated the unique challenges of adolescence with chronic illness, I designed this project based on my own personal experiences. Throughout my childhood, adolescence, and transition into young adulthood, the constraints of my illness prevented me from exploring the world and gaining a full understanding of who I was and how I related to others. Theatre and the community around it helped me feel less isolated and gave me the opportunity to explore my identity in ways I was unable to in my daily life; however, I still knew I was different than my typically developing peers, and I longed for connections with those who understood my experience. Now, as a chronically ill drama therapist, I am uniquely situated to offer this experience to others facing similar challenges today.

Originally, this project was conceptualized as a group drama therapy intervention to be implemented with adolescents at the internship site at which I am practicing at the time of writing. Due to some unforeseen circumstances, the group was unable to run within the allotted time frame, and this project underwent a significant shift away from implementation and towards the establishment of a theoretical framework. After establishing a strong base of literature, I chose to maintain the proposed intervention and run pieces of the protocol on myself so that I might gain a deeper understanding before offering it to others.

The specific intervention and my reflections will be discussed in more detail in a later section of this thesis, but as part of the process I wrote monologues about finding my footing as a chronically ill child and teen. Based on those reflections and inspired by Rachel Keeling's (2023) sharing of memory in her own work, this paper is interwoven with those monologues so that I might offer a window into my own identity journey. With this literature review and the proposed intervention, I will lay the theoretical foundations for the establishment of a drama therapeutic group designed to support the identity development needs of chronically ill adolescents.

The Americans with Disabilities Act defines ‘disability’ as “a physical or mental impairment that substantially limits one or more major life activities” (ADA, 2020, n. page). Through this lens, preconceived notions of ‘disability’ are expanded to include those with mental illnesses and chronic medical illnesses (Cook, 2020; Cook, et al, 2022). Various researchers (Wolbring, 2012; Young, 2014) have suggested that disability is not a failing of the individual, but instead is a social concept that is created, maintained, and perpetuated by a society not designed for all bodies to succeed. Though current literature exploring the experiences of chronically ill adolescents is sparce, some researchers (Kirk & Hinton, 2019; Kuhlmann et al., 2023; Wicks et al., 2019) have recently begun inquiring into the impacts of a diagnosis early in life. Across these recent studies, participants expressed a shared narrative of struggling with changes to their physical abilities, sense of self, and social groups.

Research (Edgar-Bailey & Kress, 2010; Fraser & Keating, 2014; Gladding, 2011) has also emphasized the benefits of creative and embodied treatment approaches, and these approaches can be effectively implemented to support the unique needs of chronically ill adolescents. Expressive mediums, such as photography and creative writing, can be used to empower individuals with chronic illness, chronic pain, and/or invisible disabilities to proudly tell their stories and gain a deeper critical understanding of their disability identity and how it is shaped through relationships with self, other, and society (Allen, 2020; Kattari & Beltrán, 2022).

Considering the unique identity development needs of chronically ill adolescents, I believe that drama therapy can provide a much-needed container for exploration. In the context of a tailored drama therapy group, participants can form connections with peers who experience similar challenges thereby lessening their sense of isolation. They would be provided with a *safe-enough* space in which to try on different roles and identities that may otherwise feel too threatening to experiment with in their daily lives. Finally, by being witnessed in these new roles, participants can begin to build their self-confidence and self-advocacy skills as they engage in their identity development journey.

Interlude I - 8 years old…

For a short time, I wore a heart monitor that looked like a handheld tape recorder with long colored wires running under my shirt. At seemingly random times, my heart would race, my body would shake, I would get dizzy and pass out—my body was currently a mystery and we were searching for answers.

I carried my tape recorder and wires around with my textbooks. I tried to make myself small and unnoticeable. But to my horror a teacher called me out in front of the class. She told me to stand up, she told me I couldn't have a device like that in the classroom, and I needed to go put it away. I felt heat spread across my cheeks, and I stared at my feet as I explained that I couldn't. It was connected to my heart. The wires were part of me. I wonder what my heart monitor recorded in that moment as my pulse skyrocketed with embarrassment.

