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The Hero's Journey as a Novel, Narrative, and Improvisational Group Intervention on Quality of Life for People with Parkinson's Disease

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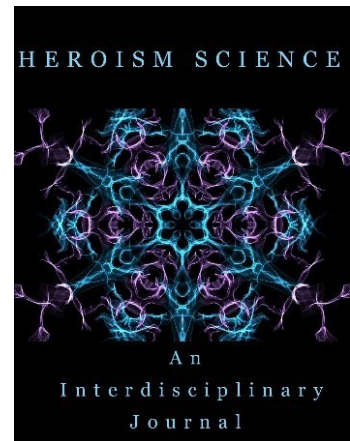
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The Hero's Journey as a Novel, Narrative, and Improvisational Group Intervention on Quality of Life for People with Parkinson's Disease



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ABSTRACT: Parkinson's disease (PD) is one of the fastest-growing neurological diseases in the world. Pharmaceutical and surgical interventions continue to advance to better address motor symptoms. However, disability from non-motor symptoms, such as depression, anxiety, and stress persist. Expressive therapies, including art, music, and dance are being explored and implemented more frequently to address this growing need. We developed this study to examine the feasibility of a novel program using online narrative therapy, with constructs from Joseph Campbell's Hero's Journey, and improvisation for people with PD (PWPD). Participants from across the U.S. and U.K. met online via Zoom once a week for one hour over the course of 27 consecutive sessions. A PhD student with a professional background in filmmaking and improvisation developed the sessions and led the program. The primary aim was to assess feasibility, the threshold for which was set at 70% of participants attending a minimum of 75% of the classes. Sixteen of 21 participants (76%) completed the study, with all 16 attending at least 85% of the classes. All participants who completed the study stated they enjoyed the class and would like to continue in the program and see it offered to others with PD. The secondary aim was to explore the participants' experience within the program using a phenomenological approach. Four major themes emerged: 1) There was a high level of interest in the intervention itself as it was deemed unique; 2) Participants struggled to see their own heroic qualities; 3) They reported high levels of connection within the group and 4) The emphasis on having PD faded, replaced by journeys of self-discovery beyond having PD.

1 INTRODUCTION

While advances in pharmacological and surgical therapies have helped many PWP live longer lives, many PWP experience the stigma of PD and the subsequent isolation (Maffoni, 2017). Many PWP are shocked by their initial diagnosis, and some try to deny the diagnosis or hide it from others (Quackenbush, 2011; Nijhof, 1995). This behavior, often rooted in the shock of receiving the diagnosis, can delay PWP from taking helpful treatments, engaging in exercise that is well-known to ease motor symptoms, and addressing or even recognizing increasingly prevalent non-motor symptoms including anxiety, stress and depression (Bermejo, 2020; Baker, 2004). Both motor and non-motor symptoms negatively affect the quality of life of PWP and can lead to a vicious cycle of avoidance behavior, lack of exercise, and isolation (Bryant, 2015). Non-motor symptoms are often difficult to recognize and diagnose because of the way they manifest individually within PWP (Gulunay, 2020). Non-motor symptoms compound the more generalized motor symptoms (Antonini, 2012).

Motor symptoms of the disease reduce the ability of PWP to perform activities of daily living, such as driving, bathing, and shopping for food (Soundy, 2014). Reduced abilities, combined with stress, anxiety, and communication issues, can lead to a decrease in social activities and increased isolation (Soundy, 2014). Because of the unknown, progressive nature of their illness, PWP are forced to adapt daily. It has been suggested that individuals with PD who are able to manifest positive attitudes and emotions as well as acceptance of the disease have better outcomes (Vescovelli, 2018).

