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One Step at a Time: A Journey of Hope, Inspiration, and Determination

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Abstract

Approximately three million persons in the United States face the challenge of living with Parkinson's Disease (PD). In spite of medical and surgical interventions, the disease progresses, resulting in bradykinesia, rigidity and postural instability that impair functional ability and quality of life. The purpose of this case study is to illuminate the impact an exercise program may have on an individual with PD. A single case study design was used to explore the effect of exercise on the quality of life of a 73-year old gentleman with advanced PD. Interviews and field observations of the client, wife, and staff at a community based exercise facility were conducted. Analyses were based on coding of verbatim transcripts and field notes. Three themes emerged from the study: hope, inspiration, and determination. This case study is an exemplar of the impact exercise conducted in a supportive environment may have on improving the functional ability and quality of life for persons with PD.

Keywords

Exercise, Parkinson's Disease, Case Study

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One Step at a Time: A Journey of Hope, Inspiration, and Determination

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Approximately three million persons in the United States face the challenge of living with Parkinson's Disease (PD). In spite of medical and surgical interventions, the disease progresses, resulting in bradykinesia, rigidity and postural instability that impair functional ability and quality of life. The purpose of this case study is to illuminate the impact an exercise program may have on an individual with PD. A single case study design was used to explore the effect of exercise on the quality of life of a 73-year old gentleman with advanced PD. Interviews and field observations of the client, wife, and staff at a community based exercise facility were conducted. Analyses were based on coding of verbatim transcripts and field notes. Three themes emerged from the study: hope, inspiration, and determination. This case study is an exemplar of the impact exercise conducted in a supportive environment may have on improving the functional ability and quality of life for persons with PD. Keywords: Exercise, Parkinson's Disease, Case Study

George*, a 73 year old gentleman with advanced Parkinson's Disease (PD) stated "...It's okay if I have Parkinson's but Parkinson's can't have me." Parkinson's disease, one of the most common, chronic, and progressive neurodegenerative diseases, can impact one's quality of life (Koplas, Gans, Wisely, Kuchibhatla, Cutson et al., 1999). As the disease progresses, symptoms such as tremor, bradykinesia, rigidity and postural instability, become unpredictable. It is estimated approximately three million persons in the United States face the challenge of living with PD each year (PDF, 2013b). "A recurring theme is the experience of loss, such as loss of independence and self-esteem..." (Haahr, 2011, p. 409).

Treatment of PD

Treatment options for PD include medication management, with L-dopa being one of the mainstays of the antiparkinsonian agents, and surgical procedures, such as deep brain stimulation (DBS) of the subthalamic nucleus. DBS is often reserved for those individuals who suffer from L-dopa-induced dyskinesia with severe motor fluctuations and advanced stages of PD. In spite of medical and surgical interventions, the disease may still progress to the point that walking and self-care are no longer feasible.

Evidence suggests exercise may play an integral role in delaying the progression of the disease (PDF, 2013a). Existing research on PD and physical activity confirm the importance of exercise and the need to increase activity to decrease rigidity, improve balance, and increase one's overall mood (Johnson & Almeida, 2007). Quality of life (QOL) can be significantly improved with physical activity (Rose, Lokkegaard, Sonne-Holm, & Jensen, 2013). However, very few facilities or programs can accommodate persons with PD. A similar challenge to persons with cancer, who also have special exercise considerations, led to the development of the Cancer Foundation for Life's (CFFL) FitSTEPS for Life (FSFL) program.

FitSTEPS for Life

FitSTEPS for Life is a free, community-based exercise program for persons with cancer (Haas, & Kimmel, 2011). The program is open to persons with a history of any type or stage of cancer. All participants are physician referred. Following an initial evaluation, trained staff members prescribe an individualized exercise program for each participant. Participants exercise at least two times a week and are progressed on a weekly basis. Safety and effectiveness of the program in improving QOL has been established in previous research (Haas, Kimmel, Hermanns, & Deal, 2012).

Seventy percent of FSFL participants have co-morbid conditions, such as hypertension, diabetes, arthritis, and PD. Because of previous history of squamous cell carcinoma, George was referred to the FSFL program. His PD was much more severe and problematic than his cancer. It soon became evident that the FSFL program was having a major impact on George's functional status. This observation highlighted the uniqueness of George's case and determination was made to explore his experience in-depth through use of a single case study design.

The primary author has expertise in qualitative research design and methods. As a caregiver of a family member with PD, she has focused her research on the experience of persons and caregivers facing the challenge of living with this progressive condition. The co-author, with a background in oncology, has a 12-year relationship with FSFL, serving on both the board of directors and as the CFFL Research Director. Her research has focused on the role of exercise in improving quality of life for persons with cancer and has been primarily quantitative in nature. The researchers have a long-standing working relationship. This project evolved out of the researchers' desire to meld their expertise in addressing health promotion for persons with chronic illness. The case study reported here is the first project in a program of research that utilizes the expertise of both researchers. In the future, we plan to use mixed methods research designs to more fully understand the role of exercise and other health promotion interventions in improving quality of life for persons with chronic illness.

