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

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Abstract

The purpose of this study was to explore the illness experience of persons living with Parkinson's disease. Using the visual elicitation method, Photovoice, we asked participants to take a series of photographs that for them, represented the everyday challenges related to the disease. The photos served as starting and reference points for the individual narratives provided by each participant as they engaged in a follow-up dialogical interview with the researcher. Using thematic analysis of the interview data, the research team, together with the participants, identified one overarching theme, "staying determined," and five sub-themes "staying active," "finding purpose and meaning," "finding joy," "keeping it private," and "staying connected despite a loss." We were able to gain important insights into how participants perceived their disease, including the "inward" and "outward" coping strategies they used in their daily lives. We believe that through this visual elicitation participatory, action-oriented data collection method the participants also gained new insights into their lives through their photographs and the related interviews, and were empowered as a result.

Keywords

Parkinson's Disease, Photovoice, Illness Experience, Empowerment, Co-Learning

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The purpose of this study was to explore the illness experience of persons living with Parkinson's disease. Using the visual elicitation method, Photovoice, we asked participants to take a series of photographs that for them, represented the everyday challenges related to the disease. The photos served as starting and reference points for the individual narratives provided by each participant as they engaged in a follow-up dialogical interview with the researcher. Using thematic analysis of the interview data, the research team, together with the participants, identified one overarching theme, "staying determined," and five sub-themes "staying active," "finding purpose and meaning," "finding joy," "keeping it private," and "staying connected despite a loss." We were able to gain important insights into how participants perceived their disease, including the "inward" and "outward" coping strategies they used in their daily lives. We believe that through this visual elicitation participatory, action-oriented data collection method the participants also gained new insights into their lives through their photographs and the related interviews, and were empowered as a result. Keywords: Parkinson's Disease, Photovoice, Illness Experience, Empowerment, Co-Learning

"Whatever is real has a meaning."

Michael Oakeshott ([1933] 1978, p. 52)

Parkinson's disease (PD) is one of the most common chronically disabling disorders of the nervous system (Parkinson's Disease Foundation [PDF], 2014). PD is a result of widespread destruction of dopamine in the substantia nigra, the primary area of the brain that is responsible for the production of dopamine (Guyton & Hall, 2006). From a biomedical perspective, the nature and treatment of Parkinson's is well-documented throughout the literature. However, little is known about what it is like to live with PD. While the symptoms of PD differ from person to person, the cardinal symptoms are uncontrollable tremors, muscle rigidity, and difficulty initiating movement. As the disease progresses, difficulty walking, talking, writing, and performing other actions that require a high degree of muscular coordination may ensue. The unknown etiology of PD raises many questions, but what is known is that there is a deficiency of dopamine in the brain. How or why certain neurons die remains a mystery. Hypotheses include exposure to unknown viral agent(s) and environmental toxins, breakdown of the body's protective mechanism with advancing age, and unexplained acceleration of the normal aging process (Rajput, Rajput, & Rajput, 2008). Currently, there is no cure, but symptoms may be managed through medications and/or surgical treatments. Current drug therapy is symptomatic and aimed at restoring dopaminergic function in the brain (Brooks, 2000).

According to current disease incidence data, approximately 60,000 Americans are diagnosed with PD annually and approximately 7 to 10 million individuals living around the globe are afflicted with the disease (Parkinson's Disease Foundation, 2014). Given that Parkinson's disease is a chronic, progressive disorder, imagine, for a moment, that *you were told that you have PD*. What would this mean to you? How would this affect your daily life?

The way in which an individual copes with PD or any other chronic illness is personal. For many, the physical and psychological changes may not be obvious or bothersome while for others, visible manifestations are more apparent and worrisome. Several researchers have found that living with a degenerative disorder such as advanced PD, affects one's daily life in a variety of ways (Haahr, Kirkevold, Hall, & Ostergaard, 2010). Depression (Yamanishi et al., 2013), anxiety (Hanna & Cronin-Golomg, 2012), loss of control (Van Der Bruggen & Widdershoven, 2004), and decreased self-esteem (Caap-Ahlgren, Lannerheim, & Dehlin, 2002) have all been reported in the literature. While there is limited qualitative research on what it is like to live with PD, this manuscript provides a unique glimpse of PD through the participants' lens. The purpose of this study is to *describe the experience of living with PD through the participants' capture of photographic images, using the Photovoice method. The research question that guided the study was:* What insights might we gain about the lived experiences of persons with PD through participant generated photographs?