We developed this study to test the feasibility of an online group to positively affect the way a group of PWP understood and felt about having PD. Participants met once a week for one hour over the course of 27 sessions (Table 1). The sessions comprised three main

modalities: theatrical improvisation games, lecture, and discussion about the hero's journey, as defined by the work of Joseph Campbell and the Hero's Journey. Additionally, guest speakers from a variety of backgrounds joined the group for 12 of the 27 sessions.

| Class with guest speaker (12 classes) | Class without guest speaker (15 classes) |
|---------------------------------------|--|
| Improvisation: 20 minutes | Improvisation: 25 minutes |
| Guest Speaker: 30 minutes | Power Point (Hero's Journey): 30 minutes |
| Q&A and review: 10 minutes | Q&A and review: 10 minutes |

Table 1 – An overview of the classes. There was a total of 27 classes in the program.

The first element of the intervention was improvising, defined in this study as unplanned collaborative response. It involved listening and responding to unexpected and unknown prompts, encouraging participants to heighten their focus, listening skills, and becoming present-minded. Improvisation has been shown to be an enjoyable activity that promotes feelings of acceptance, compassion, and confidence in PWP (Bega, 2017). Improvisation has also been shown in clinical trials with older adults to reduce anxiety, stress and depression (Zarate, 2016; Morse, 2018; Lindquist, 2021). Improvisation requires active participation, communication, and unconditional acceptance, via the foundational phrase “yes, and.” “Yes” refers to acceptance of the information. “And” is used to add novel information to the original information. In PD, terms that can be operationalized to say, “**Yes**, I have PD, **and** here's what I'm going to do about it”. Participants in similar programs have reported feelings of heightened awareness, listening, and improved connection to their own feelings and those of their fellow participants (Bega, 2017; Zarate, 2016; Leonard, 2015).

Improvisation has also been shown to help participants enter a flow state, where novel thoughts and creativity thrive (Limb, 2008; Csikszentmihalyi, 2014). Positive flow states, often engaged in through exercise or connection to an activity where skill-level meets challenge-level equally, have been associated with increased focus, happiness, and self-esteem (Mao, 2020; McHugh, 2016). Creativity, via divergent versus convergent thinking, has been shown to help individuals produce novel thoughts, solutions and even products, which may contribute to psychological wellbeing and self-efficacy (Shen, 2020; Felsman, 2020).

The second element of the intervention was learning and applying Joseph Campbell's Hero's Journey. The hero's journey is an archetype prevalent in every known culture's storytelling, dating back to cave art (Allison, 2019; Campbell, 2008). In short, a hero's journey is a linear series of narrative steps including innocence in an ordinary world, a call to adventure, tests, empowerment, death (which may be literal or metaphorical), resurrection and a celebration of new understanding and the hero's newly earned elixir to heal the ordinary world (Figure 1) (Williams, 2019). Research shows the universal human appeal of transformation from ordinary to heroic in societies across all geographies, time periods and cultures (Allison and Goethals, 2017; Efthimiou and Franco, 2017; Efthimiou et al., 2018). As Parkinson's is a neurodegenerative disease, understanding the process of neurogenesis, or growth of new brain cells in the hippocampus via exercise, meditation and learning as part of the hero's journey may be of particular interest (Allison, 2019). The hero's journey is highly adaptive and has been used effectively in therapy sessions to treat anxiety, depression, addiction, and trauma (Lawson, 2005; Halverson, 2021; Rubin, 2009). We employed a framework based on Joseph Campbell's Hero's Journey in this study as a form of narrative therapy, which encouraged participants to rewrite their personal narrative by deconstructing, reconstructing then merging new understandings into their current lives (Lopes, 2014).

