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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.¹ 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 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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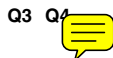
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Q6



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

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

68 The data reported in this article were part of a larger study that sought to understand
69 how people with PD construct their illness experience and manage living with PD on
70 a daily basis.⁵ This article focuses on the individual and the group descriptions of their
71 explanatory models (EMs) of people with PD describe their disease in terms of iden-
72 tification and causation, which are based on Kleinman and Benson's¹² EMs that
73 include a description naming, causation, understanding what happens to the person
74 with the disease, prognosis or course of the disease, and what one might do to
75 make it better. The application of the Clinically Relevant Continuum Model is also dis-
76 cussed as a means of promoting culturally competent care in a group of individuals
77 who share a common cultural experience, PD.

78 79 80 **METHOD**

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

92 The analysis for this report is based on Kleinman's⁹ work on EMs. Kleinman's origi-
93 nal approach to medical anthropology involved an exploratory process of qualitative
94 inquiry and examined how clinical reality exists in the minds of health care profes-
95 sionals and patients. This ethnographic interview approach leads to complex and
96 multilayered responses that carry with them information about social rituals, symbols
97 in communication, forms of knowledge, and illness narratives. Kleinman perceived the
98 clinical reality of the patient as consisting of psychological reality, biological reality,
99 and physical reality. He termed the patient's reality and cultural or societal reality

100 the “symbolic reality.” Health care professionals who endeavor to understand
101 a patient’s symbolic reality can potentially tap into individuals’ rich view of the world
102 and their experience of illness within that world. Kleinman labels these reflective
103 processes as effects to an individual as EMs of illness. Using this holistic and reflective
104 language may give patients a window of understanding their suffering even without the
105 potential for recovery. EMs can be investigated through the use of socioanthropolog-
106 ical research strategies of participant observation and individual and group open-
107 ended conversations. Kleinman and Benson¹² identified a specific area of conical
108 ethnography as contrasting the patient’s EMs of disease with the biomedical model.
109 Western health care professionals tend to be oriented to descriptions of disease,
110 thus focusing on the diagnosis and treatment rather than the patient’s total experience
111 of the illness.⁸ Patients’ constructions, on the other hand, are oriented to illness as an
112 individual and shared process. Spradley¹⁴ contends that people with a shared experience
113 become a culturally defined social group. Q7 Q8

114 **SAMPLE**

116 Fieldwork was conducted in East Texas over a 2-year period. The sites for fieldwork
117 were 2 PD support groups in East Texas. This study purposively sampled persons
118 in the various stages of PD in an attempt to illuminate the illness experience. In addi-
119 tion, purposively sampling was used to allow access to patient groups in settings that
120 were related to the health care system and also support groups that were patients and
121 family. The sample of key informants selected for the long individual interviews
122 included 14 participants with PD and attendees of 2 local PD support groups. Accord-
123 ing to Spradley,¹⁵ human experiences from a cultural perspective are an important
124 aspect to understand the lives of others within contextual realities and from their
125 own native point of view.
126

127 **ETHICAL CONSIDERATIONS**

129 Ethics approval was obtained from university committees as well as letters of support
130 from the neurology offices, PD support groups, and hospital affiliates. Written consent
131 was obtained after informing participants of the study the purpose and their role in the
132 research.
133

134 **DATA COLLECTION AND ANALYSIS**

136 Detailed field notes were kept by the researcher on each interview and field observa-
137 tion session. Field notes were dictated immediately following the interviews and
138 support group experiences in an effort to capture pertinent thoughts and reflections.
139

140 **INTERVIEWS**

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

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

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

155 FINDINGS

157 Findings fell into 2 overlapping categories, those similar to the components of Klein-
158 man and Benson's¹² EM. These were Constructing the Disease and Causation and
159 Their Quest for Knowledge. This interpretation of experience has been termed the
160 worldview of an individual or group.¹⁴