Review of the Literature

We were unable to locate studies that specifically addressed the holistic/whole-body approach: physiological, psychological, social, and spiritual characteristics of persons with PD from the patient's perspective. Florence Nightingale, known as the "mother of modern nursing," recognized that people are multifaceted individuals and stressed the importance of employing a holistic approach when caring for the "whole person": one's physical, psychological, social, and spiritual well-being (O'Brien King & Gates, 2007). Based on this fundamental belief, it is important to conduct a holistic assessment in an effort to fully understand a person. As nurses, the authors subscribe to the theoretical orientation of the holistic/whole body approach and feel that a qualitative means of exploration helps convey the individual introspective/perspective of life with a chronic illness. We were able to locate a limited number of studies that provided an introspective exploration of how patients manage their illness experience in their daily lives. Stanley-Hermanns and Engebretson (2010) examined the illness experience of persons with Parkinson's disease using an ethnographic approach. Other qualitative researchers have taken a narrower approach, focusing on living with PD in middle-aged life (Habermann, 1999), and the problems of anxiety/depression as they relate to quality of life (Quelhas & Costa, 2009). Although a few researchers used Photovoice methodologies in some studies of chronic disease (Harper, 2002) we found no studies located in which the researchers used Photovoice for investigating PD. There is some evidence to support using photographs to aid in understanding life with PD, in that the method may result in obtaining richer and more meaningful data than when interview methods are used alone (Cooper & Yarbrough, 2010).

The first researcher to use photographic images in social science research was Collier (1967). John Collier Jr. and John Collier Sr. were American anthropologists best known as early pioneers in the discipline of visual anthropology (Harper, 2002). Their research methods served as the inspiration for the development of "photo-elicitation" techniques in which photographs were used systematically in interviews to elicit information and insight (Harper, 2002). The Colliers believed that one of the foremost benefits of using photographs as a research tool was that photographs functioned as a language bridge (Collier, 1957). They felt that photographs can assist a participant who lacks language fluency to make clearer statements about complex processes and situations (Collier, 1957). Since then, the use of photography in research has increased and taken on a variety of names and forms, for example, participant photography and photonevella (Riley & Manias, 2004). Although a number of researchers have used Photovoice in studies of persons with other chronic diseases such as HIV (Rhodes, Hergenrather, Wilkin, & Jolly, 2007), mental illness (Thompson,

Hunter, Murray, Ninci, Rolfs, & Pallikkathayil, 2008), chronic pain (Baker & Wang, 2006), and neurodegenerative disorders such as Huntington's disease (Aubeeluck & Buchanan, 2006), we were unable to find similar ones involving persons with PD.

The researchers involved in the design, data collection, and analysis phases of this study are all licensed professional nurses with extensive experience in caring for individuals with chronic illness. All have published studies involving qualitative methodology and one has published research specific to the Photovoice method. The first author, a board certified psychiatric mental health nurse, educator, and researcher, has extensive experience with PD and has published in this area. Additionally, she is a caregiver of a close family member with Parkinson's. The second author is a nurse educator, a researcher, and is a board certified medical/surgical nurse. Her interests are chronic illness and health promotion. She is interested in helping persons with chronic illness manage their disease and discovering evidence-based best practices that strengthen the discipline of nursing research.

The third author has used the Photovoice (PV) method in several health-related research studies in a variety of cultural settings with a group of villagers living in remote regions in Central America, African student nurses enrolled in an African University, and, and Asian Indian women studying in an American university. In addition, she uses the PV method in the classroom setting as a way to engage students in the health-related concerns of communities. Her major contribution was primarily in the analysis component of this study through reviewing the photo narratives provided by the participants, and discussing with the research team the many different concepts found in the narratives, looking for common or dissonant meanings and finally developing emergent themes.

Methodology

Photovoice

Photovoice is a qualitative, participatory, action-oriented data collection method whereby study participants use cameras to record their real-life experiences. Also known as *participatory photography*, Photovoice was developed by Wang and Burris (1994) for their study of rural women of Yunnan Province, China. Participant photographs are used as starting and reference points for entering into a dialogic discussion between the researcher and the participant. This differs from the traditional approach, in which researchers usually control the means for imaging the world (Wang & Burris, 1994). Photovoice can be thought of as a tool for enabling participants to record, reflect on, and to communicate their concerns and coping strategies. It has been described as a method for eliciting data that serves to deepen one's understanding of the lived experience (Plunkett, Leipert, & Ray, 2013). Through the medium of photography, researchers are able to perceive the world as viewed by the participants. The information gathered can then be used for promoting positive change in the lives of the participants and people like them. Several researchers have found that the Photovoice method often has the unexpected benefit of empowering the participant photographers who use their photos to express themselves in creative ways that sometimes reveal a sophisticated understanding of the social determinants of their health and well-being (Ornelas et al., 2009).

Photovoice as Participatory Research: Collaboration and Co-learning

Participatory research (PR) may be defined as "systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and/or taking action or effecting change" (Jagosh, Macaulay, Pluye, & Salsberg, 2012, p. 312).

Some proponents of PR for health intervention studies, state that among its benefits are that it serves to strengthen relations between the community and academia; ensures the relevancy of research questions; and increases the capacity of data collection, analysis, and interpretation (Jagosh et al., 2012). Research involves a blurring of the line between researcher and participant. (Spoon & Arnold, 2012). In the Photovoice method of participatory research, the researchers bring their clinical expertise and knowledge of the research process, while the participants bring their expert knowledge about the reality of their lives, and use their cameras to give their expertise expression through photographic imagery. Photovoice as utilized in health research, is designed to encourage individuals to engage with others about their lived experiences, by taking photos that reflect their health-related concerns and perspectives. One of the key principles of this method is that it promotes a co-learning and empowering process that attends to social inequalities (Israel, Schulz, Parker, & Becker, 1998, p. 179). Further, this method “facilitates the reciprocal transfer of knowledge, skills, capacity, and power” (Israel et al., 1998, p. 179) between investigators and the participants.

