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Culturally Competent Care for Parkinson Disease

Melinda Hermanns, PhD, RN, BC, CNE

KEYWORDS

- Parkinson disease
 Clinically Relevant Continuum Model
- Culturally competent care

Parkinson disease (PD) is a devastating and disabling disease that interferes with a person's ability to perform routine activities of daily living. An estimated 1 million Americans witness the daily effects of this neurodegenerative disorder.² PD is a complex, mysterious disorder with a high degree of individual variation. PD may take 20 years or more to develop in some, whereas in others, the progression may be much more rapid. Nevertheless, PD can transform people with little or no disability to total impairment over the progressive stages of the disease. Although the cause is Q6 known, it is not well understood, but researchers continue to search for a treatment and possible cure. The goal of treatment is generally palliative, with the administration of antiparkinsonian agents and/or surgery. Deep brain stimulation (DBS) is a surgical procedure that is used when symptoms cannot be adequately managed by medication. DBS has been fairly successful in controlling the physical manifestations of the disease.3

Although substantial information is known about the pathophysiology, little is known about the patient's illness experience of living with PD.4 With 50,000 individuals diagnosed with PD annually,2 the paucity of research on the experience of living with a neurodegenerative disorder is significant. Most of the research in PD focuses on the biomedical approach to care that supports traditional medical interventions. Few qualitative studies have been located that examine the illness experience.⁵ In addition to the biomedical research, other studies have focused on the psychosocial experience of the patient⁶ and the caregiver perspective⁷ using self-report instruments.

The collective evidence reinforces the idea that the chronic illness experience is embedded in the structural realities and cultural knowledge inherent in the social world of the patient.⁴ The current understanding of the illness experience in chronic disease

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has been shaped by the contributions of an array of academic disciplines. Epidemiologically, the illness experience is viewed as the number of people sharing a specific chronic disease in a given population. Psychologically, the literature has focused on coping and adaptation and other related psychological disturbances. Socially, evidence has examined the role of chronic illness and its affect on human relationships. Philosophically, being sick and staying sick have 2 distinct meanings. Anthropologist Arthur Kleinman⁸ cogently differentiated the meaning of disease and illness. The disease is what the physician treats, and the illness is what the patient lives and experiences. PD is complex and multifaceted, making the subjective experience difficult to examine. Kleinman⁹ advocated for eliciting the illness experience, which encompasses the explanation models that reveal how patients understand their disease. These applications to persons with PD can help to further understand the pragmatic issues of living with this chronic, progressive disorder.

Anecdotal testimonies substantiate that chronic illnesses have a major effect on one's daily life and illuminate the importance of understanding the perspective of the illness experience of the person with the disease. ¹⁰ Kleinman^{11(p48)} posits "the meanings of chronic illness are created by the sick person and his or her circle to make over a wild, disordered natural occurrence into a more or less domesticated mythologized, ritually controlled, therefore cultural experience."

The data reported in this article were part of a larger study that sought to understand how people with PD construct their illness experience and manage living with PD on a daily basis. This article focuses on the individual and the group descriptions of their explanatory models (EMs) of people with PD describe their disease in terms of identification and causation, which are based on Kleinman and Benson's EMs that include a description naming, causation, understanding what happens to the person with the disease, prognosis or course of the disease, and what one might do to make it better. The application of the Clinically Relevant Continuum Model is also discussed as a means of promoting culturally competent care in a group of individuals who share a common cultural experience, PD.

METHOD

Denzin and Lincoln¹³ proposed that human experiences about which little is known, as in the case of meaningful construction of the illness experience in persons living with the disease on a day-to-day basis, is best suited for qualitative inquiry. In the larger study, an ethnographic approach was used in an attempt to understand how people experience, describe, and interpret their illness experience in their daily life.⁵ Data were collected from fieldwork and long semistructured interviews. In the larger study, the illness experience was captured by the personal accounts of 7 men and 7 women with PD. The 3 content themes were PD and the Impact on the Self: The Reflective Process, Daily Negotiations in the Midst of Uncertainty, and the Impact of the Transitioning Self on Day-to-Day Existence. The metaphor, "sailing the sea in the eye of the storm" was used to depict their voyage of living with PD.⁵

