


# Moving beyond the physical: exploring the holistic benefits of a therapy-based physical activity program for individuals with Parkinson's disease

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## Abstract

In individuals diagnosed with Parkinson's Disease (PD), a chronic neurodegenerative disorder affecting movement and functionality, therapy-based physical activity (PA) that includes repetitive, quick motions benefits physical and cognitive functioning and can positively impact the disease course. Furthermore, the benefits of therapeutic PA participation may extend beyond physiological outcomes by positively influencing social and psychological well-being, thus increasing the overall quality of life (QoL). The current research examined a regional healthcare system-supported group therapeutic boxing/PA program for PD using a biopsychosocial lens to synthesize the holistic benefits of long-term program participation. Researchers conducted semi-structured focus group interviews with program participants (n = 18) and their caregivers (n = 7) to explore the perceived benefits of a combination boxing/PA program that included 30 minutes of boxing and 30 minutes of an alternate rotating PA 1-3 times per week. Results indicated a positive impact on participants' and caregivers' QoL by increasing socialization and empowerment and improving/maintaining physical function. These results demonstrate the importance of using a biopsychosocial approach in program design and

evaluation of PA-based PD interventions. In addition to addressing PD-specific physical needs, PA programs should be constructed to include supportive social atmospheres and consider non-physical needs and overall QoL outcomes of patients and caregivers.

**Keywords** Quality of Life • Physical Activity • Parkinson's Disease • Boxing • Self-efficacy

## Introduction

Parkinson's disease (PD) is a neurodegenerative disease characterized by diminished motor activity, tremors, rigidity, balance instability, and cognitive deficits, resulting in reduced physical functioning and decreased quality of life (QoL) (Hoehn & Yahr, 1967). Due to the progressive nature of PD, successful treatment is characterized by the maintenance of the status quo or small improvements, with the best-case-scenario being the maintenance of current abilities for as long as possible before inevitable decline (Rosenthal & Dorsey, 2013; Santiago et al., 2015). There is a growing body of literature suggesting a positive impact on both physical functioning and overall QoL when individuals with PD participate in regular physical activity (PA) as a complement to drug therapies (da Silva et al., 2016; Lucia et al., 2014; Rosenthal & Dorsey, 2013; Schrag, Jahanshahi, & Quinn, 2000). For many individuals with PD, this means finding adaptive PA that caters to the physical limitations specific to PD (Lucia et al., 2014).

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PA programs which include repetitive quick motions, such as dance and boxing, are effective for therapeutic rehabilitation for individuals with PD (Šumec, Filip, Sheardová, & Bareš, 2015). These programs have demonstrated positive physical outcomes, but have only undergone cursory examinations related to psychosocial outcomes. Additionally, the majority of interventions have been based on a single PA modality. Therapeutic PA programs that concurrently combine aerobic and strength-based activities, and incorporate repetitive quick motions have not been explored in-depth in a qualitative manner to identify patient-perceived physical and psychosocial benefits to QoL.

While the physical benefits of PA participation for people living with PD are understood, exploration continues into the most effective PA modalities to maximize psychological benefits and maintain participation (Nimwegen et al., 2011). Long-term PA participation depends on the development of self-efficacy and intrinsic motivation (Sweet, Fortier, Strachan, & Blanchard, 2012; Teixeira, Carraça, Markland, Silva, & Ryan, 2012). Self-efficacy can be understood as situation-specific self-confidence and is an essential component of maintaining behavior (Bandura, 1997). In a PA context, self-efficacy enables the individual to feel enjoyment and satisfaction thus developing intrinsic (internalized) motivation for the behavior (Sweet et al., 2012). For individuals living with PD, maintaining high levels of self-efficacy for PA is challenged by the inevitable physical decline (Urell, Zetterberg, Hellström, & Anens, 2019). Participants in PA programs that incorporate self-efficacy protocols report decreases in depression and increases in QoL (Wu, Lee, & Huang, 2017). Furthermore, when intrinsic motivation and self-efficacy are facilitated in group settings with social support, individuals exhibit higher levels of self-efficacy, and report more satisfaction with the activity, thus increasing long-term adherence (Edmunds, Ntoumanis, & Duda, 2006; McAuley & Blissmer, 2000).