Later, on the playground, the other kids in my class avoided me. They spoke in hushed tones on the jungle gym and stopped talking when I approached. Eventually, an emissary was sent out from the group of girls I normally played with—they determined I must be an alien and humans don't play with aliens.

Methods

Sources for this literature review were collected the Lesley University Library Database, drama therapy textbooks, TED talks, Google Scholar, and my own experiences as a chronically ill and disabled individual. Care was taken to prioritize not only peer reviewed sources, but sources that either emphasized the voices of folks living with chronic illness or were written by an author who disclosed their own status as chronically ill and/or disabled. Some key search terms used to identify appropriate sources included but were not limited to: "chronic illness and drama therapy," "chronic illness and adolescents," "chronic illness and creativity," and "adolescence and identity development." Boolean operators "and" and "or" were utilized to both expand and refine searches. For example, searches included modifiers such as "adolescents *or* teens *or* teenagers *or* youths" to incorporate articles that may have otherwise slipped through the proverbial cracks due to their use of synonyms in their titles. The goal of this literature review is to investigate the impacts of adolescent-onset chronic illness on identity development, what supports are currently available within the expressive therapies, and how drama therapy can better serve this population.

Interlude II - 15 years old…

I'm getting sicker again. The doctors warned me this would happen during puberty as hormones ran rampant in my body. I'm having flares left and right and struggling to get out of bed most days. My brain fog is so bad I feel like I'm watching the world from behind a pane of glass. I try to keep it together, but I'm missing classes. Too many classes. So many that the school administration reaches out to my parents.

"If this pattern continues" they say, "we'll have no choice but to hold her back a year."

The idea of my friends going on without me cracks my heart open.

I think of the jokes I'll miss, the memories I won't be a part of, the "classic" high school experiences I won't have.

What if they forget me entirely as we grow into ourselves? We were supposed to do this together.

"The only other option is online schooling. She can study from home and rejoin the school next school year if she's ready."

I take the small sliver of hope they offer, and I promise myself I will be ready.

Literature Review

Chronic Illness, Adolescence, & Identity

Though exact definitions of 'adolescence' differ, western society generally marks this period of life as encompassing the most developmental change compared to other life stages (Wicks et al., 2019; Williams et al., 2002). Theorists (Erikson, 1968; Goffman, 1968) have long suggested that our identity is shaped by the relationship between our expectations, our perceptions of ourselves, and the perceptions of those around us. An individual's identity in turn influences our self-esteem, behaviors, beliefs, and susceptibility to mental health challenges (Stephenson, 2023). During what is already a highly unpredictable point in one's life, diagnosis of a chronic illness can disrupt one's expected course and invite stigma that negatively affects both self-perception and the perceptions of others (Charmaz, 1983; Jóhannsdóttir et al., 2021; Monaghan & Gabe, 2019). Since adolescence is a key part in our developmental foundation, it is crucial to understand how chronic illness during this life stage impacts identity formation.

Though current research regarding identity development with this population is limited, more studies (Kirk & Hinton, 2019; Kuhlmann et al., 2023; Wicks et al., 2019) have emerged in recent years with the goal of investigating experiences of chronically ill adolescents. In addition, other studies have focused on the psychosocial development of adolescents with specific illnesses, such as juvenile idiopathic arthritis (Cartwright et al., 2014), celiac disease (Olsson et al., 2009), human immunodeficiency virus (Hosek et al., 2002), and diabetes (Dovey-Pearce et al., 2007). As researchers invited these young people to share their unique stories, similar themes became clear across studies.

A common sentiment shared by many adolescents who were interviewed (Cartwright et al., 2014; Dovey-Pearce et al., 2007; Hosek et al., 2002; Kirk & Hinton, 2019; Kuhlmann et al., 2023; Olsson et al., 2009; Wicks et al., 2019) was a strong sense of difference between themselves and their ‘healthy’ peers. This ‘otherness’ was amplified by the physical restrictions, unique self-care routines, and lack of awareness around chronic illness they experienced day to day—the cry of, “I just want to be a normal teenager” rang out from participants across all studies. Adolescence and childhood are often thought of as being an age of health and vitality; however, chronic illness can disrupt this expectation and create dissonance for young people and their sense of self. The uncertainty created by chronic illness adds an additional layer of challenge and complication to planning for future goals, such as attending college or entering the work force. Participants across studies noticed that they carried the burden of educating those around them about their illness, and the weight of long-term medical consequences forced them to grow up quicker than their peers.