The analysis for this report is based on Kleinman's work on EMs. Kleinman's original approach to medical anthropology involved an exploratory process of qualitative inquiry and examined how clinical reality exists in the minds of health care professionals and patients. This ethnographic interview approach leads to complex and multilayered responses that carry with them information about social rituals, symbols in communication, forms of knowledge, and illness narratives. Kleinman perceived the clinical reality of the patient as consisting of psychological reality, biological reality, and physical reality. He termed the patient's reality and cultural or societal reality

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the "symbolic reality." Health care professionals who endeavor to understand a patient's symbolic reality can potentially tap into individuals' rich view of the world and their experience of illness within that world. Kleinman labels these reflective processes as effects to an individual as EMs of illness. Using this holistic and reflective language may give patients a window of understanding their suffering even without the potential for recovery. EMs can be investigated through the use of socioanthropological research strategies of participant observation and individual and group openended conversations. Kleinman and Benson¹² identified a specific area of conical ethnography as contrasting the patient's EMs of disease with the biomedical model. Western health care professionals tend to be oriented to descriptions of disease, thus focusing on the diagnosis and treatment rather than the patient's total experience of the illness.8 Patients' constructions, on the other hand, are oriented to illness as an individual and shared process. Spradley¹⁴ contends that people with a shared expe- Q7 Q8 rience become a culturally defined social group.

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Fieldwork was conducted in East Texas over a 2-year period. The sites for fieldwork were 2 PD support groups in East Texas. This study purposively sampled persons in the various stages of PD in an attempt to illuminate the illness experience. In addition, purposively sampling was used to allow access to patient groups in settings that were related to the health care system and also support groups that were patients and family. The sample of key informants selected for the long individual interviews included 14 participants with PD and attendees of 2 local PD support groups. According to Spradley, 15 human experiences from a cultural perspective are an important aspect to understand the lives of others within contextual realities and from their own native point of view.

ETHICAL CONSIDERATIONS

Ethics approval was obtained from university committees as well as letters of support from the neurology offices, PD support groups, and hospital affiliates. Written consent was obtained after informing participants of the study the purpose and their role in the research.

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DATA COLLECTION AND ANALYSIS

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Detailed field notes were kept by the researcher on each interview and field observation session. Field notes were dictated immediately following the interviews and support group experiences in an effort to capture pertinent thoughts and reflections.

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INTERVIEWS

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The narrative interview is the most common method of qualitative data collection and is well suited to explicating how individuals make meaning of their life and illness experience. 13 Structured interviews focused on how persons with PD construct their illness experience and manage living with the disease. Interviews lasted approximately 30 minutes to 1.5 hours. Open-ended questions and probes were incorporated in an attempt to elicit rich descriptions of participants' experiences.¹⁴

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All interviews were tape-recorded and transcribed verbatim and, along with field notes, thematic analysis was conducted. Once data were collected, the researcher reviewed each transcript, identifying salient thematic content in each profile and substantiating the common meaning structures with participants' verbatim accounts,

 and compared with field notes as a means of developing coding and categories. Two years of fieldwork was conducted, and comments from the 14 individual interviews as well as the attendees of the PD support groups relative to the individual and groups' naming and causation of the disease are reported.

FINDINGS

Findings fell into 2 overlapping categories, those similar to the components of Kleinman and Benson's ¹² EM. These were Constructing the Disease and Causation and Their Quest for Knowledge. This interpretation of experience has been termed the worldview of an individual or group. ¹⁴

CONSTRUCTING THE DISEASE

The EM developed by people with PD was a beginning point for the researcher to understand their view of reality. Participant constructions provided the researcher with a clinical biomedical description of the disease itself, but a deeper meaning was needed to better understand the subjective construction of their illness experience.

Once the researcher established initial rapport, the participants were extremely forthcoming in discussing their disease. All of the participants openly shared the process by which they labeled their disease. Mr H was selected as an exemplar case. Mr H talked about his journey of constructing/naming his disease. Before the formal medical diagnosis of PD, he began to experience subtle symptoms of tremor in his hands and dragging of his feet, all of which became increasingly noticeable and hugely annoying. On his awareness of his initial symptoms, he and his wife started reading about various neurologic disorders that may have accounted for his symptoms as he admitted to the enjoyment of reading and his passion for learning. In his living room, the researcher noticed an extensive collection of encyclopedias and a computer with Internet access, which they both stated that they used. It was not long before they became convinced that he had PD. He made an appointment with his local medical doctor who referred him to a neurologist, at which time their suspicion of PD was confirmed. Although he had associated his symptoms with the diagnosis of PD, hearing the diagnosis was devastating; there were no longer any doubts; he indeed had PD. Mr H did not have a family history of PD nor did he know anyone with the disease. In talking with Mr H, the biomedical discourse of PD as a neurologic disease with its unique pathophysiology, epidemiology, and symptoms was identified as the major focus in his responses.

