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Lived Experiences of Adult Children Who Have a Parent Diagnosed with Parkinsons Disease

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Abstract

Little is known about the experience among adult children who have a parent with Parkinsons Disease (PD). The purpose of this study was to explore, appreciate, and describe their experiences using a phenomenological methodology. Narratives were collected from seven participants who have a parent diagnosed with PD and analyzed according to Colaizzis (1978) phenomenological data analysis method. Seven thematic clusters were identified and an exhaustive description is presented to summarize the essence of their lived experience. The study indicates a strong sense of essential positivism from the participants stories, and overall, it seems PD has brought some degree of biological, psychological, socially, and/or spiritual meaning to their lives that they may not have otherwise noticed or experienced.

Keywords

Parkinsons Disease, Phenomenology, Biopsychosocial-spiritual, Adult Children, and Illness

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Lived Experiences of Adult Children Who Have a Parent Diagnosed with Parkinson's Disease

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Little is known about the experience among adult children who have a parent with Parkinson's Disease (PD). The purpose of this study was to explore, appreciate, and describe their experiences using a phenomenological methodology. Narratives were collected from seven participants who have a parent diagnosed with PD and analyzed according to Colaizzi's (1978) phenomenological data analysis method. Seven thematic clusters were identified and an exhaustive description is presented to summarize the essence of their lived experience. The study indicates a strong sense of essential positivism from the participants' stories, and overall, it seems PD has brought some degree of biological, psychological, socially, and/or spiritual meaning to their lives that they may not have otherwise noticed or experienced. Key Words: Parkinson's Disease, Phenomenology, Biopsychosocial-spiritual, Adult, Children and Illness

Introduction

“The bond between mother and child is so deeply rooted in our emotions that we fear to discuss openly anything that threatens the bond” – Glenna Atwood (1991)

Establishing links between chronic illnesses and family impact are not novel (e.g., Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Kielcolt-Glaser & Newton, 2001, Martire, Lustig, Schultz, Miller, & Helgeson, 2004). However, much of the attention to study inclusion of a family caregiver into the care experience has focused on the spouse (Keefe, Buffington, Studts, & Rumble, 2002) or children under the age of 25 (e.g., Olsen & Clarke, 2003; Pakenham, Bursnall, Chiu, Cannon, & Okochi, 2006), and not as much attention has been paid to the experiences of the adult children who are also involved in providing some level of care.

The parent-child bond is one of the most enduring familial relationships (Golish, 2000). In fact, most parents and children share 50 or more years of their lives together (Hagestad, 1987). With increasing numbers of chronically ill older adults in America (Anderson, 2002), there is a growing trend of adult children who inevitably become the caregivers for their parent(s) (Walker & Pratt, 1991) and who themselves experience biomedical, psychological, and social stresses and strains associated with their care giving role (Kaufman & Uhlenberg, 1998; Lieberman & Fisher, 1995). Adult children are voicing an increased need for support from helping professionals as they take on added responsibilities for their parent's care and well-being.

Chronic Illness and the Family

Several researchers have studied the systemic implications of chronic illnesses on the family unit (Johnston & Martin, 1992; Lieberman & Fisher, 1995; Papadopoulos, 1995; Rehm & Catanzaro, 1998), but few have focused on what happens to the parent-adult child sub-system. It is known that “chronic illness often creates shifts in interdependence, independence, and dependence within a parent-child relationship” (Roberto, 2001, p. 69), and whereas some parent-adult child relationships transform with ease, others experience a lack of intimacy, understanding or acceptance, and/or poor communication.

According to Rose-Itkoff (1987), when chronic illness enters the family it initially takes a central role requiring that families organize around it and adapt accordingly. However, excessive centrality of an illness may lead families to become “stuck” in patterns appropriate for short term use, but not for long term effectiveness. Families may also organize around a certain belief or explanation of the illness (Phipps & Lazzarini, 1987). For example, some believe that illness in the family may be a blessing because it brings their family closer together. Their interpretation of the illness may promote group identity and interaction and this may determine how they address, resolve, or avoid conflict within their family.