Along with the daily impacts, participants also shared insight into what experiences helped them integrate their chronic illness as a piece of their larger identity (Cartwright et al., 2014; Dovey-Pearce et al., 2007; Hosek et al., 2002; Kirk & Hinton, 2019; Kuhlmann et al., 2023; Olsson et al., 2009; Wicks et al., 2019). Many adolescents shared that accepting what they could not change, while still finding ways to regain a sense of control over their lives helped them step into their new identity. A common theme across studies was that those who had access to more supportive, normalizing relationships among peers and family members expressed more positive feelings towards themselves, their life, and their diagnosis. In addition, participants' sense of isolation decreased when they were able to interact with other chronically ill adolescents whom they felt could truly understand them and their experiences. Another important theme for many was the ability to control disclosure around their diagnosis. This idea included not only controlling the dissemination of information about their chronic illness, but also a request for necessary accommodations to be offered in ways that do not single out or draw undue attention to the adolescent.

The final theme that emerged was the importance of not only acknowledging the negative impacts, but celebrating the ways in which their experiences with chronic illness shaped them positively as well (Cartwright et al., 2014; Dovey-Pearce et al., 2007; Hosek et al., 2002; Kirk & Hinton, 2019; Kuhlmann et al., 2023; Olsson et al., 2009; Wicks et al., 2019). Participants expressed that they felt more confident after accepting their diagnosis, learned unique skills they otherwise would not have, and gained more resilience from the challenges they faced. This thinking is echoed by other chronically ill and disabled activists (Davison, 2022; Young, 2014) who emphasized that chronic illness and disability are not something to cure, fight against, or succeed 'in spite' of, but rather an important piece of one's identity to honor and take pride in.

Creativity, Mental Health, and Arts-based Exploration

Research (Edgar-Bailey & Kress, 2010; Fraser & Keating, 2014; Gladding, 2011) has emphasized the benefits of creative and embodied treatment approaches for supporting individuals from all walks of life. Higher rates of creativity have been shown to increase emotional expression (Gibbs & Green, 2008), self-esteem, and ability to cope with challenging circumstances and major life changes (Prescott et al., 2008). Though research is limited with this specific population, some studies (Naghibzadeh et al., 2018; Tolleson & Zeligman, 2019) indicated that chronically ill individuals who experienced higher levels of creativity also experienced higher levels of post-traumatic growth, better quality of life, and a greater sense of hope for the future with their illness.

Artistic interventions that foster creativity, such as photography, creative writing, and dramatic vignettes, have the potential to empower individuals with chronic illness to proudly tell their stories and gain a deeper critical understanding of their identity and how it is shaped through relationships with self, other, and society (Allen, 2020; Kattari & Beltrán, 2022; Keeling, 2023). While limited research exists utilizing creative methods with chronically ill adolescents, there has been an increase in research performed by chronically ill researchers reflexively investigating their own experiences alongside their communities. A key example of this investigation is Kattari and Beltrán's (2022) use of a modified photovoice exploration and reflexive journaling to explore experiences of self-perception versus external perception for individuals with invisible disabilities, chronic pain, and/or chronic illness.

The photovoice methodology—which involves the use of photography by community members to document their lived experiences—was made more accessible to disabled participants by offering multiple modes of engagement, such as scheduling photoshoots with a professional photographer or allowing individuals to submit their own photos, artwork, and/or writing (Kattari & Beltrán, 2022). By offering the option to submit writing or artwork in lieu of photos, the researchers made space not only for differing access needs but also for differing levels of anonymity. Expression through multiple mediums helped to elevate and clarify the participants' voices, and their work was displayed at both in person and virtual receptions to promote greater community connection and visibility for their unique experiences.