Methods

A single case study design was used to examine the effect of a community-based physical activity program on the quality of life for an individual with PD. As researchers, we believe that no single research approach provides a full understanding of the complexities associated with living with a chronic illness. Although we have observable data that supports physical improvement, it is only through hearing the perspectives of those involved that we are able to capture the essence of the impact an exercise program has on one's quality of life. Therefore, we selected a case study approach as the ideal design to present a unique case. The methods followed the case study research process as outlined by Yin (2009). The question guiding the study was "What has the FitSteps for Life (FSFL) program meant to you?". Specific propositions included:

1. The FSFL program improves functional status in a person with PD.
2. Quality of life improves for the participant with PD.
3. Exercise for persons with advanced PD is feasible in spite of physical challenges.

Prior to data collection, the study was approved by the university institutional review board. The primary unit of analysis was determined to be an individual (Yin, 2009). George, the 73 year old male who claimed "Parkinson's can't have me" had a history of squamous

cell carcinoma and advanced PD. He could not walk and was unable to stand unaided. His speech was soft and difficult to understand. He had experienced complications of PD, including hypotension, dehydration, and aspiration pneumonia, coupled with physical exhaustion. He had been admitted and treated at a rehabilitation facility. After three weeks of therapy at the rehabilitation center, he was still unable to walk or stand and had subsequently developed a nosocomial staph infection. On two prior occasions, a medical facility and a rehabilitation center had also failed to address his declining functional status. He was discharged with a referral for in home physical therapy.

At a routine follow-up appointment with the dermatologist for his squamous cell cancer, George's wife of 10 years expressed feelings of devastation, hopelessness, and grief over George's situation, stating they were told by the in-home physical therapist "there is nothing more we can do for you". The rehabilitation facility and in-home physical therapy staff were simply not equipped to address the physical and emotional needs of a person with PD. The dermatologist provided a brochure and referred George to the FSFL program.

A few days later, George and his wife reported to a local FSFL center. At this point, George and his wife expressed apprehension because George was in a wheelchair and nearly immobile. The Clinical Director of FSFL, who is also a medical oncologist, performed baseline physical and psychological assessments. Because his PD was so advanced, the Clinical Director and FSFL staff members were skeptical about their ability to help George. However, after determining that George and his wife were committed to doing what was necessary to help improve George's current condition, the FSFL Clinical Director prescribed an exercise regimen that included attending the FSFL center five days a week. On the initial visit, he was assisted by two FSFL staff members who helped lift him on to a treadmill where he stumbled for two or three seconds. And thus, George's journey began.

Data Collection and Analysis

Based on the propositions, semi-structured interviews were conducted with George, his wife, and three FSFL staff members over a two-week period. The research team consisted of two researchers, both certified in protection of human subjects. One researcher has expertise in qualitative methods and the other is an expert in exercise and chronic illness. The researchers jointly conducted all interviews. George and his wife were interviewed in private sitting area at the FSFL center; the interview lasted an hour and 15 minutes. Since George's speech was often difficult to understand, George's wife was present to help clarify indiscernible words. She also validated the statements expressed by George and contributed her perspective of the FSFL program's impact on their quality of life. Two FSFL staff members who worked most frequently and closely with George were interviewed together per their request. This interview lasted 1 ½ hours and was conducted in a private office. The third interview, conducted with the Clinical Director, also took place in a private office and lasted two hours. Open-ended questions were used and varied depending on the role of the interviewee. George and his wife were asked the grand tour question "What has the FitSTEPS for Life program meant to you?" An example of additional questions was "How has the FSFL program changed your life?" Prompts included statements such as "Tell me more about that" and "Tell me how you that made you feel." The interviews with the FSFL staff members began with asking "What do you think this program has done for George?" Further questions asked "How do you think the program has changed his life (or has it)?" and "From your perspective, were there unanticipated benefits George experienced by being in this program?" All interviews were digitally recorded. Field work, which included participant observation during four different exercise sessions, was also employed. Anecdotal comments were documented.

Thematic analysis was used to analyze the data. Interviews were transcribed verbatim and read multiple times by the research team to gain an understanding of the entirety of the content. A conscious effort to bracket any biases was made. Commonly used words and repetitive phrases within the transcripts were grouped and patterns identified (Miles & Huberman, 1994). Coded content was then combined into themes. Field notes of the researchers' thoughts and reflections of the direct observations indicated on margins of the transcripts were reviewed and compared to transcript data. The field notes of observations supported the themes. The data was considered in view of alternative explanations; none were identified (Yin, 2009).