In the wake of a chronic illness diagnosis, families have to negotiate new role definitions, coping methods, and loss of or added responsibilities (Papadopoulos, 1995). In addition, continual role changes may emerge as an illness progresses and “deeply held notions about relationships and obligations are suddenly subject to reevaluation and alteration” (Rose-Itkoff, 1987, p. 313). For instance, there may be a greater likelihood for role reversals to occur between a parent and a child when the parent becomes ill. Parents may become dependent upon their children for survival leaving children to take more of a decision-making role. According to Papadopoulos, families often grieve the loss of role definitions, physical functioning, responsibilities, dreams, and the prospect of a long life span for their ill family member. Adaptations to the demands of a chronic illness may far exceed a family’s expectation for what life should be like at this stage of the illness. With progressive chronic illnesses “families must be prepared to keep reforming its system to keep pace with the changing picture of illness” (Rolland, 1994, p. 25). The chronic disease focused on in this study was Parkinson’s disease. In particular, investigators examined the biopsychosocial experiences of adult children who have one parent diagnosed with it.

Parkinson’s Disease

Parkinson’s disease (PD) is a progressive disorder of the central nervous system (Young, 1999). There is no biological marker that confirms its diagnosis. The diagnosis of PD is made based on the presence of the classic triad of major motor signs: tremors, rigidity or muscle stiffness, and postural instability or imbalance (Dawson, 2000). It is a disease that has no age, race, sex, or socioeconomic boundaries. In addition to the hardwired biology inherent to the illness, PD patients have to learn to psychosocially adjust and reorient their lives to achieve a new sense of themselves (Anderson, 1999).

According to Poewe and Luginger (1999), 40-50% of PD patients experience mild to severe depression. Ellgring, Seiler, Perleth, Frings, Gasser, and Gertel, (1993) reported that, "Patients with difficult relationships showed the highest degree of depression, followed by single patients, and then those with a stable partnership" (p. 42). They explained that while relatives and partners may have contributed to the psychosocial problems of patients with PD, they were still regarded as a potential source of support. Similarly, Ehmann, Beninger, Gawel, and Riopelle (1990) noted that social supports and the perception of supportive relationships may protect people from becoming depressed and may have a direct effect on mental well-being.

Similar to the statistics found with depression, 40% of PD patients may also experience anxiety, a secondary symptom of the disease (Ellgring et al., 1993). Anxiety is often viewed as an indirect consequence of the motor symptoms. It is sometimes overlooked as a symptom because physicians see it as a normal response to the progressively more challenging physical symptoms. The most common form of anxiety in PD patients is social anxiety and panic. Ellgring et al. stated that patients are often afraid of being negatively viewed in public and lose self-confidence. Many have had the experience of being mistaken for someone who is intoxicated. Panic may ensue when frozen in place, or the fear that one may suddenly be unable to move. Depression and anxiety not only complicate and exacerbate the physical symptoms; they also place enormous pressure on the family to help manage the illness.

In 2004, Harkness-Hodgson, Garcia, and Tyndall conducted a phenomenological study with couples in which one partner was diagnosed with PD. They found that some couples with dependent adult children expressed challenges such as lack of financial resources, energy, open communication, and the children's acceptance of the disease. According to the participants, some children did not appear to want to accept the diagnosis, its progression, or the loss of the parent they once branded a hero, while others stepped forward and provided care, conversation, and companionship at their parents' request. It appeared that the relationship between the parents and their children varied depending on the severity of the illness and the complexity of the children's lives. This is the only known inquiry that has addressed the implications of PD on the adult child-to-parent relationship studied from the parents' perspective.

The philosophies inherent in a phenomenological research design, and the biopsychosocial approach, were employed in this study. Phenomenologists assume all knowledge is relative thus, the same illness experience can be interpreted to mean very different things for different people (Boss, Dahl, & Kaplan, 1996). According to Engel (1977), illness is not simply a breakdown of the body, it is a systemic experience. Engel (1980) further stated, "nothing exists in isolation...every system is influenced by the configuration of the systems of which each is a part" (p. 537). Given these two interpretations, it is likely that all parts of a system are uniquely influenced by illnesses such as PD. Therefore, a phenomenology and a biopsychosocial-spiritual framework were employed to offer insight into how the adult child, experiences PD systemically.