Co learning occurs through the dialogue that takes place between the researcher and the participant photographers, as the participants describe the meaning they ascribe to their photos. Because so little research had been conducted for the purpose of understanding the lived experience of persons with PD, the researchers approached the study with an assumption that the participants would be to some degree, their teachers. The researchers through their voiced responses to the photographs including follow-up questions posed to the participants, served indirectly as teachers, by helping the participants to clarify their narratives and perhaps to enrich their appreciation of their personal resources and needs as they cope with chronic disease. Through this dialogic process the researchers and the participants become both the agents and the receivers of knowledge.

Study Instrument

The Hoehn and Yahr (H & Y) scale was designed to be a simple descriptive staging scale that provides a general estimate of clinical function in PD, combining functional deficits (e.g., disability) and objective signs (e.g., impairment) (Hoehn & Yahr, 1967). It consists of a five-point scale (1-5) and is based on a two-fold concept that the severity of overall Parkinsonian dysfunction relates to bilateral motor involvement and compromised balance/gait (Goetz et al., 2004). The scale is used to access increasing motor impairment unilaterally (Stage 1) to bilateral disease (Stage 2) without balance difficulties, to the presence of postural instability (Stage 3), loss of physical independence (Stage 4), and being wheelchair- or bed-bound (Stage 5). Although the H & Y is used as a clinical tool and does not have the psychometrically established reliability and validity of a research measurement scale, it is the most commonly and widely used scale to estimate the severity of PD (Zhao et al., 2010). The H & Y has been validated in several studies (Fereshtehnejad, Hadizadeh, Farhadi, Shahidi, Delbari, & Lökk, 2013; Franco, Leão, Townsend, & Rieder, 2011) as a means of external validity with other instruments of neuromuscular dysfunction in PD.

The first author administered the Hoehn and Yahr (H & Y) scale (see Table 1), a commonly used classification system or clinical demarcation to delineate stages of disease and disabling symptoms, at the beginning of the study to determine level of disability in order to better describe the participants (Hoehn & Yahr, 1967). The stages clearly depict the progressive, disabling nature of PD. The first author has received advanced training in Parkinson's disease, through a home-study course sponsored by the Parkinson's Foundation of the Heartland entitled, "The Parkinson Care Series." Additionally, inter-rater reliability between the first author and a Parkinson's disease Nurse Specialist-Nurse Practitioner in the identification of the staging of PD were established. The procedure for administering the H &

Y is as follows: (a) explain to the participant that you will be determining the stage of PD for the purposes of this study only, (b) observe the participant in a standing and sitting position, and (c) indicate the identified stage on the participant information form. All participants were staged by the primary author in order to discuss changes over the progression of the PD, as well as relate some of the experiences inherent in the different stages.

Table 1. The Hoehn and Yahr Scale for Staging the Severity or Progression of PD^a (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: ^aPD: Parkinson's disease.

Ethical Considerations

The Institutional Review Board at a south central US university approved the study. The participants received printed information that explained the purpose of the study and what their involvement would entail. The first author explained that the information they provided would be stored securely, that it would be available only to the members of the research team, and that their personal identity would be protected by using pseudonyms in any eventual manuscripts.

Setting and Sample

The setting for this study was a mid-sized public university in the south central United States. Participants were recruited from the local PD association assisted in the recruitment of study participants by sending mailers to active members in the organization, who might be eligible to participate. The inclusion criteria were as follows: a participant must be at least 21 years of age, have a diagnosis of Parkinson's disease, have attended a PD support group, and be able to physically and verbally participate in the data collection process. Of the 50 potentially eligible members, 9 contacted the first author and all of those agreed to participate after the details of the study were explained and questions answered during an initial phone interview with the first author. Six were non-Hispanic White females, one a Native American female, and two non-Hispanic white males. The ages of the females ranged from 49-76 years and ages of the males were 39 and 76 years. None of the participants were newly diagnosed (within the past year). The sample consisted of a diverse representation of stages of disease (see Tables 1 and 2) ranging from zero (asymptomatic) to four (bilateral physical disability).

At a mutually agreed upon date and time the first author took a camera to each participant's home, carefully reviewed the informed consent document with the participant,

answered questions about the study and obtained the participant's signature. After the informed consent was signed, the first author collected demographic data including sex, age, race/ethnicity, and date of diagnosis as well as information about PD symptoms experienced currently. The symptom data obtained from the Hoehn and Yahr scale (1967) was used to evaluate the stage of disease currently experienced by the participant.

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 ^a	
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. ^aPD Parkinson's disease.