Social support is essential to PA participation (Rodrigues de Paula, Teixeira-Salmela, Coelho de Moraes Faria, Rocha de Brito, & Cardoso, 2006), and individuals living with PD repeatedly report higher QoL when they are part of PD-specific groups (Hackney & Earhart, 2009; Rodrigues de Paula et al., 2006). Additionally, social support for the individual with PD and their caregiver has the potential to increase program retention and compliance (Quinn et al., 2010; Rodrigues de Paula et al., 2006). Unfortunately, social, psychological, and QoL

benefits are rarely considered in PA program design, evaluation, or outcome assessments. Given the degenerative nature of PD, if programs are being assessed only on functional improvement, benefits may be interpreted as negligible or limited at best. Instead, programs should be purposefully designed to address psychosocial well-being to provide holistic program benefits.

One model for PA programming that effectively incorporates a holistic approach is the biopsychosocial model of patient care. The biopsychosocial model posits that in addition to physical symptoms, social and behavioral constructs influence an individual's experience of their disease, therefore programming should address physiological, psychological, and social factors (Wade & Halligan, 2017). This model has begun to garner support in treatment with chronic disease populations (Black & Dorstyn, 2015). Programming based on a biopsychosocial model addresses the biomedical component of care but also considers how a person's beliefs, behaviors, knowledge, and social environment affect the person (Wade & Halligan, 2017). Intuitively, some programs already do this. By examining the lived experiences of participants in these programs, we can better understand programmatic factors that contribute to psychological and social benefits beyond the frequently reported physical benefits. For a disease such as PD, this is crucial for the development of patient-centered therapeutic care.

Numerous studies have examined the impact of PA on the QoL for individuals living with PD (Chen et al., 2020); however, to our knowledge, there is no research examining the holistic impact of PA programming through a biopsychosocial lens. The current study focuses on a local healthcare system-supported program that has been intuitively incorporating biopsychosocial components of PA programming into a PD-specific group boxing/PA program. The program began three years before data collection and consisted solely of boxing as the means of PA, but was switched to include additional PA modalities in conjunction with boxing 6 months before data collection. Given the aforementioned information, the current project aimed to use an observational descriptive qualitative approach (Sandelowski & Barroso, 2007) to examine this existing PD-specific boxing/PA program through a biopsychosocial lens to explore the reported experiences of participants and caregivers. The goal was to provide an in-depth understanding of the lived experience of the program participants.

## Method

### Participants

Participants were recruited from a regional healthcare system-supported boxing/PA-based program for individuals living with PD called Thrive - Parkinson's Exercise Program (Thrive-PD). All individuals who participated in Thrive-PD were approached for inclusion and eighteen participants (13 male, 5 female), aged 60-86 years, enrolled in the Thrive-PD program at a regional health and wellness center, agreed to participate in the study - representing all but 2 current program participants. The participants had varying PD severity and symptoms, physical and mental abilities, and years since diagnosis (Table 1). All participants had a medical diagnosis of PD or related neurodegenerative disorder, had been referred to the program by a healthcare provider, and had been actively participating in Thrive-PD for at least 3 months. Two participants did not have PD but had other unspecified progressive neurological disorders for which their physicians felt the Thrive-PD program would be beneficial. When available, the participant's caregiver (n = 7) also took part to aid the interview process and provide their perspectives. Three Thrive-PD program administrators/staff were also interviewed. Participant demographics and indicators of disease severity/duration are presented in Table 1.

**Table 1.** Descriptive data

Variable	n	%
<i>Gender</i>		
Males	13	72
Females	5	28
<i>Age</i>		
60-69	4	22
70-79	10	56
80-89	4	22
<i>Time since diagnosis</i>		
0-5 years	5	28
5-10 years	4	22
10-15 years	3	17
15-20 years	2	11
Unknown	3	17

**Table 1.** Descriptive data (continued)

Variable	Median	Range
<i>Parkinson's Disease Questionnaire - 39</i>		
Mobility	39	(20-88)
ADLs	40	(27-77)
Emotional Well-being	32	(20-80)
Stigma	25	(20-50)
Social Support	23	(20-60)
Cognition	50	(20-80)
Communication	47	(20-87)
Bodily discomfort	47	(27-80)
PDQ-39 Summary Ind.	42	(25-59)
	n	%
<i>Use of Assistive Device*</i>		
None	9	50
Cane	6	33
Walker	3	17
Wheelchair	2	11
Other Unspecified devices	1	6