Throughout the research process, Shanna Kattari, the first author who also identifies as chronically ill, engaged in their own reflexive journaling and artmaking to deepen their understanding of how their own experiences of chronic pain, illness, and disability intertwined with those of the participants (Kattari & Beltrán, 2022). The authors emphasized that not only was this art-based research important as an opportunity for creative expression, but that the participants also expressed feeling a stronger sense of community after they witnessed the experiences and stories of other individuals with chronic illness, chronic pain, and invisible disabilities.

When focusing on drama therapy for chronically ill children and adolescents, these creative interventions are written about most often in the context of a hospital setting (Ofer & Keisari, 2022; Omens, 2014). This tendency may be because hospital settings are where those children and adolescents who need the most immediate or acute care are first encountered; however, this leaves a gap in the body of research. How are these young people being supported in their development once they leave the hospital and enter outpatient care? What happens when an adolescent receives a diagnosis during their hospital stay that they must now integrate as a piece of their developing identity?

Drama Therapy Theories

The following section details two main theories of drama therapy—Performance Theory and Role Theory—that could be utilized in a targeted intervention to support the identity development of adolescents with chronic illness. More details about the proposed intervention will be offered in the Discussion section of this paper.

Performance Theory

Called by many names in different contexts, autobiographical therapeutic theatre involves the performance of an actor's personal material with the goal of personal growth (Pendzik et al., 2016). The actor can devise and perform their piece of theatre alone or with fellow castmates, and their embodiment of their personal narrative is witnessed by some form of audience. Drama therapist, Jan Stirling Twist has shared her thoughts on the power of witnessing: "To have one's story heard and retold with care, to be able to tell one's story into receptive, compassionate ears—these are the things that all too rarely happen for the people we work with" (Jones, 2007, p. 106). Performing one's story for an audience provides a much-needed opportunity to say "this is me"—to proudly put forth an authentic picture of the performer as a culmination of all the hard work they have done to get to this moment. In turn—and perhaps for the first time—their community can witness their vulnerability and say back to them, "I see you." Especially when working with systematically oppressed populations, such as chronically ill and disabled individuals, performance can make a significant difference in how their community perceives them and, in turn, how they perceive themselves (Bailey, 2009).

From the beginning of the devising process through the end of the show and beyond, building a supportive community among a group of performers is also integral to positive mental health outcomes (Bailey, 2009). When working within a group and co-constructing a narrative, the group members begin to form a common language and build relationships on a foundation of mutual understanding. The group can also become a microcosm of the outside world, offering valuable opportunities to build and practice social skills within a more controlled and less judgmental environment. These strong connections to fellow cast members do not end when the show is over, which is a significant reason it is important that the therapeutic experience does not end when the curtains close.

A study conducted by David Read Jonson (1981) which examined the effect of performance with hospitalized psychiatric patients illustrated the importance of post-show support for actors engaging in therapeutic performances. Johnson found that when support ended immediately after the show, clients showed an increase in symptoms and a decrease in social connectedness; however, when cast meetings continued after the show closed, clients were able to better process their experiences and maintain the skills they gained throughout the process. As individuals grapple with the new roles they have stepped into during their performance and how the ending of this long performance process may impact their daily lives, it is necessary to gain closure with and support from the group who has been present with them through the transformation (Emunah, 2019).

Role Theory

Robert Landy's Role Theory (1986, 1993, 2009) was founded on the assumption that humans naturally take on roles throughout our lives that each impact the way we think, feel, and interact. To understand human behavior, we must, therefore, understand how our personalities are shaped by the roles we take on (Ramsden & Landy, 2021). Drama therapy and the dramatic realm provide the space to experiment with new roles for short periods of time—like a clothing store changing room, we can try something new on and see how we feel in it before deciding if we might want to add it to our larger wardrobe. Maybe we will set the piece down this time, but next time we will come back to it. We may try the piece on again. Each time we consider who we are now and who we might want to be. Through this process of experimentation, we can integrate new roles into our system and allow ourselves access to a more cohesive and multi-faceted existence.