The purpose of this phenomenological study was to explore, appreciate, and describe the experiences of adult children who have a parent with PD, and to then compare the findings to existing literature on other chronic illnesses, pointing out similarities and differences. Hopefully, the findings help to increase therapist and

researcher sensitivity to the issues and concerns expressed by the adult child about a disease for which no known etiology or cure is available.

Method

Research Context

Phenomenological inquiry requires that investigators serve as the primary data collection instruments (Boss, Dahl, & Kaplan, 1996; Creswell, 1998) and own their subjectivity (Boss et al., 1996; Creswell). We must realize that we are not separate from the phenomena under investigation, and that our personal beliefs and biases have influence. To that end, I, Amy Blanchard, the principal investigator, constructed a written record of my assumptions/biases about the phenomenon prior to investigation. Based on my limited understanding and personal experience with PD, I suspected tremendous influence of PD on an adult child. I assumed it to be a difficult experience for the adult child to transition from viewing his or her parent as a teacher, caretaker, and primary support to someone who now has to cope daily with the physical and emotional challenges of PD. Meanwhile, adult children may find it challenging to balance their parent's illness with their own settled lives.

The triangulated investigator, Christy Bond, also constructed a bias statement prior to working with the data. According to Lincoln and Guba (1985), a triangulated investigator is one verification method that may be used to assist with the coding of data helping to compare, reconcile, and consolidate it. Her statement included her personal experience being a caretaker of a parent with cancer and her fear, worry, and sadness throughout that experience. The co-authors on this manuscript were members of my thesis committee, who were instrumental in the manuscript editing and approval of design portions of this study. They were not intimately involved with the study's data collection or analysis phases. Their bias statements were not constructed prior to the data collection phase, but were self-monitored while reading the completed report and offering suggestions for editorial revisions to the primary investigator. Jennifer Hodgson has published in the area of Parkinson's and its psychosocial implications. Her experience with families led her to suspect that they would have a biopsychosocial-spiritual dynamic to their shared experiences. Angela Lamson also shares this theoretical understanding of the biopsychosocial-spiritual experiences of illness on humans and has experience working with Alzheimer's disease patients and their families who struggle with family/caregiver dynamics. David Dosser has not had experience with Parkinson's disease, but understands that illness has an impact on the family and it is not just an individual experience.

Research Strategy

Phenomenologists value reality as each individual, couple, or family perceives it to be (Boss, et al., 1996). Our interest is in "addressing, identifying, describing, understanding, and interpreting the experiences people have in their day-to-day lives ... precisely as those people have the experiences and understand them" (Crotty, 1996, p. 14). Influenced by Husserl, a German mathematician credited with the introduction of phenomenological

philosophy (Stewart & Mickunas, 1990), this study was designed to search for the essential, invariant structure (or essence) of the phenomenological experience of having a parent with PD. To support Husserl's notion, epoche, we followed the work of Moustakas (1994). Doing this meant that we carefully bracketed our preconceived ideas about the phenomenon through use of the bias statements, verification strategies, and adherence to Colaizzi's (1978) analysis method to understand it through the voices of the informants (Field & Morse, 1985). Thorough descriptions of the setting, participants, participant recruitment, data collection, data analysis, and verification procedures are provided below.

Setting

Interviews were held at the location of each participant's choice. Most interviews were conducted at East Carolina University's Family Therapy Clinic (FTC), however two interviews were conducted via telephone. All interviews, regardless of setting, were recorded by video and/or audiotape, for the purpose of accurately transcribing the data into written form.

Participants

Participants included 7 adult children. The first author/investigator interviewed one child per family resulting in differences among the shared narratives with respect to age, sex, socioeconomic status, and stage of their parent's PD. Two of the participants fell in the age range of 20-30, four were aged 31-40, and only one was in the range of 51-60. There were four male and three female participants. All of the participants were Caucasian and of middle to upper class income (all earning more than \$30,000 annually, most earning more than \$50,000 annually). According to Hoehn and Yahr (1967), the stages of PD range from one to five (lowest to highest in severity and progression of the disease). One participant believed his PD parent was in stage two, three believed their parents were in stage three, one in stage four, and one in stage five. All participants' parents were reportedly married at the time of the study and six of the seven adult-child participants were reportedly in committed long-term relationships.