\* – Those using an assistive device could select more than one device

### Program Structure

The Thrive-PD program was held at a hospital-managed regional healthcare rehabilitation facility that specializes in treatment and therapy programs for cardiovascular, neuromuscular, and cardiopulmonary diseases. When initially developed by a physical therapist specializing in neurological rehabilitation, the Thrive-PD program structure involved a one-hour boxing circuit, which included stations that participants rotated through with exercises involving the speed bag, standing punching bag, agility ladder drills, and individual sparring with the program instructors (see Table 2). Exercises were individualized to each participant's level of function. Classes were held three days per week with participants attending 1-3 classes weekly. Class sizes averaged between five and eight participants of various ability levels with everyone participating concurrently. Approximately two and a half years after inception, the structure of Thrive-PD was changed to accommodate growing program enrollment, provide alternative forms of PA in addition to boxing, and allow for more individualized PA programming for participants of differing ability levels and disease progression. The revised Thrive-PD program included 30 minutes of a rotating alternative PA (cycling, Tai Chi, yoga, Zumba™,

and weight training) and 30 minutes of the previously described boxing circuit workout. For each session, participants were divided into 2 groups; one group started with boxing, and the other with the alternative PA. After 30 minutes, the groups switched. Each group had a maximum of three individuals during the

boxing portion of the class to allow for more specialized training and one-on-one work with the staff. Caregivers were invited to take part in the alternative PA. As with the initial inception of the program, each participant continued to attend 1-3 times per week. skinfold.

**Table 2.** Boxing exercise descriptions

Exercise	Description
Speed Bag	Small, hanging punching bag used for punching in rapid succession to strengthen hand-eye coordination, rhythm, and speed.
Standing Punching Bag	A larger stationary punching bag is used to strengthen punching power in addition to side-to-side stepping movements.
Agility Ladder	The ladder apparatus was placed on the floor. Patients completed various footwork drills for time.
Sparring	Participants undergo sparring drills with program staff, emphasizing punching accuracy with forward and backward walking movements.

### Measures

This study was a descriptive qualitative exploration into the lived experiences of the participants, as such, primary data collection was done through qualitative interviews. To provide a detailed understanding of participants, basic demographic information including age, gender, time since PD diagnosis, common symptoms, and use/type of assistive device was collected using a basic pencil and paper survey. Additionally, the survey included the Parkinson's Disease Questionnaire -39 (PDQ-39), a 39-item self-report questionnaire that assesses PD-specific QoL constructs over the previous month. The PDQ-39 divides result into eight sub-categories: activities of daily living, attention and working memory, cognition, communication, depression, functional mobility, overall quality of life, social relationships, and social support; with participants ranking responses to individual questions on a 5-point Likert-type scale ranging from "never" to "always" (Jenkinson, Fitzpatrick, Peto, Greenhall, & Hyman, 1997). The inclusion of the PDQ-39 was to provide a numeric assessment of the participants' reported disease progression. If participants were unable to complete any portion of the survey due to physical limitations, their caregiver and/or a member of the research team assisted with completion.

For primary data collection, a semi-structured interview guide was developed and centered on the participants' views on the following general topics: expectations and goals for Thrive-PD participation, benefits/barriers of the Thrive-PD program structure,

Thrive-PD program staff, the impact of the Thrive-PD program environment on participation, the overall role of PA in the participant's life, and the benefits/barriers due to the social aspects of the Thrive-PD program. Each general topic had several questions including helping facilitate discussion. The complete interview guide can be found in Appendix A (available at: [www.shorturl.at/BLMV2](http://www.shorturl.at/BLMV2)).

### Data collection

Data were collected through in-person, semi-structured focus group interviews between the participants, their caregivers (if present), and the research team. Ten focus group interviews were conducted with two to six participants and/or caregivers per group. Interviews were conducted at the program facility immediately pre- or post-Thrive-PD program participation and participants were randomly grouped based on convenience to their schedules. Additionally, a focus group interview was conducted with the three full-time Thrive-PD staff who developed and ran the program. The same interview guide was facilitated at each interview, with a discussion between questions. Probing questions were used when appropriate to elicit further in-depth responses. Sessions were conversational with the interviewer focusing the conversation back on the questions as needed. Interviews lasted between 30 minutes and 1 hour, were electronically recorded, and notes were taken on major themes and discussion topics. Before each interview, the pen-and-pencil survey with patient demographics, disease characteristics, and the PDQ-39, was collected.