The first author instructed the participants on how to use the camera and provided the following specific instructions regarding the photographs: photographs should reflect the participant's daily life with particular attention to the challenges related to PD disease. That is, photos should reflect what it means to have this disease. The ethical issues related to taking photos of others were explained including asking permission and getting written consent from the subject(s) to be photographed, if they could be individually identified. Finally, she requested that the participant call her when the photographs had been taken, explaining that a follow-up interview would then be arranged at a mutually convenient date and time, during which the photos would be viewed and discussed.

It is important to discuss briefly here the major concerns expressed by the interested participants during the initial phone interview, and the ways that these concerns were addressed. Several participants expressed fear that they might be unable to take "good" photographs due to hand tremors, a major symptom of the disease, and uncertainty about what photos they could take that would best describe their lives with PD. To help allay anxieties, the first author explained that the camera that was going to be provided had an anti-shake stabilization and that written and verbal instructions on "how-to" use the camera would also be provided. The shake stabilization feature was extremely important as many participants were worried that their "shakiness" would result in "bad or blurry" pictures. After the stabilization feature was explained, participants were relieved and hopeful that they could potentially take "good" pictures. Regarding their concerns of not knowing what images to take, the first author reassured them by explaining that a "good" photo was any that they believed represented what life was like for them, as persons with PD.

Interview Procedure

Each participant chose five photographs which he/she felt accurately depicted daily life with PD. Using the five photographs as a starting and reference point, the participant photographers were asked to share, during a dialogic interview with the first author, the challenges of living with their disease by explaining the meaning and significance each photo had for them. The participant was encouraged to be the primary agent of his/her information, while the interviewer served as a receiver of the information. The entire interview was audiotaped. Interviews lasted from 30 - 90 minutes. At the end of the interview, participants were asked to select the top three photos that most accurately represented their life with PD. In the one-on-one interviews, a dialogue of what it is like to live with PD began.

Data Analysis

The first and second authors performed the analysis of the demographic data, using the Statistical Package for the Social Sciences (IBM SPSS Statistics for Windows, 2012), version 21. To establish credibility and confirmability we audiotaped and transcribed the responses of each participant verbatim. For the qualitative data that emerged from the dialogic interview analysis, we used Lincoln and Guba's (1985) criteria for trustworthiness as a guide. The criteria include credibility, confirmability, transferability, and dependability. The process of coding involved segmenting the data into units and rearranging it into categories to facilitate insight and comparison (Munhall, 2012). Once codes were established, we identified relationships, patterns, themes, and categories related to the phenomena of interest (Patton, 2002). From there, theme-based tables were developed. The research team, which consisted of all three authors, read each transcript at least three times, continually comparing the responses with the field notes, as a means of assuring that those two data sets did not contradict each other. Coding and thematic categories were developed by first matching each photo with the relevant section of the audiotape transcriptions and the field notes. For example, if a word or phrase suggested that the participant was expressing a need for remaining active, as a source of strength for dealing with the disease, this was noted as a possible theme. As the data analysis progressed, many expressions that suggested a similar need such as "I need to keep busy" were added. Sometimes a thematic category was suggested by the photograph alone, rather than by the participant's narrative. Often however, a theme was clearly evident in both the words that accompanied the photo and in the photo itself. From the narratives and photographs, we developed themes, then, within those, we created a sub-category which we identified coping strategies: inward and outward (Chun, Moos, & Cronkite, 2005). These subcategories expand typologies of coping strategies that occur at the individual level versus the collective level of coping (Chun, Moos, & Cronkite, 2005) and thus facilitate understanding the individual's illness experience of PD. Throughout, we remained mindful of Collier's warning that two or three individuals looking at the same photo can and do see entirely different aspects of an image, and that "what we perceive may be only part of the reality before us" (Collier & Collier, 1986, p. xvi). The researchers further inspected the photographs, analyzing the context of the subject matter, and observing other details that might suggest a deeper meaning for them. The photographs chosen for this study were categorized with respect to the conceptual framework for contextualizing coping strategies as either inward or outward (Chun, Moos, & Cronkite, 2005). Inward coping strategies involve attempting to control one's response to a stressor. Outward coping strategies involve dealing with the stressor by reconstruing or controlling one's external environment (Chun et al., 2005). Conversely, inward coping strategies are

used to avoid the stressor by disengaging from self. For each photograph we labeled them as inward outward coping and categorized them as illustrated in Table 3.

Table 3. Participants' Photographs Categorized by Conceptual Framework for Contextualizing Coping

Participant Photograph	Inward Approach Coping	Outward Approach Coping	Inward Avoidance Coping	Outward Avoidance Coping
Hobby Horse	X			
Biblical Inscribed Necklace	X			
Holy Bible	X			
Table of Memorabilia		X		
Dog		X		
Walking Stick		X		
Backyard Office		X		
Backyard		X		
Cloud		X		
Television		X		

Chun et al. (2005) between coping that occurs at the individual versus the collective level explain that within each level of coping, the coping strategies can be categorized by the focus of coping action and the direction of coping effort. The focus and direction of coping strategies shown in Table 3 are geared toward the individual's approach towards approaching or avoiding the stressors of PD.