Mr H's responses were in line with Kleinman's EM in that he integrated the professional sector, that is, the health care professional's understanding, into his own explanation. In this study, he was given an opportunity to talk about PD from his perspective in an effort to understand his construction of his illness experience. He acknowledged that this was difficult because no one had ever asked him to explain PD in his own terms. Mr H's experience was similar to Murphy's 16 narrative of his illness experience of being disabled. Murphy explicitly stated that no one ever asked him what it was like to be paraplegic; rather, the focus of the health care professionals was objective, clinical and focused on the mechanisms of the disease not the perspective of the person with the illness. Mr H cogently described PD as a disease that is always there, with the symptoms serving as a constant reminder that he has the disease. He was aware that PD is a progressive disorder and that it will get worse over time. He was knowledgeable about his symptoms and medications, sharing ways in which he adjusted his medications according to his symptoms.

In terms of naming the disease, participants used a variety of terminologies. Echoed in the support group was the language they used to describe PD: a brain disease, a neurologic disorder. The predominant use of medical terminology served as their means of communicating with each other about their disease and symptoms, for example, tremor, freezing, rigidity, and may indicate the group's cultural orientation to the biomedical facilities. Many talked about their symptoms, and no 2 persons with PD were the same. Participant beliefs of having a uniquely personal experience of the illness are illustrated by these comments:

You can't compare your symptoms to another person. No two people with Parkinson's are the same.

In addition, the symptoms and the individual illness experience may further contribute to the complexity of PD and highlight the importance of examining how persons with chronic diseases cognitively construct their world.

CAUSATION: THEIR QUEST FOR KNOWLEDGE

The 14 participants and the support group attendees shared similar attempts in their quest to learn about what caused their PD. Many admitted that they were not otherwise familiar with PD before their formal diagnosis. Once diagnosed, they shared that they used a variety of sources in their quest for knowledge. Most admitted that they reverted to books, magazines, and the Internet in an attempt to identify a cause. Yet, most stated that they considered their physician and nurse practitioner as a reliable source of information and asked the trusted professionals to explain the causation. All were on a quest to find knowledge, some explanation, an answer to "what caused my PD?" Evidence substantiates that communication between provider and client is essential. When there are differences in the understanding of the illness, communication suffers and adherence to treatment decreases.

PD was frequently referred to as a mysterious disorder because the cause of PD was unknown. Individual and group discussions about possible causes included thoughts of living in rural areas in which well water was the primary source of water, the use of pesticides on crops, and childhood trauma involving an automobile accident. Many of the participants did not have a family history of PD; in contrast, Mrs C's mother and aunt died of PD. Mrs C was identified as an exemplar case. Despite her familiarity with the symptoms of PD from family observations as well as observations in a long, varied career in the medical field, she was dismayed and skeptical when the original diagnosis of PD was made. Mrs C's constructions of PD stemmed from witnessing her mother and aunt's physical and mental decline. Conversely, Mr H did not have a history of PD. Mr H shared an enlightening preliminary encounter years before he was diagnosed with PD. His inspiring story is as follows: Mr H was asked by one of the ministers at his church if he would mind picking up a lady who could not longer drive to church because of her PD. Mr H was willing to help, as he would take her to church every week for more than a year until at which time, her PD had progressed to the point that she was no longer able to ride in the car. She became homebound and required nursing assistance. At that point, he continued to visit her, dropping off sermon tapes of the church service. Mr H talked about how it was difficult to see this dear lady's condition deteriorate, but was happy that he was able to help her. Years later, Mr H was diagnosed with PD. He recalled all the times he had driven that special lady with PD to church. Mr H said that he thought it was God's way of preparing him of what was to come, his diagnosis of PD. Although Mr H did not have a family history of PD, he thought that his cause was ordained by God.