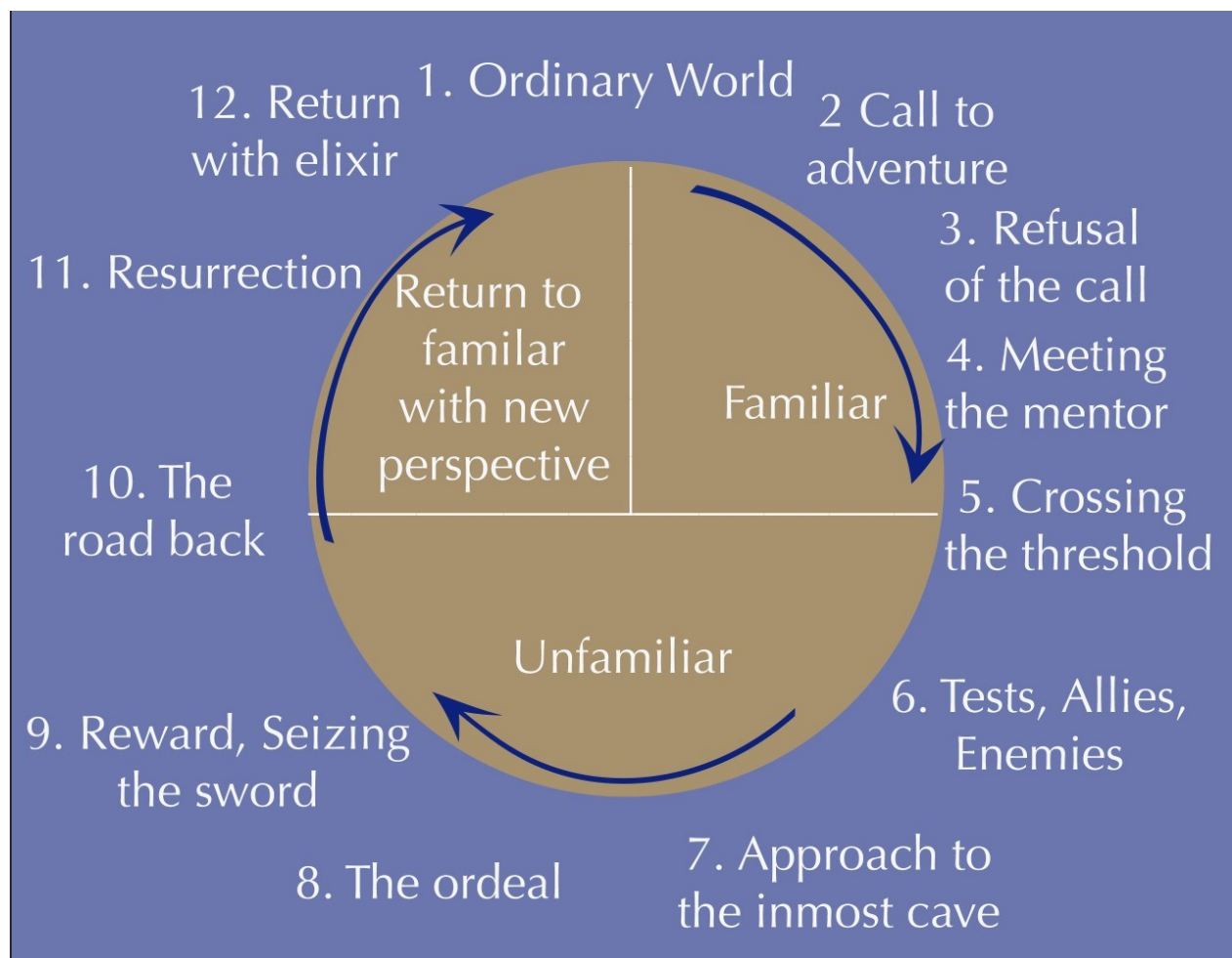


Figure 1 - The Hero's Journey, based on the work of Joseph Campbell.

The first stage of the hero's journey for participants in this study, the "Ordinary World", is their life before being diagnosed with PD. The second stage, the "Call to Adventure", is the moment of the diagnosis. There is research that suggests that, in PWPd, accepting PD as a part of their lives will allow a new perspective, helpful medications, exercise and socialization to become normalized (Gardenhire, 2019; Maffoni, 2019; Holt-Lunstad, 2011). As noted above, the "Refusal of the Call", or diagnosis, is common (Eccles, 2011; Rosinczuk, 2019; Rosinczuk, 2017). Even with the acceptance of their diagnosis, many PWPd have not processed how they feel about it or measured how they have adapted to it. (Rosinczuk, 2017). In the fourth stage, "meeting the mentor", the PWPd find or recall an individual who has helped them understand or adjust to the new reality of having PD. As the

remaining stages become more subjective as each PWPD's journey branches in unique directions, we include a more generalized definition of each step:

1.5 CROSSING THE THRESHOLD

The hero steps into full acceptance of the journey. There are often threshold guardians, which can manifest as people, animals, elements, or even belief systems that block the hero's path. They may mean well. They may simply warn. It does not have to be a violent conflict, nor do they have to be vanquished. The hero can transform them into powerful friends or allies.