The major task of the researchers was to use both the participant's narrative and the photos to assure as much as possible, that all the participant's expressions of challenges and sources of strength were captured and brought to the final analysis. An iterative process involving the three authors continued throughout the entire analysis process to ensure that there was agreement that all the data were appropriately considered.

Photographic and Interview Data

Data were collected until saturation occurred and redundancy was identified. Data saturation occurs when each category is rich, thick, and well-established and replication of data is confirmed (Munhall, 2012). In the study, saturation was reached when repetitive themes of "staying determined," "staying active," "finding purpose and meaning," and "finding joy" emerged. Sequential interviews were conducted for the purposes of clarifying or exploring any other themes that evolved over the course of the research, when needed (Patton, 2002). This data consisted of the participant photographs and the subsequent information provided during the follow-up participant–researcher dialogue relating to the photographs (Collier, 1957).

Findings

The overarching theme that was evident among all of the participants was "Staying Determined"; it was their determination to continue to live life to its fullest despite the unpredictable progression of PD. One participant stated, "Parkinson's, you learn to live with it... .and be determined to not let it stop you." As one participant was going through her photos, she commented on a photo of couple who was celebrating 50 years of marriage at the church celebration. In that photo, everyone was smiling, including the participant and her

husband and she passionately stated with a huge smile on her face, “with Parkinson’s you can still have fun. It’s all in how you want to view it. I’m determined to keep on going.” Additionally, they all indicated that they were committed to “staying determined” through faithfully taking their medications and adhering to a healthy and balanced diet. “Staying Determined” was the overarching theme from which the following sub-themes were created: “Staying Active,” “Finding Purpose and Meaning,” “Finding Joy,” “Keeping it Private,” and “Staying Connected Despite a Loss.”

Staying Active

The theme of “Staying Active” was dominant in the participants’ photographs. This was expressed in a variety of ways. For example, the youngest participant stays active at his home taking care of his horses, cutting trees for firewood, and taking care of his immediate family including his mother. One participant discussed the importance of exercise in her daily life as she displayed a photo of herself on her exercise bike (see Figure 1).

Oh, it's so important to Parkinson's. You have to do it and you have to make yourself do it. Exercise it builds them up, keeps you limber and loose, you just have to do it. You have to make yourself do it. Whether you want to or not.

Figure 1. (Participant B) Exercise Bike *note hobby horse



“Staying Active” through physical activities of swimming, gardening, and exercising were shared: “Staying active in the yard doing yard work, gardening, oh, that’s what keeps me very busy.” While the participants all talked about the physical benefits of staying active, they also shared similar sentiments about the psychological benefits of exercise. “Exercise even helps my psychological spirits. It [exercise] makes you feel better, it makes you think you are doing better and I think you are. But there again its attitude. It’s so important.” Another participant stated, “I just, I believe in just taking one day at a time and just not even knowing what I might be facing, but uh, I am just gonna work, keep working, stay as active as I can.” One participant photographer was all smiles when she talked about the swimming pool stating,

You need that [exercise] for Parkinson’s. That’s mainly why I like to get in there [the swimming pool]. I love the water but it works well both ways. It works for me, physically, and it’s just a good tool for exercising.

Finding Purpose and Meaning

In today's society, people are often categorized according to their occupation and their contribution to society. Much emphasis is placed on holding a job or maintaining a household and value/self-worth is labeled according to the success of the aforementioned and assumptions are made in terms of one's sense of purpose in life. Two of the participants worked outside the home. The others were either disabled from PD or retired. Those who were no longer able to work expressed that they missed working in their occupation/profession and placed value on their previous contributions to society. It appeared that for most of them, replacing work with purposeful activities gave them a sense of purpose. Through various comments such as: "Well, it's just something I just love and it's just something that I am good at it and I can take cuttings and things . . . it keeps me very busy but I love it and every time, I've been really working at trying to, well I took down the flowerbed out in the front that was so big with the arbor. . ." She shared that prior to PD, she owned a nursery and that was her life, and now, to continue her passion for gardening and flowers, she has a little nursery of her own in her backyard that appeared to give her a sense of purpose in her life.

Another source of strength and purpose was found through Biblical scriptures. One of the participants took a picture of her necklace in which Psalm 46:10 was inscribed – "Be still and know that I am God" (see Figure 2). She stated that this verse was a continual reminder that God is present in her life and that she indeed has a purpose. One of the male participants stated that he participated in two Bible study groups. The 73-year-old participant photographer took a picture of her Bible (see Figure 3) and stated, "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."