While a large set of integrated roles may make it easier for an individual to navigate challenging experiences, Landy suggested that an individual's distress and dysfunction result from having limited roles they are allowed to play and/or being unable to easily move between different roles (Landy, 2009; Kaynan & Wade, 2018). An individual may also experience dissonance because they are trying to play a role that is inadequately developed or is unaligned with the other roles they are required to play in their daily life. The health of our ever-changing role system (and by extension our personalities and identities) is marked by how it achieves balance—when life's ambiguities destabilize our sense of self, how do we find our way back to equilibrium (Landy, 2008; Landy & Butler, 2012). As we seek greater stability and a healthier sense of self through role theory, we turn not only to the roles we play but also to our counterroles and guides.

Each role available to us also has its own unique counterrole distinct to the individual, their experiences, and cultural background. Like the dark side of the moon, every role has its other half that is obscured, unexplored, and avoided (Ramsden & Landy, 2021; Landy & Butler, 2012). The counterrole is not inherently negative or bad, nor is it always the prototypical opposite of the role. In order to fully understand the roles that an individual plays in their life, they must be able to examine and come to terms with their counterroles. Bridging the gap in understanding the role and counterrole stands the guide. In many clinical settings, the guide is embodied by the drama therapist who supports the client's journey towards deeper understanding and acceptance.

Over time, the ideas of role theory have been distilled into eight-part and then four-part models for simpler practice (Butler, 2017; Landy, 2012). The simplest four-part model placed role exploration into the context of the hero's journey, focusing on the roles of the hero, destination, obstacle, and guide. Each central role also embodies its own central question, which are, respectively: Who am I? Who do I want to be? What is blocking me? And who can help me? (Ramsden & Landy, 2021). From this foundation, individuals create a story which can be explored using a range of dramatic techniques to gain insight into their identity development journey.

Interlude III - 19 years old…

I want so badly to keep up with my classmates. I want this so badly that I pushed myself too hard trying to make it to my college classes and play rehearsals. I'm determined to prove that I can keep up with everything—I can make new friends, I can walk to all the places my classmates can, I can keep up with my busy schedule, I can work a job, I can, I can, I can…

Until I can't.

And then I crash into a huge flare. My heart races, my body shakes, everything hurts, I'm exhausted. I hide away in my dorm and call my mom in tears. She comes to my school and takes me to the ER. My cardiologist tells us I should be able to show up there and they'll give me intravenous saline. A little poke, a bag of salty water, and I should be on *my way, right? Once we finally see a doctor, I explain the situation to them and everything my cardiologist told us, and I'm met with skeptical looks.*

"What's it called again? I've never heard of that."

The doctor taps his pen against his clipboard, clearly annoyed I'm taking up his precious time with my obvious lies.

"Dysautonomia. POTS, specifically. Postural Orthostatic Tachycardia Syndrome."

I explain it again to them. I've had all this medical terminology memorized since I was little to explain my body to others. My body has never felt entirely mine.

The doctor gives me a sly smile, "you just drank too much, didn't you? You're dehydrated from the alcohol. We get college students in here all the time. You can just be honest and we'll get you on your way."

I feel my frustration rise. I wish that was the problem. I wish I had too much fun underage drinking at a college party. Smuggling cheap vodka into the dorm in my backpack and hiding from the RA. Instead, my body just can't keep up. Besides, I'm taking too many prescription medications to touch alcohol without dire consequences anyways.

I silently send a wish out to the universe that maybe for once I could just feel 'normal,' and then I begin my explanation over again.

Discussion

Based on my firsthand experiences and review of the current literature, there is a gap in supports available to promote the healthy identity development of chronically ill adolescents. In light of this concern, I propose to fill this gap by designing a targeted drama therapy group based on the identity development concerns presented in the literature (Cartwright et al., 2014; Dovey-Pearce et al., 2007; Hosek et al., 2002; Kirk & Hinton, 2019; Kuhlmann et al., 2023; Olsson et al., 2009; Wicks et al., 2019) Group members would have the opportunity to form connections with peers who experience similar challenges thereby lessening their sense of isolation. Utilizing the hero's journey, they will be provided with a safe-enough space in which to try on roles and identities that may otherwise feel too threatening to experiment with in their daily lives (Butler, 2017; Landy, 2012; Ramsden, 2021). Finally, by being witnessed in these new roles through a devised performance, participants can begin to build their self-confidence and self-advocacy skills as they engage in their identity development journey (Bailey, 2009; Jones, 2007; Pendzik et al., 2016). This group would be intended to meet once per week for an hour and a half over a total of six weeks.