Rigor was maintained throughout the study. To enhance credibility, all participants were authentically represented by using their own words. Transcripts were verified by the researchers. Data collection and analysis procedures were documented to ensure confirmability. An audit trail was maintained to foster trustworthiness.

Results

George's functional status improved remarkably over time. At his initial visit to the FSFL center, George was confined to a wheelchair and only able to stand for a few seconds with assistance. In just over three months (112 days), George was walking independently and able to climb stairs with assistance. He was able to tolerate 28 minutes on the treadmill at 2.0 miles per hour. His advances in mobility are summarized in Table 1. Other physical improvements were also noted. Staff members commented "I know this sounds crazy but even his voice improved." In considering alternative explanations, one alternative to the voice improvement may be that the staff became accustomed to his speech patterns.

Table 1. Mobility over Time

Time	Duration	Speed	Comments
Baseline	2-3 seconds	none	Held up on treadmill
Day 30	4 minutes	1.3 mph	Treadmill <ul style="list-style-type: none"> • Stretch band exercises added; • Walking with walker
Day 60	19 minutes	2.0 mph	Treadmill <ul style="list-style-type: none"> • Stretch bands • Stability ball exercises added; • Walked with cane in hallway and stairs
Day 112	28 minutes 2 minutes	2.0 mph Level 1	Treadmill Elliptical <ul style="list-style-type: none"> • Stretch bands and stability ball • Squat machine added • Walking independently

Themes

Three distinct content themes emerged from the transcript data, supporting the original study propositions. Field notes and observational data, which include the physiologic improvements noted in Table 1, supported the identified themes: hope, inspiration, and determination.

Hope

Hope, in this case study, is defined as the *internal* belief that a situation will improve. The theme hope may be linked to the proposition that the FSFL program improves functional status in a person with PD. The dedicated staff that assisted George in his journey shared that every person that they encounter have a mindset that they can be better as a result of exercise. They have hope – hope for improved health. Eloquently stated, “...if there is a will, what you do then is give them the hope and the vision by providing some tools, very simple, and easily mastered, so they say ‘I can use these tools. I can do this.’ It was George and his family’s hope, that despite the fact that George could not stand unaided or walk, he was going to have good outcomes as a result of exercise. It was their belief, their hope that he would improve. The staff referred to a quote by Kubler-Ross to further describe the hope expressed by George and his wife: “it’s only when we truly know and understand we have a limited time on earth and we have no way of knowing when that time is up, that we begin to live each day to the fullest as if it was the only one we had” (Kubler-Ross & Kessler, 2000).

Inspiration

Inspiration is the *external*, achievable outcome that provides motivation. The theme inspiration may be linked to the proposition quality of life improves for the participant with PD. Prior to the PD diagnosis George was independent, accomplished, and unselfishly cared for others. To lose the ability to function independently, coupled with being newly married at the time of his diagnosis, was a major life stressor. The journey George and his wife traveled is one of determination and inspiration...one step at a time. Exercising and being active (for George it was his daily involvement in FSFL) were described as “it’s an everyday thing.”

The unique individualized activity plan for George at FSFL included a supportive and encouraging staff that not only assisted him with the treadmill and the squat machine but also encouraged him to sing songs. The singing may have helped strengthen George’s voice, which is frequently affected with persons with PD. George would occasionally yell out, celebrating his accomplishments. His spontaneous expressions of joy were shared by the staff, who were observed cheering and clapping for George. This supportive environment fosters an atmosphere of care and support. As George stated “There’s no danger –it’s safe. You can’t say that about very many places. Mentally, emotionally, physically, spiritually safe. That gives the courage to try.”

The supportive staff at CFFL and the individualized plan helped inspire George. It is what kept him motivated and committed to exercising every day. The people he and his wife met were described as being “like family.” The impact of the FSFL exercise program on George and his wife is summarized in his wife’s comment: “After 10 years with PD, this [CFFL] has saved our life. Uh it is our life. It’s literally this spiritual, mental, emotional, and physical experience – balance and love, training, professionalism, guidance, encouragement, sensitivity, intuition, and inspirational.”

PD is a complex disorder that permeates all aspects of one’s life: physical, psychological, and spiritual. Treatment of PD is multifaceted and individualistic; the literature substantiates the importance of individualized care (Chaudhuri, Yates, & Martinez-Martin, 2005). George’s experience at CFFL poignantly highlights the complexities of this degenerative disorder and the possible results when individualized care is provided.

Determination

Determination is the *observable* movement toward a goal. The theme determination may be linked to the proposition exercise for persons with advanced PD is feasible in spite of physical challenges. George's PD advanced to the point that his mobility was severely compromised and he was unable to even stand unaided. While insurance-covered providers dismissed George from care, saying "there is nothing more we can do", George and his wife were determined to continue trying. The referral to the CFFL's FSFL exercise program was challenging to George and his wife. The preparation to get to the center was laborious for George's wife and difficult for George due to his limited mobility, but their commitment to persevere never wavered.