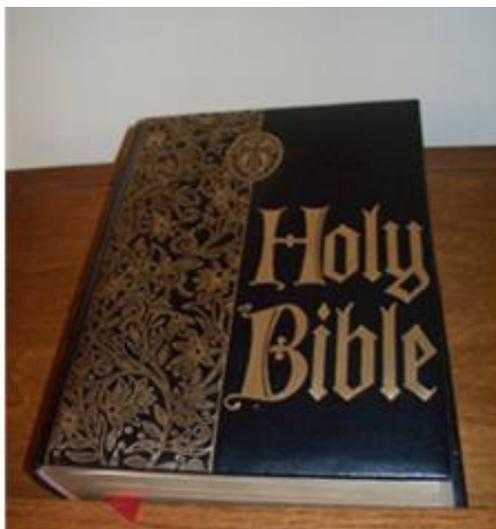
Figure 2. (Participant I) Photograph of Participant's Biblical Inscribed Necklace of Psalm 46:10



While participants worked to manage their own health challenges, they admitted that this was a process that took time. Many shared the process from diagnosis to present time and while there were tears shed when talking about their trials and tribulations, it seemed to suggest that finding purpose was a part of the process of accepting who they are now. "Well uh, at first, um, I tried to hide it, you know, because it was something that come on me so quick and just something I couldn't control, in fact the more I tried to control it, the worse I got and um, but um, I'm just one that knows, I mean that we have to accept a lot of things in life and um, I've just done the best I can with it and I have a lot of friends that tell me that that's what they tell me when they see me, you just look great, I guess they think I'm going to go down, but uh, anyway and I do shake at times, but you know most of the time I'm, and I do hurt, but I don't hurt a whole lot. What really helped me accept my Parkinson's my

children and my grandchildren . . . all of them have been so helpful and positive about it, you know, family support. Not being able to work at the nursery, but still able to use my talents in my own backyard has been a blessing and is who I am.”

Figure 3. (Participant B) Photograph of Participant’s Bible



Finding Joy

All of the participants reported “finding joy” in “the little things.” The 73-year-old participant stated that joy for her was talking on the telephone and emailing using her computer. Referring to these devices she said,

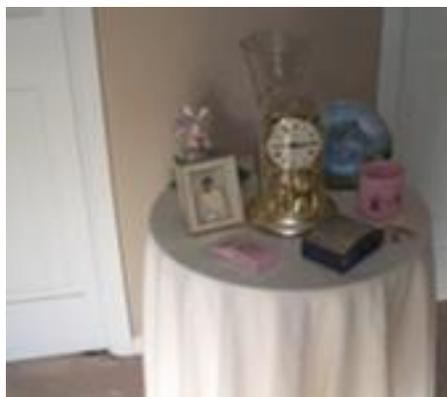
It's everything, to me it is because I, that is how I stay in touch with people. And it's just, I don't know I don't know what I would do without it, there are so many people that I call and up and so forth. And my computer . . . That's [the computer] my outside world.

Her son who lives in a different city along with her grandchildren send her emails and pictures which give her immeasurable joy and connection with the outside world.

The 68-year-old participant photographer selected a photo of her family as her most important photograph, stating that with PD, “You have to depend on your family or friends or someone.” One of the youngest age participants also selected a picture of his 10-year-old daughter as well as a photograph of his teen-aged daughter as his most important photos. He said the younger child is good for his PD; she’s good “entertainment and is positive; whenever I’m having a bad day, she shows me stuff to cheer me up. She helps out a lot; does a lot of the cooking and cleaning.” In various ways, all of the participants talked about the importance of family and friends. For many, it was keeping memorable collectables and looking at them frequently served as memorabilia of great times in life, past and present (see Figure 4). While some of the participants did not live close to their grown children and grandchildren, they talked about how pictures and various figurines and collectables that were given to them by family and friends were reported to give joy. Additionally, all expressed in some way that they found comfort, support, and joy in family members, friends, and pets. “Oh, it's just uh, the greatest feeling to see them come in and hug you and kiss you and do something.” Those who were miles apart from their family referred to their pets as

family. One woman shared how important her dogs were to her PD (see Figure 5). There were pictures of her dogs, and during the interview, the dogs stayed close to her which clearly showed a loyal, loving relationship.

Figure 4. (Participant B) Memorabilia



They [her two dogs – Rat Terriers] keep me company and I'm always laughing at this one, he's just funny, he just does funny things and then it helps me, you know, since I'm by myself and um, since I lost my husband, they're just a blessing to me.

The 76-year-old female participant showed a picture of a monarch butterfly using the butterfly as an analogy:

Well the butterfly itself is a symbol of renewal, of coming out of a tomb. And in doing this, I just felt I could just fly out of this body that I've used up. Well, it's a symbol of new life and it's a symbol of resurrection and it's, butterfly is just a symbol to me of living.

Figure 5. (Participant A) Dog



While talking about the photograph, she shared that prior to her Parkinson's diagnosis, she enjoyed raising monarchs, but now she can no longer do that due to her unstable balance and difficulty walking. She recalled her early love of butterflies and was able to relate her current state of Parkinson's to that of a butterfly, joyfully living life.

One of the male participants displayed a photo of a hand-carved walking stick (see Figure 6) that he had carved himself at his home, which he referred to as his office, "The Healing Place." Figure 7 depicts his home/office/"The Healing Place" where he makes various walking sticks. Those made from exotic woods are his favorite, especially one that he

made from a sassafras tree. Additionally, he finds joy in building and constructing items for his “Healing Place, “I can sit on the porch, on my bike and watch nature on the 60-foot porch and we can have guests sit out there.” His comments and his many handmade items displayed inside and outside his home suggested that he took pride in his building skills. In a photo of his walker, an outward coping approach was suggested by the following comments.