162 CONSTRUCTING THE DISEASE

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

168
169 Once the researcher established initial rapport, the participants were extremely
170 forthcoming in discussing their disease. All of the participants openly shared the
171 process by which they labeled their disease. Mr H was selected as an exemplar
172 case. Mr H talked about his journey of constructing/naming his disease. Before the
173 formal medical diagnosis of PD, he began to experience subtle symptoms of tremor
174 in his hands and dragging of his feet, all of which became increasingly noticeable
175 and hugely annoying. On his awareness of his initial symptoms, he and his wife started
176 reading about various neurologic disorders that may have accounted for his symp-
177 toms as he admitted to the enjoyment of reading and his passion for learning. In his
178 living room, the researcher noticed an extensive collection of encyclopedias and
179 a computer with Internet access, which they both stated that they used. It was not
180 long before they became convinced that he had PD. He made an appointment with
181 his local medical doctor who referred him to a neurologist, at which time their suspi-
182 cion of PD was confirmed. Although he had associated his symptoms with the diag-
183 nosis of PD, hearing the diagnosis was devastating; there were no longer any
184 doubts; he indeed had PD. Mr H did not have a family history of PD nor did he
185 know anyone with the disease. In talking with Mr H, the biomedical discourse of PD
186 as a neurologic disease with its unique pathophysiology, epidemiology, and symp-
187 toms was identified as the major focus in his responses.

188 Mr H's responses were in line with Kleinman's EM in that he integrated the profes-
189 sional sector, that is, the health care professional's understanding, into his own expla-
190 nation. In this study, he was given an opportunity to talk about PD from his perspective
191 in an effort to understand his construction of his illness experience. He acknowledged
192 that this was difficult because no one had ever asked him to explain PD in his own
193 terms. Mr H's experience was similar to Murphy's¹⁶ narrative of his illness experience
194 of being disabled. Murphy explicitly stated that no one ever asked him what it was like
195 to be paraplegic; rather, the focus of the health care professionals was objective, clin-
196 ical and focused on the mechanisms of the disease not the perspective of the person
197 with the illness. Mr H cogently described PD as a disease that is always there, with the
198 symptoms serving as a constant reminder that he has the disease. He was aware that
199 PD is a progressive disorder and that it will get worse over time. He was knowledge-
200 able about his symptoms and medications, sharing ways in which he adjusted his
201 medications according to his symptoms.

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

210 *You can't compare your symptoms to another person.*
211 *No two people with Parkinson's are the same.*
212

213 In addition, the symptoms and the individual illness experience may further
214 contribute to the complexity of PD and highlight the importance of examining how
215 persons with chronic diseases cognitively construct their world.
216

217 CAUSATION: THEIR QUEST FOR KNOWLEDGE

219 The 14 participants and the support group attendees shared similar attempts in their
220 quest to learn about what caused their PD. Many admitted that they were not other-
221 wise familiar with PD before their formal diagnosis. Once diagnosed, they shared
222 that they used a variety of sources in their quest for knowledge. Most admitted that
223 they reverted to books, magazines, and the Internet in an attempt to identify a cause.
224 Yet, most stated that they considered their physician and nurse practitioner as a reli-
225 able source of information and asked the trusted professionals to explain the causa-
226 tion. All were on a quest to find knowledge, some explanation, an answer to "what
227 caused my PD?" Evidence substantiates that communication between provider and
228 client is essential.¹⁷ When there are differences in the understanding of the illness,
229 communication suffers and adherence to treatment decreases.

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

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

256
257 *Parkinson's dictates my day. I mean there are days that I feel good and I want to*
258 *get out and just go, go, go, but my body just won't work. My mind tells my body to*
259 *go but it doesn't listen. It does me no good to plan things, because I never know*
260 *what I am physically going to be able to do on any given day.*

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

274
275 *It is frustrating. You can't do what you normally want to do or like I can't tie my*
276 *shoe sometimes. Now I am to the point that I can't get dressed without help.*
277 *Everything that I go to do is hard to do. Getting the lids off of jars or opening*
278 *a box or trying to read or anything I do is more difficult...Things you just take*
279 *for granted until you can't do it.*

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

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

304 The way in which one reflects on the self can have a vital effect on the cognitive
305 constructions of the illness experience as seen in the 14 participants in the larger
306 study.⁵ Their ability to reflect on their illness experience as well as the process of reas-
307 sessing who they are and who they can become seemed to aid in their ability to
308 accommodate to the physical losses and reunified body and self fittingly.
309