Participant Recruitment

Following approval from East Carolina University's Institutional Review Board, participants were recruited from a local PD support group. Since adult children did not typically attend the meetings on a regular basis, the principal investigator announced the study opportunity to the parents who were asked to see if their children would be willing to participate. After participant-initiated contact was established, consent forms were administered to both the adult child and both parents. Consent was needed from both parents of the adult child participant, since some of the demographic data that was gathered, and questions asked during the interview, pertained to information about both parents. According to Cain, Harkness, Smith, and Markowski (2003) it is important that, when collecting information about a family, that all of its members be considered secondary subjects.

Data Collection Procedures

Upon obtaining written informed consent, basic demographic information was requested from each adult child participant (i.e., age, sex, stage of parent's disease, race, ethnicity, and socioeconomic status), creating a context for the phenomenological experience. Open-ended questions followed by probing questions allowed for more specific, detailed explanations to emerge about the biopsychosocial-spiritual experience under investigation. The biopsychosocial-spiritual approach has emerged as a pioneering technique to assist researchers in the collection of comprehensive data (e.g., Brown, 2002; Harkness-Hodgson et al., 2004; Kerns, Kassirer, & Otis, 2002). However, as Crotty (1996) stated, in a true phenomenological research study, only one question is asked to elicit data. Therefore, the investigator initiated each interview with one question, "What has been your experience of your parent's Parkinson's Disease?" We found that this one question replaced the need for probing questions in most occasions as participants naturally covered the biopsychosocial and spiritual areas of their lived experience.

Data Analysis Procedures

The data collected from this study were analyzed according to Colaizzi's (1978) phenomenological data analysis method. The final themes reflected our agreement on interpretation of the collected data. In the end there were no discrepancies, thus, the intercoder reliability percentage was 100%. The process for reaching complete agreement was as follows: (a) Amy Blanchard, principal investigator, and Christy Bond, triangulated investigator, read through all recorded narratives at one time, (b) they coded the data separately and then came together to discuss similarities and resolve any differences, (c) if differences could not be resolved, the peer debriefer, Jennifer Hodgson was brought in to help interpret the data, and (d) once all agreed on how the data would be coded, the data was finalized. Few instances occurred where Dr. Hodgson, was needed during the analysis process. She mainly provided feedback regarding the finalization of the thematic cluster titles, consolidation of meaning statements, and verification that the exhaustive description was grounded in the actual data. The procedural steps used in this study were as follows:

1. All transcripts were read in one sitting by the principal and triangulated investigators to acquire an overall feeling and understanding of each participant's experience.
2. Significant statements, meaning key words or phrases, related to each adult child's experience of having a parent with PD were extracted. Phrases that were tangential and off topic were omitted. The principal investigator and triangulated investigators completed this initial step separately. Then, the investigators went line by line in each transcript to determine if there were any inconsistencies in the statements/key words/phrases extracted. For example, one adult child stated, "PD plays a pretty big role, it's a lot of the reason I spend more time with him now."

3. Meaning statements were formulated for each significant statement. For example, regarding the above significant statement, the principal and triangulated investigators each independently attributed meaning to it and then came together to confirm agreement. These formulations both uncovered and highlighted participants' shared meanings. Formulations were double-checked by the peer debriefer to make certain that they were grounded in the data. For example, a series of statements spoken by several different participants resulted in the establishment of the following meaning statement, "PD influences time spent together."
4. Formulated meanings were organized into clusters of themes by the principal and triangulated investigators, reflecting a series of common meaning statements. Using the same example from above, the meaning statement, "PD influences time spent together" was clustered with other meaning statements that addressed how participants' family systems have changed since PD. This thematic cluster was named "family system."
5. An exhaustive description was written by the principal investigator incorporating data from all of the above steps, reflecting the fundamental structure of the adult children's experiences.
6. Verification strategies were instituted throughout all steps of the data analysis process by both investigators and the peer debriefer to preserve the integrity of the data and maintain the rigor of the study. The data collection and analysis process continued until the thematic clusters reached saturation.