Proposed Intervention – A Six Week Group Curriculum

Weeks 1 &2 – Introduction and Group Dynamics

The first two weeks will focus on building trust and group cohesion as well as laying the foundation for participants' later exploration. These first sessions will consist largely of introductory drama games with an emphasis on group members getting to know each other—learning each other's names, likes, dislikes, and experiences. In doing so, participants will also be introduced to the fundamentals of drama therapy, such as play, witnessing, embodiment, and dramatic projection (Frydman et al, 2022; Jones, 2007). At the end of these sessions, the group will also be invited to establish their own closing ritual together that will be performed at the end of each session to encourage a greater sense of solidarity and ownership over their experience.

Weeks 3 & 4 – Exploration and Rehearsal

In the following two weeks, focus will shift to more direct exploration of identity and establishing the story the participants wish to present to friends and family during Week 5. As a container for this exploration, Robert Landy (1993; 2021) offers us the model of the hero's journey and its four primary queries—Who am I? What do I want? What is keeping me from getting there? Who can help me? Participants will be invited to explore these ideas as they relate to their unique journey through storytelling, mask making, monologue writing, and other forms of creative expression. As a group, participants will determine how they wish to tell their stories and will co-create a performance to be given to invited friends and family.

Weeks 5 & 6 – Performance and Closure

The final two weeks will encompass the performance itself, group debriefing, and closure activities. Renée Emunah (2019) emphasized the importance of leaving time and space following a therapeutic performance to integrate participants' new self-image into their daily lives and to "soften the highs and lows of the performance process" (p. 301). It will be necessary to honor the participants' vulnerability and the bonds that have been formed over the weeks together. Participants will reflect on memories made together and consider what they would like to carry with them from this experience and what they feel no longer serves them. Following the conclusion of the group, everyone involved will also be invited to anonymously submit feedback that will be incorporated into future iterations of the group.

Anticipated Outcome

Through this process, I anticipate that participants will find support, solidarity, and community by engaging with a group of chronically ill peers who share similar life experiences.

These connections and the container of the drama therapy group can provide a safe-enough space in which these adolescents can try on new roles and explore their unique identities. By placing themselves in the role of the hero and being given the opportunity to tell their stories to affirming witnesses, participants will hopefully discover an increased sense of confidence and mastery over who they are, who they want to be, and how they relate to the world around them.

Personal Reflection – Testing the Proposed Intervention

Though I was unable to run the group portions of the protocol, I sought to test key elements on myself as I reflected on my own experiences—past and present—living with chronic illness. Because I did not have access to other group members and already have a foundation in drama therapy, I chose to focus on pieces of the protocol from weeks three through six. I engaged in a role sort using the questions of the hero's journey as set forth by Robert Landy (1993; 2021). Choosing the roles that felt most salient to me, I reflected on my story and began drafting monologues (Table 1). These monologues, which are interwoven throughout the sections of this thesis, were performed for several close friends. Immediately after the performance, they were asked to relay their experience of witnessing back to me. Finally, in an act of closure, I reflected on the creation, performance, and witnessing of my story, considering what pieces of these roles and identities I discovered that I wanted to carry with me or leave behind.