1.6 TESTS, ALLIES AND ENEMIES

Crossing a threshold is not necessarily easy nor comfortable. Some crash upon arrival. At this stage, the hero orients herself to her new world. She meets new people - some who will help, some who may hinder. She sees what they offer and need in this new environment. This may be a time for training, building strength, gaining knowledge and preparing to make The Approach.

1.7 APPROACH TO THE INMOST CAVE

The hero identifies the central conflict and the plan to engage begins. However, setbacks occur that cause the hero to try a new approach or adopt new ideas. The cave is often metaphorical, a place the hero must go to face the central conflict in The Ordeal.

1.8 THE ORDEAL

This is often the low point on the hero's journey - where all seems lost. There may, in fact, be a literal or metaphorical death here. The hero may have to kill off a belief system held to progress on the journey. In terms of PD, many people struggle with getting enough exercise to have a positive effect on their quality of life. Negative or limiting belief systems may

include: “I’m not an athlete,” “But I’ve always eaten this way,” “The way I feel doesn’t matter,” “I show up to exercise classes already.”

1.9 THE REWARD

The Ordeal has been faced and something has been won. This can be literal, like a sword in the case of King Arthur, or metaphorical like headspace earned from a voice or belief system being vanquished.

1.10 THE ROAD BACK

The hero now must demonstrate what she has learned and that she truly is a hero. For example, a PWPDP exploring their relationship with exercise in their hero’s journey, this may be where they demonstrate growth and a new community.

1.11 RESURRECTION

Before the hero can return home, he must face one final encounter. In this moment, there is often a death – sometimes of an antagonist or a personal belief system. The hero demonstrates mastery over the skills that have been learned.

1.12 RETURN WITH ELIXIR

The quest is complete. The world is set right for the hero. Evil has been defeated (for now). The heroic acts are recognized, celebrated and those who remained in the ordinary world will now receive the knowledge or gifts earned by the hero.

Understanding the psychological benefits of the hero’s journey may be helpful to PWPDP, as it is common for PWPDP to feel isolated and stuck in a ruminating cycle of fear, regret, and sorrow. The hero’s journey is constructed to encourage the hero to look beyond herself, moving from egocentricity to sociocentricity (Campbell, 1988, p. 188). The hero

must believe he or she is worthy and capable of having something of value for others, however that can only be illuminated in the action of the journey itself. Many PWPD fear an increased dependence upon others and a loss of autonomy. This can result in a loss of physical, emotional, and spiritual movement. Heroes are often forced to overcome losses and obstacles in their journeys. Campbell argued that the psychological transformation comes from not only acceptance of the current self, but a love and a service to the preservation and growth of it (Campbell, 1991, p. 207). This also fits the principles of acceptance and commitment therapy, which focuses leading participants to acceptance over avoidance, promotes the act of being fully present, and promotes patterns of committed action (Hayes, 2006). The principles and psychology of both the hero's journey and improvisation also fits the greatest block in being transformed: saying no to the journey. This can happen if the participant sees himself as a victim and therefore incapable of making the transformation to become a hero (Allison, 2019). While it is not necessary, nor even necessarily beneficial, to take responsibility for having PD as there is no clear path to how PWPD become afflicted, it is crucial to accept the reality of the diagnosis and the inevitable progression of symptoms in order to affect change and improve quality of life.