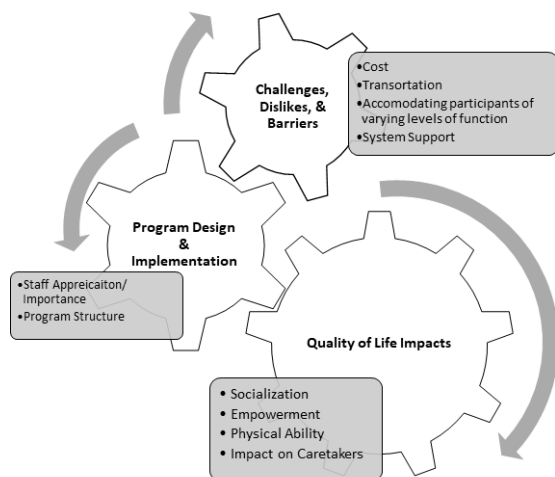


Figure 4. Primary Themes<sup>2</sup>

### QoL Impacts

*Socialization - being with similar others.* Participants discussed how Thrive-PD created an opportunity for socialization. They explained, “We look forward to mingling with the other people”; “It’s so wonderful having this group to relate to.” The word “camaraderie” was used often to describe the relationships within the program. Participants had a common goal - disease management - and this created meaningful relationships. “[We] don’t sit around and complain to each other about PD, [we participate] and find solutions.” and “Even if we aren’t slowing down the disease, we are not alone in the fight.” The staff emphasized how social connections were important during program design. One staff member explained, “healthcare should [develop programs for the]...inclusion of all people who want to benefit from this [group PA] environment.” Inclusion meant creating a holistic program where social connections were emphasized. Staff members described these social connections by saying, “It’s created friendships as a result and it takes away that isolated feeling ... they all really support each other.”

*Empowerment - feeling capable and strong.* The environment made participants feel like they could mitigate the effects of PD; “It helps [slow my PD]”; “I needed to do something”. The idea of “doing something” was echoed by most participants. They knew they weren’t going to beat PD, but they were slowing progression and this was psychologically

rewarding. As one participant stated, “Rather than just saying, ‘Well, I have Parkinson’s and I shall now [waste] away’ ... [I’m] doing something.” Another participant said, “I would like to think [Thrive-PD] has slowed the progression of the disease.” The staff spoke about how the group connectedness of Thrive-PD empowered participants, saying “at least they’re not alone.”

*Benefits to physical ability.* Participants reported increases in balance, coordination, strength, and ability to perform activities of daily life. Specifically, most participants felt the improvements in strength “strength that has come from the exercise”, and balance “the footwork has been really beneficial [to balance]” were critical for them. They attributed this to the consistent PA. As one caregiver shared, “We took two weeks off to [travel] and he couldn’t even stand up [when we got back]. It took three weeks to recover.” Participants reported a perception of slowed PD symptom progression. “I’m just slowing it [PD] down. I think [Thrive-PD] has done a good job of that.” The staff also reported perceptions of physical benefits for participants. “I can tell you these people are falling less because they’re coming to this program.” “Trust me, they’re better.”

*Positive impact on caretakers.* Caregivers were supportive of the program in general and specifically spoke about socializing with each other. “It’s wonderful having this group to relate to for the caregivers.” Additionally, the program gave caregivers personal time for their own needs. “That hour is a lifesaver for me, even if I just go and have coffee.” Many caregivers stated that Thrive-PD gave them time to exercise and take a break from caregiving, making the program beneficial to their physical and mental health. “If we were not involved in a program like this, I would be haphazardly exercising.”