The staff was also determined to try and support George and his wife in their efforts. Previous physical therapy attempts had been unsuccessful and George's wife shared with the staff, "he's been through all the physical therapy there is—what should I do now because he's in a wheelchair now and he's bedfast—what am I going to do with him? I can't take care of him." The staff reported responding, "I don't know and can't tell you what to do. So, what our program has taught me—if the person has the will..." and noted "and George and his wife had the will 'determination', the will 'determination' was there!"

It is worth noting that there were times early in George's journey that the staff were uncertain that he would walk again, but yet were determined to help him try. One staff member described their mind set: "we [CFFL staff] would say he's not rehabilitatable [sic] ...we didn't look at it that way. We looked at it as if he was. I don't know if he was but I thought this is going to be fun! Let's see what he can do. What that taught me was that everything is rehabilitatable [sic] until proven otherwise if you give it enough time.

Thus the referral to FSFL was the impetus to improving George's quality of life. "I don't want to miss a day [Cancer Foundation for Life (CFFL)] because Parkinson's is a viscous disease and you just leave it alone. You give it that much leeway and it gets a hold of you. It's OK if I have Parkinson's but Parkinson's can't have me." It was the determination of George, his wife and the staff that helped make his journey possible.

Discussion

The main finding in this study was the positive benefit of exercise at the CFFL FSFL. Other than participation in the exercise program, no changes were made to George's treatment regimen during the 3-4 months he was observed exercising. These findings highlight the positive benefits of physical activity and are in line with other study findings. "Maintaining a high level of independence and living with the illness as part of life have been found to be a main goal in various kinds of long-term illness..." (Haahr, 2011, p. 414). Furthermore, Rose and colleagues (2013) reported statistically significant improvements in the areas of clinical status, walking and quality of life as a result of an eight week training program in which participants with PD participated exercised on a positive pressure treadmill for three days a week. The similarity in the positive patient outcomes in our case study of George and other studies (Haahr, 2011; Rose et al., 2013) may be explained by understanding the role of dopamine.

Research suggests that an exercise regimen can increase dopamine levels and metabolism, which subsequently increases functional independence in Parkinson's subjects. (Baatile, Langbein, Weaver, Maloney, & Jost, 2000, ¶3)

Higher levels of dopamine have been found during moderate exercise, which suggest a regular program of moderate intensity exercise may serve to reduce the progression. (Baatile et al., 2000, ¶3)

When reflecting on George's experience, one might ponder George's fate had his dermatologist not referred him to the CFFL FSFL program. Previous providers and rehabilitation centers, covered by United States health insurance, had dismissed him. Though it is far beyond the scope of this single case study, one must question the costs of care for George as he was rapidly approaching a point his wife could no longer care for him at home. The expectation that a short term program will address a long-term chronic illness appears short-sighted from both a fiscal and a quality of life perspective. For George, living with PD is a life long journey. Daily exercise has proven to be the key to George's ability to be more independent, ultimately walk and stand unaided. His declaration was "I'm going to walk now." His wife states, "This is his joy." An added benefit was the improvement in the quality and volume of his voice as a result of his exercise team who understood PD. George eloquently stated, "I have Parkinson's, but Parkinson's doesn't have me!"

Limitations

The method of inquiry, an intrinsic case study, focusing on one participant may evoke varying opinions related to reliability and generalizability. Considering this was part of a larger study (Haas & Kimmel, 2011), with the focus of one participant with PD, the research team genuinely feels that this study is reliable and effectively focused on the uniqueness of the CFFL program. The ability to generalize is a common limitation in all qualitative studies. Of note, not all locations have a program similar to the CFFL FSFL, thus this case study may be applicable to locations that have a CFFL FSFL or a similar program.

Implications

Future research efforts will consider a qualitative inquiry with additional participants. Testing a community-based exercise program for PD similar to the FSFL program offered to persons with cancer could provide objective measures and evaluation of the effect of exercise over an extended time frame. Meanwhile, practitioners are encouraged to recommend exercise to their patients with PD, particularly when a safe, low-cost option is available.

In conclusion, this study contributes to the narrow body of qualitative literature in PD and serves as an exemplar of the potential impact of exercise on the lives of those living with PD. The diagnosis of PD may affect one's physical, psychological, and spiritual being. Understanding the complexity of PD and supporting the patient's journey is an integral part of caring for persons with PD. Having the determination to live each day and the inspiration to remain active and keep moving aids in the improvement of mobility and the activities of daily living required for everyday life, thus enhancing quality of life: *One step at a time.*

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