The third and final element of the intervention was interacting with guest speakers. Twelve guest speakers shared their expertise from a multitude of disciplines, including music, dance, mythology, metaphors, physical exercise, vocal exercise, beat boxing, rap music performance, apparel, and art therapy to broaden participants' perspectives. Many PWPD feel powerless in their loss of abilities, functionality, and communication, which can become a vicious cycle leading to lack of movement and growing isolation (Bermejo, 2020; Eccles, 2011; Subramanian, 2020). A 2019 study on Parkinson's UK's "First Steps," an early intervention program to educate and motivate PWPD to live well, identified the positive effect of storytelling elements on newly diagnosed PWPD and showed improved exercise and

coping mechanisms by participants (Soundy, 2019). We hypothesized that exposing participants to new modalities and activities in a positive, reaffirming group setting, combined with a structured journey, might allow them to see their own possibilities, capabilities, and narratives differently.

2 METHOD

We recruited participants via flyers from groups including the American Parkinson's Disease Association Northwest, Parkinson's Foundation and Parkinson's UK. The program began in October 2020 with 21 participants. The inclusion criteria were males and females with a diagnosis of idiopathic PD (of unknown cause); Participants had to be on a stable PD medication regimen prior to starting the study and remain on it throughout; All participants were required to sign the informed consent form. There was no exclusion for age or Hoehn and Yahr scale rating. The Hoehn and Yahr scale is a five-point scale measuring the motor progression of PD for the individual, with a score one indicating the least severe symptoms (e.g. a minor tremor in one hand) and a score of five signifying the most severe symptoms (e.g. being bed-ridden). This study was funded by a Parkinson's Foundation community grant and approved by the University of Nevada, Las Vegas institutional review board (1645598-3).

We asked participants (Average age: 66, 14 females, two males, average number of years since being diagnosed = 7, range of year of diagnosis = 2005-2019, mean age = 66, range = 46-81) to write one page per week about the stage of the Hero's Journey discussed in class and their feelings about it. Participants submitted their writing with their fellow participants in a password-protected Google Drive. The instructor read and gave feedback on all assignments. Participants were encouraged to read each other's work and offer feedback

as well. The same instructor led every class and took attendance at each session. All sessions were recorded.

The primary aim was to assess the feasibility of the hero's journey with elements of theatrical improvisation as an intervention. We set the threshold for feasibility at 70% of participants attending a minimum of 75% of classes. Classes began with an upbeat song chosen by one participant for everyone to move or dance to. Whoever chose the song would share why that song was meaningful to them with the group. Participants then practiced theatrical improvisation games to build teamwork, develop confidence, and improve communication skills within the ensemble. For example, the foundational game of "mirror" begins with participants following the leader's movements, which are intentionally slow, simple, and easy to follow. Once participants show understanding, the game becomes a "switch mirror". When the leader calls "switch", participants can choose to lead or find someone new to follow. Participants learn the value and power of choice, as well as what it feels like to rapidly shift roles from leader to follower, and vice versa. In the final iteration of the game, we instructed participants to mirror (yes), then exaggerate (and) the movements and sounds they were reflecting. We encouraged them to be large physically and vocally, increasing amplitude and reminding themselves of their full and creative potential. Participants were asked what they felt during the game and why they thought we played it. This often led to discoveries, with participants reporting the potential for transformation of perspective and behavior in their weekly writings.

To make the Hero's Journey more recognizable, we demonstrated it in each of the 12 steps with brief video clips from *Star Wars: A New Hope*. We used this 12-step model developed by author Christopher Vogler from Joseph Campbell's work as a framing device (Figure 1) (Vogler, 2017). Vogler is well-known for his use of the Hero's Journey to break

down the structure of popular films (Vogler, 1985). Star Wars Director George Lucas was the first filmmaker to overtly credit Joseph Campbell and the Hero's Journey as a way of connecting his historical space opera ("*a long time ago in a galaxy far, far away...*") with a modern audience (Vogler, 2017). Participants also watched 12 clips from the award-winning documentary, *Boys of Summer*. Once again, each clip highlighted a step from the Hero's Journey. *Boys of Summer* tells the story of a father with PD and his son road-tripping across the United States to see a game at each of the 30 Major League Baseball parks and learn about PD along the way. The writing assignments helped participants further explore their own feelings about PD, their actions, and inactions, and to consider themselves as heroes on a journey that includes PD, rather than being solely defined by the disease.