Table 1

Role Sort Results

Who Am I?	Who do I want to be?	Who is blocking me?	Who can help me?
Child*	Rebel	Vampire	Parent*

Adolescent*	Wise Person	Victim	Angry Person
Adult*	Free Person	Beast	Clown
Elder*	Beauty	Orphan	Visionary*
Friend	Average Person*	Saint	Believer
Optimist*	Hero	Critic	Warrior
Outcast	Healthy Person	Doubter*	Healer
Sick Person*	Happy Person	Pessimist	Killer
Dreamer*		Poor Person	
Lover		Rich Person	
Helper		Ignorant Person*	
Fearful Person		Innocent	
Witness*		Sinner	
Special Person*			
Survivor*			
Artist*			
Zombie			
Perfectionist			

* Denotes salient roles chosen for additional reflection and monologue writing

The process of personally testing portions of my proposed intervention was invaluable for my understanding of its drama-therapeutic potential as well as the vulnerability necessary to engage with it. Memories that I’ve discussed before without issue became much more visceral when turned into performance. I felt an unexpected amount of anxiety performing for my friends—will this be too much for them? Will they accept the pieces of my identity that I’m sharing? Will they take me seriously or are they humoring me? As my monologues brought me to tears, I was struck profoundly with the difference between speaking practically/academically about my illness versus speaking to its impacts on *me* as a person. As witnesses shared their experiences of sitting with my performance, I found it validating and comforting to receive their words. They pointed to roles that I mentioned in my closing monologue and expressed how they see me embodying them. Overall, the sentiment was that my friends felt that they knew me better now and thanked me for sharing these pieces of my story.

The journey of exploring roles, writing monologues, and performing my story emphasized for me the need for intentional scaffolding of distance for group members. I can understand how moving too close too fast to sensitive material could leave participants feeling flooded and overwhelmed. On the other hand, never moving past the practical and academic prevents participants from experiencing the catharsis of embodying their chosen identity. In addition, this experience also brings to question the importance of group leader's disclosure and personal work. As a rule, I generally do not ask my clients to do something I am not also willing to do. While every group will be different, it takes a great deal of vulnerability to explore foundational questions of self. Therefore, it may be in service of the clients for the group leader to show themselves and their journey authentically to model that necessary vulnerability.

Conclusion

Adolescent-onset chronic illness can deeply disrupt the establishment of our personal identity, internal values, and social autonomy (Christie & Viner, 2005) and lead to feelings of isolation, uncertainty, and an inconsistent sense of self (Chisholm, 2018; Wicks et al., 2019). Originally conceptualized as an intervention based on my personal experiences growing up with chronic illness, this project shifted to the establishment of a theoretical foundation for a drama therapeutic group designed to support the unique identity development needs of chronically ill adolescents. As the available literature reinforced the necessity of such a group, I chose to still offer the proposed intervention and ran pieces of the protocol on myself to gain a deeper, more personal understanding of its efficacy.

Reviewed literature was collected from the Lesley University Library Database, drama therapy textbooks, TED talks, Google Scholar, and my own experiences as a chronically ill and disabled individual. Throughout the research process, I prioritized sources that either emphasized the voices of folks living with chronic illness or were written by an author who disclosed their own status as chronically ill and/or disabled. The goal of this literature review is to investigate the impacts of adolescent-onset chronic illness on identity development, understand what supports are currently available within the expressive therapies, and consider how drama therapy can better serve this population.

An overview of the literature indicated that identity development, which is influenced by our expectations, self-perceptions, and the perceptions of other, is necessary to understand because an individual's identity influences their self-esteem, behaviors, beliefs, and susceptibility to mental health challenges (Erikson, 1968; Goffman, 1968; Stephenson, 2023). A chronic illness diagnosis impacts identity by disrupting one's life and inviting stigma that negatively affects both self-perception and the perceptions of others (Charmaz, 1983; Jóhannsdóttir et al., 2021; Monaghan & Gabe, 2019). Chronically ill adolescents who were interviewed across several studies (Cartwright et al., 2014; Dovey-Pearce et al., 2007; Hosek et al., 2002; Kirk & Hinton, 2019; Kuhlmann et al., 2023; Olsson et al., 2009; Wicks et al., 2019) shared common narratives of "otherness" and uncertainty that impacted their relationships to self and others. Participants expressed that what helped them most was regaining a sense of control over their lives and stories, having access to more supportive, normalizing relationships among peers and family, and interacting with other chronically ill adolescents whom they felt could understand them and their experiences.