310 DISCUSSION

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

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

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

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

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

REFERENCES

1. Lee AJ. Problems in diagnosis. In: Factor SA, Weiner WJ, editors. *Parkinson's disease: diagnosis and clinical management*. New York: Demos; 2002. p. 243–50.
2. Parkinson's Disease Foundation. About Parkinson's page. Available at: <http://www.pdf.org/AboutPD/>. Updated January 31, 2010. Accessed October 31, 2010.
3. Piper M, Abrams GM, Marks WJ Jr. Deep brain stimulation for the treatment of Parkinson's disease: overview and impact on gait and mobility. *NeuroRehabilitation* 2005;20(3):223–32.
4. Thorne S, Paterson B, Acorn B, et al. Chronic illness experience: insights from a metastudy. *Qual Health Res* 2002;12:437–52.
5. Stanley-Hermanns M. The illness experience of persons with Parkinson's disease. (The University of Texas Health Science Center at Houston doctoral dissertation). ETD collection for Houston Academy of Medicine-Texas Medical Center; 2008. Paper AAI3308879.
6. Backer J. The symptom experience of patients with Parkinson's disease: review of literature. *J Neurosci Nurs* 2006;38(1):51–7.
7. Maier K, Calne S. Informal caregivers: a valuable part of the health care team. In: Manuchair E, Pfeiffer R, editors. *Parkinson's disease*. London: Taylor & Francis; 2006. p. 999–1008.
8. Kleinman A. *Patients and healers in the context of culture*. Berkeley (CA): University of California Press; 1980. p. 85–6.
9. Kleinman A. Interpreting illness experience and clinical meanings: how I see clinically applied anthropology. *Med Anthropol Q* 1985;16(3):69–71.
10. Frank A. *The wounded storyteller*. Chicago: The University of Chicago Press; 1995. p. 1–27.
11. Kleinman A. *The illness narratives: suffering, healing and the human condition*. New York: Basic Books, Incorporated; 1988. p. 3–30; 48.
12. Kleinman A, Benson P. Anthropology in the clinic: the problem of cultural competency and how to fix it. *PLoS Med* 2006;3(10):1673–6.
13. Denzin NK, Lincoln Y. The discipline and practice of qualitative research. In: Denzin N, Lincoln Y, editors. *Handbook of qualitative research*. Thousand Oaks (CA): Sage; 2008. p. 1–29.
14. Creswell JW. Five different qualitative studies. In: *Qualitative inquiry and research design choosing among five traditions*. Thousand Oaks (CA): Sage Publications, Incorporated; 1998. p. 34–5.
15. Spradley JP. In: *Doing participant observation*. Participant observation. New York: Holt, Rinehart, and Winston; 1980. p. 53–8.
16. Murphy RF. In: *The body silent*. New York: WW Norton; 1990. p. 5–16.
17. Neuman B. Resonating with the whole. In: *Transforming presence: the difference that nursing makes*. Philadelphia: FA Davis; 2008. p. 33–50.
18. Charmaz K. The body, identity, and self: adapting to impairment. *Sociol Q* 1995;36(4):657–80.
19. Engebretson J, Mahoney J, Carlson B. Cultural competence in the era of evidence-based practice. *J Prof Nurs* 2008;24(3):172–8.
20. Campinha-Bacote J. The quest for cultural competence in nursing care. *Nurs Forum* 1995;30(4):19.



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465
21. Kennedy I. Patients are experts in their own field. *BMJ* 2003;326:1276–7.
 22. Phillips L. Dropping the bomb: the experience of being diagnosed with Parkinson's disease. *Geriatr Nurs* 2006;27(6):362–9.
 23. Brod M, Mendelsohn GA, Roberts B. Patients' experiences of Parkinson's disease. *J Gerontol B Psychol Sci Soc Sci* 1998;53B(4):P213–22.
 24. Abudi S, Bar-Tal Y, Ziv L, et al. Parkinson's disease symptoms-patients' perceptions. *J Adv Nurs* 1997;2(5):54–9.
 25. Engebretson J, Littleton LY. Cultural negotiation: a constructivist-based model for nursing practice. *Nurs Outlook* 2001;40:223–30.

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Q3	This is how your name will appear on the contributor's list. Please add your academic title and any other necessary titles and professional affiliations, verify the information, and OK MELINDA HERMANNNS, PhD, RN, BC, CNE , Assistant Professor, College of Nursing, The University of Texas at Tyler, Tyler, Texas
Q4	The following synopsis is the one that you supplied, but lightly copyedited. Please confirm OK. Please note that the synopsis will appear in PubMed: Findings from a qualitative ethnographic study that examined the experiences of a group of persons with Parkinson disease are presented in this article. Culturally competent care for persons who share a common illness, such as Parkinson disease, is facilitated when the findings are incorporated into the Clinically Relevant Continuum Model. Use of this model allows providers to evaluate and use appropriate published evidence in addition to provider expertise and patient preferences and values.
Q5	Please verify the affiliation address and provide the missing information (department name).
Q6	Please verify edit to "Although the cause...."
Q7	There is a discrepancy between the author name "Spradley" in the text and reference list in the sentence "Spradley contends that...." Please check.
Q8	Refs. 14 and 15 have been renumbered so that citations appear in sequential order. Please verify.
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Thank you for your assistance.