We used the following prompts for participants' post-intervention analysis:

- When I first heard about this class I thought...
- I decided to sign up for this class because...
- After the first session, I thought...
- The first time I did improv I thought...
- When I heard about the Hero's Journey I thought...
- When I was asked to consider myself a hero I thought...
- When I saw we were going to study Star Wars I thought...
- When we completed the Hero's Journey I felt...

Finally, we recorded interviews with participants after the program to assess their satisfaction with the program.

3 METHOD

Of the initial 21 participants, 16 completed the program. The five participants who dropped out cited scheduling conflicts, all leaving the program within the first five sessions. The remaining 16 all attended at least 85% of the classes. There were 13 participants from across the U.S. and three from the U.K. The participants who completed the study noted the unique and enjoyable nature of the program, the feelings of acceptance within the group, as well as its practical value in terms of safety and convenience. Covid-19 was a major isolating factor for many participants during this program. Participants formed their own group for a weekly discussion on their progress, which they dubbed “sidekicks.” We invited participants to share their feedback as a creative expression based on anything they learned in the class at the final online meeting on April 19, 2021. We invited friends and family to the Zoom webinar to observe what was shared. Participants created and sang songs, shared artwork, and performed skits. All the participants said they would recommend the class to others with PD, and all requested a continuance and expansion of the Day One program.

Because of the open-ended, individualized nature of the program, we also distributed a series of prompts related to the experience at the end of the program for participants to fill out on their own. The prompts are included in the supplementary materials. Additionally, we conducted a series of semi-structured one on one interviews between each participant and the class facilitator via Zoom lasting approximately 25 minutes apiece. This style of interview has been noted to be effective in previous studies with elderly populations with mild to moderate dementia (Stevens, 2012).

3.5 THEME 1: HIGH LEVEL OF INTEREST IN THE INTERVENTION ITSELF AS IT WAS DEEMED UNIQUE

Many participants reported the initial shock of their PD diagnosis was so great that it sent them into extreme feelings of shock, anger and fight or flight. The opportunity to explore their feelings about their diagnosis retrospectively and how they were living with the disease within a group of peers was seen as novel and intriguing. Many of the major PD agencies, including the Michael J. Fox Foundation, Parkinson's Foundation, and Davis Phinney Foundation solicit and share individual's stories of living with PD. There are no other known programs that assist PWP in learning how to explore and write their story. Participants in this program were given a highly structured and still flexible pathway to question, discover, understand, and ultimately share their unique stories.

"The concept of the Hero's Journey is fascinating, especially as applied to Parkinson's. I am mystified, curious and interested all at the same time."

"Never heard of this before. Hmmmm, how does the Hero's Journey apply to the course and to me? It's uncharted territory but let's see where this goes."

"I've had Parkinson's for 16 years and I'd never seen a study like this before."

These reported levels of engagement and curiosity are important because of the high levels of reported isolation and apathy in the PD community (Lazcano-Ocampo, 2020; Bega, 2016; Hermanowicz, 2022).

3.6 THEME 2: PARTICIPANTS STRUGGLED TO SEE THEIR OWN HEROIC QUALITIES

The word "hero" caused significant discomfort when participants were asked to apply it to themselves or their own lives. Feelings of unworthiness and doubt were expressed. The

question of what a hero was, in the classic and metaphorical sense, as well as the modern interpretation, was explored. Several participants mentioned the classes closer look at Luke's journey in *Star Wars*, beginning as a typical teenager on a farm longing for adventure, then suddenly being thrust into a battle at the highest level, gave them greater understanding of the arc of a hero. Similarly, several participants said seeing Robert's father and Robert explore the beginnings of their own relationship with PD in the first *Boys of Summer*, gave them confidence to look back at how they felt at the early stages of their diagnoses.

"I did not connect anything I had experienced in life as 'heroic'—it was a far reach to connect my life with the 'Hero's Journey'. I thought being a hero was something someone else might say about me, but not me say about myself."

"For me, at first, the concept of 'Hero' was a cartoon-like image—someone with superhuman power and strength who has exaggerated traits like the ability to fly or see through walls. That wasn't me; I was a person of quiet human qualities like empathy and patience and acceptance, which I didn't see as 'heroic'".