### Program Design and Implementation

*Staff appreciation/importance.* Participants described the staff as dedicated, focused, and helpful. “They [the staff] will do anything to help you...” The staff excelled at focusing on individual needs while simultaneously working with a group dynamic. “They’re concerned about the whole group and don’t stay focused on one person” and “[Staff member] is

<sup>2</sup> The following three main themes and sub-themes were identified from participant interviews: 1) quality of life impacts (subthemes: socialization, empowerment, physical ability, and benefits for caretakers); 2) program design and implementation (subthemes: importance/appreciation of

staff and program structure); and 3) challenges, dislikes, and barriers.

willing to work with each person as an individual” Participants perceived the staff as well trained and knowledgeable, “I think [the classes] are very well planned out...” “I have nothing but praises for the instructors. They work with me really close because I'm a little more advanced, so they're making some more challenges for me.” Participants reported a positive environment as a result of the staff efforts. Similarly, the staff reported a strong investment in participants, even though they knew long-term progress against PD would be limited. “The hard part is when they can't come back... Just to watch the decline... that part sucks.”

*Program structure.* Class size/structure was discussed by all participants. The Thrive-PD program had recently undergone structural changes - shifting from all boxing to a hybrid of boxing and an alternate PA, thus reducing class size, and participants were divided on format preference. Some wanted larger classes for socialization, “...I want more people in my class. [instructor] has narrowed us down to only three.” and “[instructor] likes the smaller classes because he can give more personal attention... But it was more fun when we had more people”, while others wanted smaller classes for individual attention, “I think this new program is more encompassing” and “This is more one-on-one...You get more attention.” There were mixed feelings about the incorporation of the alternative PA into the previous boxing-only program. The activities included Zumba™, stationary cycling, tai chi, yoga, and weight training. Participants noted that dividing the class into different activities was sometimes enjoyable “I like the bike. I like the weights. I like the dancing (Zumba™)”; however, certain activities were not as widely accepted. “The spinning is excellent. I hate the rumba [Zumba™], or whatever it is.”

The staff discussed how the Thrive-PD program was developed with a holistic approach. “We needed a multifaceted program, ... we knew we needed different opportunities to match the different domains [participants] had deficits in.” This included creating an “increased quality of life, activities, and general living, social network” as part of the program. The staff explained they were continually striving for improvements, which prompted the switch in program format “the structure is continuously changing. That's evolving as we go.” For example, as program attendance increased, the single-group single-activity structure could not effectively accommodate participants. There was also talk about future changes to incorporate additional rehabilitation principles. “We need to add dual tasking, that's really

important. When you spar, you're sort of doing that... but we could get much more organized and mindful of that.”

### *Challenges, Dislikes, and Barriers*

Although participants reported benefits, PD still progresses, which was discouraging. The cost of the Thrive-PD program is not covered by insurance, “The cost. That's the biggest issue for us.” and this was a limiter for many participants. When asked how long they planned to continue participating, one participant responded “As long as we can afford it”. In terms of the program structure, participants suggested classes should be split based on disease status rather than scheduling convenience, so participants could exercise at appropriate levels per disease progression. One participant explained “the weight program they have is for people who are a little more alone than I am.” As a result, he felt he may not always get the best workout possible. Attendance was also an issue for participants who could not drive themselves or lived a distance away. “It is a burden on me [caretaker]... three days a week I have to have him here.” “For us, it's an hour of driving.” Barriers reported by the staff included limited resources from the healthcare system without consideration for the needs of the local PD population. “The [system] infrastructure is crap, that's something that we need to improve. I think this [Thrive-PD] can help guide a direction to that.”

### **Discussion**

It was clear Thrive-PD was immensely popular with participants and their caregivers, with perceived benefits that are rarely measured in rehabilitative assessments and are difficult to quantify. The social relationships, personal empowerment, and perception of functional physical improvements were cited repeatedly as the primary reasons the participants continued to attend. All of these things contribute to an overall positive QoL. Therefore, for the participants in this program, the perceived benefits extended beyond the primary program objectives of physical gains and/or maintenance.

The social aspects of Thrive-PD were a critical component for participants. The personal relationships created a feeling of camaraderie - participants were all in the battle with PD together. Due to the physical presentation of their disease, people living with PD can feel isolated (Sunvisson & Ekman, 2001). Socializing with others who do not

have PD can cause embarrassment and frustration about their condition and their physical limitations, especially due to communication barriers that often develop as PD progresses (Perepezko et al., 2019; Schrag et al., 2000). Therefore, participation in a program specifically designed for those living with PD may create an atmosphere that alleviates these social concerns (Perepezko et al., 2019). Within Thrive-PD, this social atmosphere was evident, with participants reporting a strong sense of community. The social community was a key determinant for continued Thrive-PD participation. Creating a positive social atmosphere was considered during program development to aid in adherence; suggesting that intentionally creating programs that maximize the development of camaraderie and social interaction may increase long-term participation and positive QoL impacts.