In addition to naming the disease and attempting to identify the cause, participants were asked to describe a typical day. The concept of daily negotiation in the larger study came to light when a participant could not describe a typical day.

Parkinson's dictates my day. I mean there are days that I feel good and I want to get out and just go, go, go, but my body just won't work. My mind tells my body to go but it doesn't listen. It does me no good to plan things, because I never know what I am physically going to be able to do on any given day.

Similar responses included comments such as "I don't have any consistent days" and "My world revolves around a clock and the effectiveness of my medicine." In addition, many of the participants admitted that the physical symptoms of PD, specifically tremors, lack of coordination and balance, and freezing, kept them from a variety of activities at certain times. Their day-to-day activities revolved around how they felt and their medication regimen. Daily living requires minute-to-minute decision-making skills. Questions such as "Can I button my shirt?" and "Am I going to able to cook breakfast for myself?" are all daily realities. These statements reflect Kleinman's EMs that ask "what is happening to my body" and "what is the course of the disease." The realization that there was *no* typical day prevailed in all 14 participants. Day-to-day, often minute-to-minute, assessments depending on their PD symptoms and the effectiveness of their medication dictated their day. Mrs D responded:

It is frustrating. You can't do what you normally want to do or like I can't tie my shoe sometimes. Now I am to the point that I can't get dressed without help. Everything that I go to do is hard to do. Getting the lids off of jars or opening a box or trying to read or anything I do is more difficult...Things you just take for granted until you can't do it.

Sitting at the support group meetings, it became increasingly clear that their activities revolved around their medication schedule. The participants have to deal with their changing self in living with a progressive disorder and the simultaneous negotiation of day-to-day activities for daily living. They all admitted that they had to learn how to manage their disease. All of the participants talked about what they could do to make their PD better, stating that "resting makes it better," and when asked what makes it worse, the overwhelming response was "getting in a hurry." This response was also echoed in the informal discussions at the support groups. They all shared that they absolutely could not get in a hurry or get stressed out; "I don't sweat the small stuff." Often, they have to "sit and wait" for the medication to take effect. Although a sense of relief was felt among all when a diagnosis was determined, the unknown cause of PD remained a mystery. Many still question the cause of their PD and thus continue to seek information about PD.

Ultimately, the participants were forced to admit their physical weaknesses and seek a new identity in an effort to experience a reconstructed self with PD.⁵ The idea of a threatened identity seems to be in line with Charmaz's ^{18(p674)} research on chronic illness, in which the author states, "chronic illness attacks the body and threatens the integrity of self." Charmaz^{18(p675)} stated, "…ill people paradoxically grow more resolute in self as they adapt to impairment; they suffer bodily losses but gain themselves." Although PD was a threat to all of the participants interviewed, their strong faith, attitude, and sense of wholeness was identified as their stronghold in preserving the self. In summary, PD challenges one's life, life as they knew it and in essence, all that their lives have stood for, but many found a way to fit PD into an overall schema of a meaningful life.⁵

The way in which one reflects on the self can have a vital effect on the cognitive constructions of the illness experience as seen in the 14 participants in the larger study. Their ability to reflect on their illness experience as well as the process of reassessing who they are and who they can become seemed to aid in their ability to accommodate to the physical losses and reunified body and self fittingly.

DISCUSSION

The professional sector consists of health care professionals and is oriented around the biomedical model, in which the focus is on the medical treatment. The Clinically Relevant Continuum Model¹⁹ recognizes the patient values and circumstances, the patient's perspective of their illness, and treatment, which results in a more holistic and comprehensive approach to care as well as effective communication and interventions. Addressing patient values and circumstances is the key to cultural competency. Culturally competent care requires a commitment from the health care professions as well as other caregivers to understand and be attentive to the cultural needs of others, that is, be culturally sensitive. It is important for nurses to be culturally competent; understanding and effectively communicating with the patients ensure the best possible clinical outcome.