When considering creative means to support the identity development of young people living with chronic illness, some studies (Naghibzadeh et al., 2018; Tolleson & Zeligman, 2019) indicated that chronically ill individuals who experienced higher levels of creativity also experienced higher levels of post-traumatic growth, better quality of life, and a greater sense of hope for the future with their illness. Artistic interventions that foster creativity, such as photography, creative writing, and dramatic vignettes, have the potential to empower individuals with chronic illness to proudly tell their stories and gain a deeper critical understanding of their identity and how it is shaped through relationships with self, other, and society (Allen, 2020; Kattari & Beltrán, 2022; Keeling, 2023). While current research offers us examples of how drama therapy can be used to support chronically ill children and adolescents in hospital settings (Ofer & Keisari, 2022; Omens, 2014), there is a significant gap in our outpatient mental health supports.

To fill this gap, I have proposed a targeted drama therapy intervention based on role and performance theories. Role theory suggests that the roles we take on throughout our lives shape our behavior, personality, and identity (Landy, 1986; Landy, 1993; Landy, 2009; Ramsden & Landy, 2021). When a chronically ill adolescent becomes trapped in a role, such as “the sick one,” or cannot perform the functions of an expected role, such as “the adolescent,” they may begin to feel dissonance and dissatisfaction with their life (Kaynan & Wade, 2018). Drama therapy—specifically the container of the hero’s journey (Butler, 2017; Landy, 2012)—can offer a much-needed container to experiment with and eventually integrate new roles into our system, allowing access to a more cohesive and multi-faceted existence. When thinking about new roles, it is important for not only the individual to recognize them, but also for the individual to be witnessed and validated in these new roles by others. Especially when working with systematically oppressed populations, such as chronically ill and disabled individuals, performance can make a significant difference in how their community perceives them and, in turn, how they perceive themselves (Bailey, 2009).

Utilizing this foundation of literature and theory, I have proposed a six-week drama therapy group for adolescents with chronic illness focusing on their unique identity development needs (Cartwright et al., 2014; Dovey-Pearce et al., 2007; Hosek et al., 2002; Kirk & Hinton, 2019; Kuhlmann et al., 2023; Olsson et al., 2009; Wicks et al., 2019). Group members would lessen their sense of isolation by having the opportunity to form connections with chronically ill peers who experience similar challenges. Utilizing the hero's journey, they will be provided with a safe-enough space in which to try on roles and identities that may otherwise feel too threatening to experiment with in their daily lives (Butler, 2017; Landy, 2012; Ramsden, 2021). Finally, by being witnessed in these new roles through a devised performance, participants can begin to build their self-confidence and self-advocacy skills as they engage in their identity development journey (Bailey, 2009; Jones, 2007; Pendzik et al., 2016).

Overall, I believe there is much room for expansion when it comes to researching the benefits of drama therapy for adolescents living with chronic illness. Based on my own experiences as a chronically ill adolescent in theatre spaces as well as my experience running pieces of the proposed protocol on myself, I can attest first-hand to the power of drama therapy for understanding ourselves and our relationships to others. Looking forward, I hope to do further research in this area and implement my group protocol in clinical practice. I call my fellow drama therapy community members to consider where the gaps in our practice are and to humbly consider how we may better support the diverse and wonderful humans we share the world with. When someone tells you who they are, listen with an open heart and open mind.

Epilogue - Back to present day…

Who am I?

Who do I want to be?

With my illness, outside of my illness, because of my illness, in spite of my illness…

Right now, I'm a dis/abled and chronically ill graduate student talking to a younger version of herself. The tears flow as she remembers who she was and who she is. I hold her and let the pain come. I let her know I see her and accept all the different parts of her. I tell her….

She is sick

And she is also an artist, a dreamer, and a radical optimist.

She is sick

And she is a survivor of her own suffering and a witness to the suffering of others.

She is sick

And she is loved by so many people who do not shy away from her, and she loves fiercely in return.

She is sick

And she can change the world for other sick kids who need to know

They are sick

but also everything else they want to be too.

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

Angelle Cook

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