Participants, caregivers, and staff all felt participants had higher levels of functioning due to Thrive-PD participation and reported noticeable declines when individuals took time off. Because there were no physical assessments performed, this evidence is anecdotal. PA is beneficial in slowing PD disease progression (da Silva et al., 2016) so these anecdotal observations are not beyond the realm of expectations. It is important to consider that PD is a degenerative disease and long-term, participants were maintaining physical abilities at best. The Thrive-PD staff reported functional declines in long-term participants. Realistically, the perceived levels of physical benefits (functional improvements) and the current physical benefits (maintenance or slower decline) were likely not congruent; however, the belief among participants that the program created these benefits was important. Thrive-PD provided participants with a catalyst for increasing self-efficacy, and this self-efficacy allowed them the confidence to function at the highest level possible for their current physical ability. Therefore, the high level of self-efficacy created perceptions of physical improvement regardless of any actual physical improvements. In this way, the program empowered participants to take control of PD. Having a sense of control over the uncontrollable creates feelings of autonomy and is directly linked to intrinsic motivation (Sweet et al., 2012). This intrinsic motivation promotes continued PA participation, resulting in increases in self-efficacy for the individual (Sweet et al., 2012), thus creating a stronger sense of empowerment (Stewart & Yuen, 2011). Recent research exploring these motivational

constructs lends support to this outcome (Brunet, Price, Wurz, McDonough, & Nantel, 2021).

With degenerative diseases, it is important to consider whole-person health and well-being. Universally, participants and caregivers spoke of the program improving health. A key outcome was that even if the program had a limited impact on physical impairments, it undoubtedly motivated participation. The World Health Organization's International Classification of Functioning, Disability and Health defines participation as involvement in life situations; participation does not exist on a linear continuum with physical impairments but is a function of the interaction between an individual's condition and contextual personal and environmental factors (World Health Organization, 2013). Thrive-PD impacted all components of participants' biopsychosocial well-being with participation in physical activity, self-care, social interactions, and in some cases, participation in a shared activity with a loved one during the alternate PA. It is important to note that key personal and environmental facilitators were necessary to achieve this participation and program success. Participants referenced Thrive-PD staff's skill, engagement, and dedication as key factors in creating an environment where they felt safe and engaged. The ability to engage caretakers or provide them with a chance for their PA and personal time is also an environmental facilitator that may increase adherence to chronic disease management (O'Reilly, Finnan, Allwright, Smith, & Ben-Shlomo, 1996; Urell et al., 2019). Overall, the creation of a community between participants, caregivers, and program staff were observed to motivate participation and enhance the QoL of participants.

As with all research, this project has limitations. The evidence regarding physical benefits and improvements was anecdotal, as all data were qualitative. This provided an in-depth picture of the lived experiences of participants but limited the understanding of physiological outcomes. Future research needs to combine these methods for a comprehensive understanding of overall outcomes in this type of program. This was also a cross-sectional observational study; a longitudinal examination could provide a clearer picture of the development of many of the constructs examined and allow for conclusions to be drawn. Being a study of a single program with a limited number of participants, the generalizability is limited. This information should be used to help inform future investigations as we continue to understand the importance of holistic programming.



The perspectives reported by participants, caregivers, and staff point to a holistic program that used a biopsychosocial approach. When implemented effectively, this type of program addresses the needs of the whole-person, resulting in a positive overall healthcare experience and better overall QoL. In the context of degenerative disease, it is critical to understand benefits beyond functional ability that may be garnered through PA rehabilitative programming, thus creating overall QoL benefits. Understanding these benefits can be twofold, first, it gives providers more leverage to justify continued treatment while the patient may only be physically maintaining the status quo; and second, it lends support for developing PD-specific PA programs with intended benefits that are holistic - using a biopsychosocial approach to treatment.

### Conflicts of interest

The authors report no conflicts of interest.

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