The ability to provide culturally competent care is especially important for practicing nurses who function in a variety of roles in the health care environment. Nurses must develop cultural competency to be effective in establishing rapport with patients and to accurately assess, develop, and implement nursing interventions designed to meet patients' needs. When a cultural perspective contradicts mainstream health care practices, we must advocate for our patients and support the patient's and family's decisions. Therefore, nurses must have a clear understanding of the various cultures to be able to deliver culturally competent care to all patients. The process of seeking to understand cultural perspectives is the key to gaining knowledge, understanding, and appreciation of cultural values.²⁰

Although most research in PD has focused on the biomedical disease and treatment, extensive quantitative clinical research on the disease process, together with this ethnographic study and other qualitative studies, may assist health care professions in evidence-based practice. Cultural competency involves being attuned to cultural cues the patient and family present during the clinical encounter regarding attitudes and beliefs about illness, behaviors, treatment expectations, and family response to the person who is ill. Culture refers to the values and beliefs underlying behaviors held by a group of people. Thus, groups who negotiate living in a society with a particular chronic condition can be considered cultural subgroups sharing elements of a common experience, such as in this ethnographic study, the subgroup consisted of individuals who live in East Texas, sharing a diagnosis of PD. Their experience illuminated the cultural issues in PD and represents a subset of the population specific to East Texas.

Researchers have come to regard persons with chronic illness as experts in their own feelings, concerns, and experiences.²¹ Phillips²² contends the way in which persons incorporate PD into the ability to maintain personal control in their life, thereby emphasizing the desire to maintain control over one's life as long as possible. The patients' rich view of the world and of their illness within the world gives rise to a better understanding of their illness experience, including its meaning to the self and the healing process.¹⁶ Nurses may assist patients in the development of their own EM to elicit the patient's perspective of illness, thus challenging the explanatory paradigm of medicine, which has a predominantly biomedical model. Exploration of the patient

and nurses' EMs is valuable in developing culturally capable nursing practice. The participants' construction of their illness experience through the development of their own EM and their process of encountering, processing, and integrating information yielded a greater understanding of their illness, including its meaning to them and their illness experience. Understanding the illness experience as constructed by the patient may facilitate the communication between the popular and professional sectors. This understanding and enhanced communication may influence the future care provided to persons with PD.

Findings from the works of Brod and colleagues²³ and Abudi and colleagues²⁴ support the idea that persons' perception and experience of their PD vary from the professional's perception, thus emphasizing the need for further exploration of the patients' view of their illness experience. "The ways that an individual or group of people label an illness and seek and evaluate treatment are embedded in a cultural system that provides not only for the interpretation of an illness but also for the rules and rituals of illness behavior." 18(p658) One of the beauties of using the Clinically Relevant Continuum Model¹⁹ is that it supports a partnership between the health care provider and the individual in an effort to provide comprehensive and best possible care. The existing paradigm of nursing care in PD may be challenged through the delivery of a whole-person approach to care, for example, a holistic approach, and giving voice to the individual affected by the disease. Engebretson and Littleton^{25(p223)} state, "The holistic approach involves understanding the interrelationships of the biologic, psychologic, sociocultural, and spiritual dimensions of the person who is interacting with internal and external components of the environment." More qualitative studies are needed to develop new knowledge in understanding how individuals make meaning of their disease and integrate their illness experience into daily life.

IMPLICATIONS

The implications for further research suggested by the findings of this study are several. Future research needs to focus on the whole-body approach (biological, psychological, social, and spiritual aspects) and the individual's adaptation to a chronic, progressive disease. Explicit descriptions of the theoretical underpinnings as well as the use of a conceptual framework and models such as the Clinically Relevant Continuum Model are strongly recommended in an effort to guide research in understanding PD.

SUMMARY

Delivering culturally competent care implies a contextual understanding that treating the illness and understanding what it means to the individual are as important to resolve as the disease process. The transition from illness experience to disorder is determined by social decision points rather than a biomedical focus of the disorder. An approach to learning local systems of EMs, which are common to specific cultural groups, needs to be achieved. In light of culturally complex clinical presentations, exploration of the patient and clinician's EM is valuable in developing a culturally capable nursing practice. Using the Clinically Relevant Continuum Model promotes a more holistic approach in the delivery of patient-centered care. ¹⁹ If the provision of the best possible care for all patients is the goal, practicing nurses must have expertise and skill in the delivery of culturally appropriate and culturally competent nursing care. The delivery of culturally competent care that fosters effective interactions and

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the development of appropriate responses may be a challenge but is vital to effectively care for persons with PD.

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