"I didn't know what to make of it. Were we the heroes? Was I going to discover a hero who will come and save me? Do I need saving? So I think it raised more questions than answers."

The participants difficulty in seeing themselves as hero is consistent with the third step in the Hero's Journey, the Refusal of the Call.

3.7 THEME 3: HIGH LEVELS OF CONNECTION WITHIN THE GROUP

Participants described the program and the interactions with their classmates and the instructor as life changing. There were calls to continue the program and see it expanded so others could experience it, too. Out of the 16 who completed the group, 11 enrolled in a

second round of the program with a focus on mentoring the next group of participants through the hero's journey.

“The group of heroes are lovely, intelligent, funny, and accomplished people who just happen to have Parkinson's.”

“Amazing how a small group of people from all parts of the country, including overseas, can come together and develop a camaraderie and a shared journey. A journey that led to unexpected ideas, creations, and alternative ways of moving thru our daily trials and tribulations, mental or physical. Everyone's path was different, but each person's experience was a new path in the making.”

“I feel a little sad that our journey is coming to an end, and grateful for the experience and for my fellow superheroes.”

The participants saw and felt the connections within the group and through their shared experiences along each of their hero's journeys. These experiences relate to stage six (Tests, Allies and Enemies), where new bonds are formed through collective agreement to cross the threshold from the ordinary (known) world into the special (unknown) world. The feelings of gratitude and self-reflection indicate the 12th step, the Return with Elixir, when the hero has completed her task and is now able to reflect clearly on the breadth, difficulty, and lessons of the journey, including those who helped make it possible.

3.8 THEME 4: EMPHASIS ON HAVING PD FADES, REPLACED BY JOURNEYS OF SELF-DISCOVERY BEYOND HAVING PD

As the weeks went on, participants shared more about their lives beyond PD, including a focus on exercise goals, family, and their plans for the future. The wide variety of

guest teachers inspired participants to look at what they were capable of with open and positive attitudes, particularly when they were stretched beyond their comfort zones. Many participants shared stories of the reactions they got from loved ones about the positive changes, like improved mood and increased levels of engagement and exercise that took place during the program.

“Writing helps to clarify my thoughts, yet nine years after diagnosis I had neither explored too deeply nor written about having PD.”

“After this class I started practicing walking with intent during off times. The first time I showed my husband by walking across the room in an off state, and then walking back with intent he cried.”

“I felt a great accomplishment; that I had been called upon to go inside, dig deep, stretch, and then share the findings. For most of us on the perilous PD path, sustaining Hope and Motivation is extremely challenging, so I am thrilled to have this take away. Yes, and I wish that more PWD could have the opportunity to travel the Hero’s Journey. What if this program became available to everyone in the entire worldwide PD community?”

Seeing completed tasks and accomplishments that may have felt impossible at one point and feeling pride in them is a common part of the 12th step, the Return with Elixir. Understanding that the journey was not only about what the hero gained but, perhaps more importantly, about what he will do to make the world better with this newfound knowledge and strength is a significant step forward for a person whose Ordinary World, Call to Adventure, and Refusal of the Call may have been littered with doubt and negative self-assessment.

4 DISCUSSION

This is the first known clinical study to use elements of improvisation and Joseph Campbell's Hero's Journey as an intervention for PWD. The Hero's Journey and the consciousness one gains within it has been used as a tool for enlightenment and positive growth in a variety of health-related interventions including stroke rehabilitation, therapy and with recovering alcoholics (Charles, 2020; Vecchiolla, 2016; Rodriguez-Morales, 2019, Allison, 2019). The attendance and qualitative feedback of participants in this study seem to validate what previous non-clinical interventions suggest, including that the intervention was enjoyable, instructive, and offered practical tools for positive change for participants of different ages and disease severity.

