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Visions of Living with Parkinson’s Disease: A Photovoice Study

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INTRODUCTION

Parkinson’s disease (PD), a chronic neurodegenerative disorder, affects 60,000 Americans and 10 million people worldwide. PD is one of the most common chronically disabling disorders of the nervous system. From a biomedical perspective the nature and treatment of the disease is well documented throughout the literature, yet little is known about the individual’s perception of living with PD.

PURPOSE

To describe the experience of living with PD through the participants’ capture of meaningful images.

LITERATURE REVIEW

A gap in the literature on the holistic approach (biological, psychological, social, and spiritual aspect) of caring for persons with PD suggests the need for in-depth qualitative research on patients’ experiences of this disease. The majority of the research studies fail to provide an introspective exploration of what patients do or how they manage their illness experience in their daily lives. Using photographs to aide in understanding one’s life with PD may be helpful in attaining rich, meaningful data.

METHODS

A participative qualitative study using Photovoice and supportive narratives was employed to contextualize the experience of living with Parkinson’s disease. No studies have been located using Photovoice in this population.

SAMPLE

Following IRB approval, two males and seven females comprised the study sample. Eight were Non-Hispanic White and one Native American. Age ranged from 39 to 76 years (Mean 62± 11 years). Participants took pictures with a camera provided by the researcher that was equipped with shake stabilization technology. Each participant’s PD was staged using the H&Y scale.

Table 1. The Hoehn and Yahr (H&Y) Scale for Staging the Severity or Progression of PD* (N=9)

Stage	Symptom	N(%)
0	No clinical signs are present.	1(11.1)
1	Functional impairment is minimal, but unilateral features of tremor, rigidity, or bradykinesia are evident.	4(44.4)
2	Balance is not yet impaired, but the features in stage 1 become bilateral.	-
3	Patients still function independently. Bilateral symptoms progress but are still mild to moderate. Postural imbalance is mild.	1(11.1)
4	Patients require substantial assistance. Bilateral symptoms become more severe with significant postural instability.	3(33.3)
5	Patients are restricted to a bed or wheelchair. Bilateral symptoms are very severe.	-

Note: *PD: Parkinson’s disease.

Table 2. Socio-demographic Characteristics of Sample (N=9)

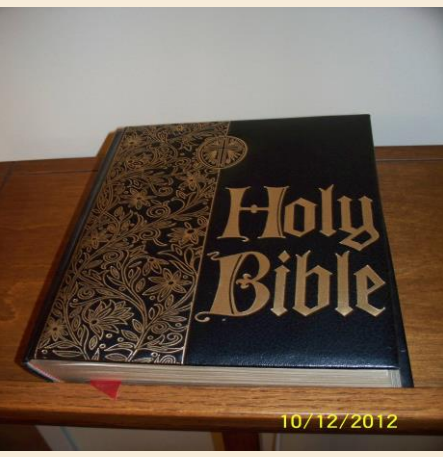
Variables	(Mean, SD, Range)
Age (years)	62.5(±11.9, 37)
Gender	n(%)
Males	2(22.2)
Females	7(77.8)
Marital Status	
Married	7(77.8)
Divorced/Separated	1(11.1)
Widow/Widower	1(11.1)
Years diagnosed with PD*	
5 years or less	4(44.4)
6 to 10 years	1(11.1)
11-15 years	2(22.2)
More than 15 years	2(22.2)
Living Arrangements	
Own Home with Family	5(55.6)
Own Home Alone	4(44.4)

Note. *PD Parkinson’s disease.

DATA ANALYSIS

Descriptive statistics were used to analyze demographics and H&Y scale. All interviews were audio recorded and transcribed verbatim. Transcripts were coded and compared with field notes and photographs. Photographs were analyzed by the authors for visual representations of participants’ lives and social environments.

Forty-five photos were reviewed. Each participant chose five photographs which they felt accurately depicted daily life with PD. The description of the five photographs was discussed in-depth during the interviews in an effort to understand the meaning of the pictures. Participants talked about each photograph during the one-on-one interview; however, at the end of the interview, participants were asked to select the top three photos that most accurately represented their life with PD.



FINDINGS

“**Staying Determined**” was the overarching theme that was evident among all of the participants; it was their determination to continue to live life to its fullest despite the unpredictable progression of PD.

- “*Parkinson’s, you learn to live with it...and be determined to not let it stop you.*”

Additional themes that emerged from participant data:

❖ Staying Active

“Staying Active” through physical activities of swimming, gardening, exercising were shared.

❖ Finding Purpose

Another source of strength and purpose was found through biblical scriptures.

- “*Spirituality is part of my life. And to me prayer is so important with this [PD].It [prayer] just helps you so much and the prayer is powerful and I do a lot of praying.*”

❖ Finding Joy

All of the participants reported “finding joy” in ‘the little things.’

- “*It’s [telephone] everything to me because I, that is how I stay in touch with people. And it’s just, I don’t know I don’t know what I would do without it, there are so many people that I call and up and so forth.*”
- “*And my computer...*” *That’s [the computer] my outside world.*”

The findings reported represent a glimpse into the lives of nine individuals living with PD. The Photovoice method used in this study highlighted a holistic view of reality in the daily lives of nine persons with PD through their eyes/lens.

CONCLUSION

We learned from this study how the participants perceived their disease and how they remained determined despite their chronic illness. Coping strategies were classified as inwardly or outwardly. Lastly, the participants in this study were empowered as experts of their own Parkinson’s disease and co-learning occurred.

“*Photography is a way of feeling, of touching, of loving. What you have caught on film is captured forever. . . it remembers little things, long after you have forgotten everything.*”
~Aaron Sussman