Well, one [source of strength] is my walker and it's become a friend. Uh, I feel a lot more stable when I have a walker with me. When I don't have it with me, I feel very shaky and very uncertain and with the walker I am almost back to normal.

His walker was identified as his source of strength which helps him to do activities that he enjoys, such as crafting, an activity in which he finds joy.

Figure 6. (Participant D) Walking Stick



Figure 7. (Participant D) The Office



Keeping it Private

Many of the participants talked about how they initially kept their diagnosis private. One of the participants reflected on the time that she was told that she had PD. As she was showing and talking about the photo that she had taken of the pendant on her necklace, she began to cry (see Figure 2). This photo was mentioned previously from a spiritual lens, but now the story behind the necklace was revealed. She said that she did not want to tell anyone at her work that she had PD. However, when a number of the employees questioned her tremor as well as other symptoms, she reluctantly shared her diagnosis with them. Sometime later, after revealing her diagnosis, one of her coworkers gave her a pendant.

Staying Connected Despite a Loss

One participant shared that before PD, she was active in the community; she would conduct public speeches at the various social functions she attended. She was very much a socialite, but because PD affected her speech as well as her mobility (she is currently in a wheelchair) she was forced to retire. Her loss of the physical connection to the community was reflected in two photos, one of her phone and another of her computer. Both of these, the phone and the computer were now, she said, her connections to the outside world. While she could no longer attend social functions or make public speeches, her phone and computer had become “everything to me . . . because I, that is how I stay in touch with people . . . and the outside world.” She shared another photo of a big picture window in her dining room. This window faced the road and she said that when her neighbors drive by or walk, they look her direction and wave. In fact, during the interview a neighbor walked by and waved. This participant said that she spends a majority of the day in front of her picture window, saying “That’s my, um, that’s my contact to the outer world.”

Another participant had owned a nursery, but after the loss of her husband and learning of her PD diagnosis was forced to sell this business which she dearly loved. One of the pictures that she selected was a picture of the gentleman who owns the business now. She stated that she frequently visits the nursery, because she enjoyed it so much. While she misses the nursery, she has focused her attention to her backyard, and joyfully plants/weeds daily. One of the photographs she selected was of her backyard (Figure 8) which was beautifully manicured and adorned with fragrant, vibrant flowers and shrubs. The photo of her backyard she explained, allows her to use her talents, gifts, and love for plants. As result of caring for her lawn, she stated that she is able to exercise which helps her PD all while enjoying her therapeutic retreat, her yard. “And see I mow, I got the self-propel lawnmower that I crank and then I got the riding lawnmower and this yard keeps me busy [active] . . . and I love it.” The interview took place under her veranda in her backyard.

Another example of connection was revealed in a photo of a cloud (see Figure 9). The participant shared that this photo was taken on one of her recent excursions. Although she has PD, she does not let her illness stop her from participating in activities. “We have a plane and he flies and we just go everywhere. And I was not real high on flying, was a little intimidated by it at first but we don’t go if we can’t fly anymore. I love taking pictures of the clouds and we just, we enjoy doing that together.” She enjoys flying, and the picture of the cloud represents her connection to the outside world; flying freely, seeing the world, and visiting friends/family who live out of town. Another participant selected a picture of her TV (see Figure 10) stating it was important to her life with PD. She experienced it as a form of connection to the outer world as well as a reprieve from her work day. “I will sit in there watching TV by myself because it gives me, it refreshes me and it gives me time to just kind of unwind and not think about cooking dinner, or whatever, so, you know, it’s an important part of my day to have a little down time.”

The youngest of all participants, has two doctoral degrees and was teaching prior to his PD diagnosis. Despite this loss, he stays connected with the outside world via his computer (the Internet) as well as phone. He enjoys online gaming: “Yeah I play, I do a lot of online gaming at night,” and communicates with his friend. “The computer gives us a way to talk.”

In summary, the spirit of the participants in this study was positive, despite the challenges they may experience on any given day. Their determination to live, their desire to find joy and purpose in life is admirable. The participants chose to focus on the positive aspects of their life and not dwell on the progressive nature of their illness. This desire to stay

determined captured and supported the overarching theme, “Staying Determined.” Additionally, this stabilization feature of the camera provided offered the participants autonomy to take clear pictures, while fostering independence, and ultimately, gave the participants a sense of accomplishment and empowerment.

Figure 8. (Participant A) Backyard



Figure 9. (Participant H) Cloud

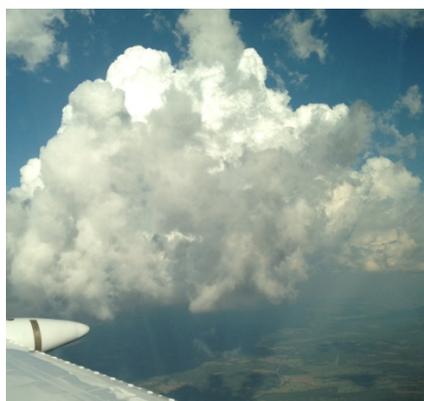


Figure 10. (Participant I) Television



Discussion

Through the use of Photovoice, 9 participants living with PD provided a glimpse into the reality of what is the experience of living with PD. We learned from this study through the participants’ images and narratives how they perceived their disease and some of the strategies they used to cope with their illness. The themes in this study corroborate with Hoppe’s (2013) premise that individuals with a chronic illness can experience happiness. The

participants in this study constructed their reality of life with PD through a positive lens, despite the struggles living with a progressive, chronic disease.