Traditional support groups are often presented as an opportunity to increase socialization and exchange information. However, the patient satisfaction measures from support groups are mixed. According to a study taken from the Muhammad Ali Parkinson's Disease Registry, only 49% of respondents who attend support groups are highly satisfied (Dorsey, 2010). One patient reported: "all a support group has done for me is show me how bad the future can get because of progression of disease. It scares me!" (Dorsey, 2010). In that same study, 85 percent reported being "very or extremely concerned" that their support group did not meet their individual needs, citing transportation to and from the meetings as an issue.

Telehealth programs may offer some solutions to those who have transportation issues. Online programs have grown exponentially since the Covid-19 outbreak (Thomas, 2022). We originally planned this program as an in-person offering but repurposed it to the online forum because of safety and health protocols brought forth to mitigate the spread of Covid-19. Even before Covid-19, interest in telehealth offerings was growing (Banbury,

2018). Being online allowed participants from a wider geographical area to take part.

Participants mentioned enjoying meeting new people in the PD community from different parts of the U.S. and U.K. It is possible that sharing this program with PWPD in relatively distant locations helped relieve feelings of isolation.

Many PWPD live “in the Parkinson’s closet”, fearful of social stigma and losing their career or medical benefits (Maffoni, 2017; Ma, 2016). Michael J. Fox wrote about hiding his diagnosis for seven years, before showing his “off-medication status” and speaking about it in front of the United States Congress in 1998 (Moe, 2012). People who are diagnosed earlier often live longer with their symptoms, making the management of their symptoms of paramount importance (Pagan, 2012). By presenting an intervention that helps people see positive opportunities while living with Parkinson’s, including their own strong, capable, and even heroic qualities, this program may help reduce non-motor PD symptoms, improve self-efficacy, and help PWPD pull themselves out of isolation.

It is also possible that by engaging in the hero’s journey, the PWPD may transform not only herself but also others in their families, workplaces and the community at large. It has been suggested that “transformed people transform people” (Rohr, 2020, p. 263). Engaging in the hero’s journey may prepare participants for leadership roles (Allison, 2019). This stage is a natural byproduct of the cycle in the role of the mentor, who passes the training she received from a mentor before her. This fits broadly into the theory of generativity, which involves the concern for and commitment to the prosperity of generations to come (Slater, 2003).

5 CONCLUSION

It is important to recognize the limitations of this study and not draw conclusions beyond the scope of the research. The relatively small, nonrandomized sample limits the reliability and generalizability of the results. The treatment, itself, is somewhat complex and likely requires an instructor or team of instructors with several specific skill sets. Because of the different modalities within the intervention, it is difficult to know, beyond the qualitative statements, what sections had the greatest impact on specific individuals. This is a global problem in the treatment of PD as the symptoms are so individualized. As the saying goes, “If you’ve met one person with Parkinson’s, you’ve met one person with Parkinson’s.”

While this program was open to all PWPD, we recommend future versions invite a few specific underserved groups within the PD community, including those who identify as LGBTQ+, ethnically diverse, care partners of PWPD, military members (current and retired), and Young Onset PD (YOPD) – diagnosed before the age of 50. Reaching out to these groups will allow participants to show the diversity of their experiences, which both strengthens our understanding of how PD manifests, and the highlight the commonality of the experiences, which strengths the community.

Helping PWPD understand and share their story also helps breaks down false and potentially dangerous belief systems. For example, YOPD are estimated to make up only 10-20% of the currently diagnosed population with PD, but the number of people who fit YOPD criteria is likely much larger (Kim, 2013). Most people live with PD for several years before being diagnosed, particularly in the YOPD population. Some people do not know they have PD, mistakenly thinking of it as solely an “old person’s disease.” Other people suspect the diagnosis but avoid seeing a specialist out of fear of what a diagnosis might mean for the future. The danger of letting PD go unchecked is in the loss of time and opportunity to delay,

manage, and improve motor and non-motor symptoms. Many PWPd can delay progression of their symptoms with exercise, medication, and socialization (Ahlskog, 2018; Ellis, 2017). While it may be difficult to find undiagnosed PWPd, the benefit of recruiting these PWPd may have a longer lasting effect, and the results may help bring more PWPd forward.

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7 CONFLICT OF INTEREST

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.