In this study, participants were shown to be experts in dealing with their disease. This finding corroborates with Bodenheimer, Lorig, Holman, and Grumbach's (2002). They deeply understood their disease process and themselves. Of importance, the average length of their Parkinson's diagnosis was 5 years; none of these participants were newly diagnosed, and, none of the participants had advanced PD (the last stage of PD, stage 5). They are not new to their disease, they became experts over time and the following examples are ways that they exemplify expertise. The female participant that was able to make the analogy of a butterfly to her living with a disease showed an understanding of her PD. The gentleman who referred to his walker as his friend also showed that he knew what he needed to do in order make his disease manageable and was able to reframe his walker as a friend rather than a negative in his life. The lady who was a public speaker displayed an understanding of her limitations and abilities by expertly substituting her enjoyment of public speaking and replacing it with current communication methods of the computer and telephone in her home.

We learned that the participant photographers were expert in describing their life with a progressive disease. They had the opportunity to learn and live with their disease. Deeply knowing themselves and what worked in their environment. Bodenheimer et al., (2002) suggest that the person living with a chronic disease can serve as the expert about his/her own disease. The combined expertise of patients, family, and health care providers can have a significant impact on chronic disease for the individual, family, health care, and society as a whole. Chronic disease self-management is an important intervention that can be incorporated into clinical practice and provide patients and their families with knowledge, decision making, and problem-solving skills, and collaborative relationships building skills to afford improved, mutually arrived at medical and daily living goals in chronic illness. Future interventions with persons with PD may include oral journaling to express the individual's thoughts and feelings about their disease to better understand from their perspective.

Catalani and Minkler (2010), in their review of the literature on Photovoice in health and public health, discuss the use of untrained photographers to take pictures and conclude that this method provides a rich source of data on cultural and social constructions using the participants themselves. With neurodegenerative disorders such as PD, primary symptoms such as tremors, rigidity, and postural instability can cause embarrassment and stigmatization. This method of inquiry allowed participants to capture meaningful images that reconstruct their realities of living with PD.

Through the photo centered dialogic interviews between the participants and the researcher, both had the opportunity to gain richer insight into the challenges of living with PD, than might have been possible if the interview method was used alone. The participant photographers became the agents of the knowledge that they shared with researchers. The questions asked of them by the researchers were generated primarily by the participants themselves through their photographs, not by the researchers, which could be an empowering experience. Based on previous findings from other Photovoice studies, we believe that the participants gained new insight into their lives through the responses and questions posed by the researcher. In this way the participant and researcher became co-learners in the process.

There were several limitations in this study, which brought the criteria of transferability and dependability of the findings into question. Among the more important was the homogeneity of the participant group, especially with respect to gender and socioeconomic status. Having greater male representation may have revealed important differences between male and female experiences with Parkinson's disease. The fact that all participants were from middle class relatively conservative cultures reduces the probability that these findings would be representative of persons with PD living in less secure

environments with different cultural experiences and influences. It is well-documented that people living in poverty or in relatively insecure financial circumstances have challenges that are qualitatively and quantitatively different from those living more economically stable existences. The influence of the researcher is difficult to assess. The fact that the researcher conducting the interviews was a health professional, a position often held in high esteem in the study community, might have affected the participants' willingness to share the negative aspects of their lives.

Researchers' Reflections

The participants in this study took photographs and selected photos that best represented what it is like to live with PD for them. And, through the participants sharing the meaning of the photos the researchers were able to reflect on what we learned from the photos through their lens/story. The participants appeared to be empowered by taking their own pictures since the majority had not taken pictures in years. Many expressed surprise that they were able to take photographs as they were worried that they could not take "good" pictures in contrast to their anxiety they displayed prior to the beginning of the study. For example, when the gentleman talked about his walking stick, he was very prideful in talking about his creation. All participant photographers enjoyed sharing their photograph and telling their story. The act of taking the photographs displayed a sense of accomplishment and empowerment as they were considered agents of knowledge.

In conclusion, this qualitative study may aid in further understanding the illness experience and perception of living with a chronic progressive disorder as expressed through photographs taken by the person living with the disease. The individual perspective is clinically relevant and useful to further understand life and coping with PD. The way in which a person understands illness is critical to understanding and treating the individual with chronic disease (Kleinman, 1988). "All illnesses are socially constructed at the experiential level, based on how individuals come to understand and live with their illness" (Conrad & Barker, 2010, p. S68). We hope that the stories of these participants illuminated how they have adapted to the illness and will help others with a chronic illness.

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