Verification Strategies

Several verification strategies were employed to help increase the trustworthiness of the inquiry process. Investigators used peer debriefing, investigator triangulation, reflexive journaling, and maintenance of an audit trail throughout the duration of the study (see Lincoln & Guba, 1985). We followed the guidelines set by Lincoln and Guba and asked ourselves the following questions: (a) What is the truth value or how do we know that the findings are from this study and its context (b) How do we determine the extent that the findings from this study apply in other situations (c) What confidence do we have that these findings would be repeated if done again, and (d) Have we imposed our own bias' and judgments onto the study and if so, to what extent? It is through these questions that we addressed issues of credibility, transferability, dependability, and confirmability.

Results

The phenomenological data analysis process transformed the combined set of seven narrative transcripts into 215 significant statements, 29 meaning statements, seven thematic clusters, and an exhaustive description summarizing the results. The exhaustive description was used to capture the essence of the phenomenon (Creswell, 1998). Effective in its synthesis of an enormous amount of information, it does not include a detailed description of each thematic cluster and how it emerged from the data. For this

reason, the following results are written to flush out the details within each thematic cluster.

Thematic Clusters

As a result of the data analysis process, the following thematic clusters were identified: (a) family system, (b) positive influence, (c) providing care, (d) future thinking, (e) PD's progression, (f) coping methods, and (g) contextual experience. Each cluster will be defined and detailed examples of supporting data provided.

Family System

This cluster describes the adult children's perceptions of how their family system has changed since PD was diagnosed in one of their parents. Some participants viewed the illness as changing the landscape of the entire family unit. They spoke of the ways PD brought their family closer together or caused it to grow further apart, role reversals between parent and child, PD's positive influence on their relationship with their spouse, and how it changed sibling and grandparenting relationships. Related to changes in emotional proximity, one participant shared that "[PD plays] a pretty big role. It's a lot of the reason I spend more time with him [PD parent] now." Others described family conflicts as being exacerbated after PD was diagnosed and subsequently reported an increase in emotional distance between family members. Another adult child shared that,

since he [PD parent] has developed PD and became increasingly an invalid, I think there's been more of a distancing [between my children and him] and I have trouble getting my boys to even go over and visit; they look for reasons to not go visit.

The adult children in this study also described role reversals that have taken place with their PD parent and sometimes the caregiving parent as well. One adult child described that growing up she had "hero worship" for her PD parent. She stated, "I had idolized him for a long time." She reported that since PD, she sees him as more vulnerable and human. Another adult child stated that,

the biggest issue [of having a parent with PD] is that my role has changed from that of seeing him as a parent and fellow adult to now seeing him as a responsibility and almost a childlike role...the roles have reversed.

Interestingly, some participants noticed improved relationships with their own spouse/partner and/or siblings that they attributed to their parent's illness. For example, one adult child stated, "[my spouse has] been very supportive through all of this. It makes me feel very positive. She's a wonderful wife." Similarly, another adult child after describing caregiving demands that his spouse has willingly accepted stated, "we've been married a long time and she's good to have put up with what she has [related to PD]. I respect her." Related to her sibling, one adult child stated, "I think my sisters really understand it fully because it's their mom too. It has really strengthened us. We have that

common bond.” Yet, despite the positive connections that were established or reinforced, some adult children described increased sibling conflict around how to best support their parents. One participant stated,

there’s some resentment going on right now and it’s directed toward my brother. He’s a good guy. It’s just unfortunate that what his expectations, thoughts, and plans were [about how to support parents]. . . just didn’t agree with what I wanted to do.

Finally, several adult children described watching changes between their own children and their parents. They reportedly saw their children grow closer to their parents because of PD. One participant stated, “My children really love their grandparents and enjoy being around them...I think it has helped with those family ties.” On the other hand, another stated, “I think there’s been more of a distancing [between children and parents] as he developed PD. It bothers me.”

Positive Influence

This thematic cluster illustrates how some of the adult children were able to be positive in the wake of a challenging diagnosis. Several of the adult children reported focusing more on the positives, turning negatives into positives, and recognizing the strengths PD surfaced in their families. They described how PD helped them to value things more and have a positive outlook. This theme was captured by one adult child when she stated, “I’ve learned to try as much as possible when we’re all together, just too...be positive...even though it’s [PD] a bad thing. I tried to turn it from being negative for him [PD parent] to something that is really positive.” Similarly, another adult child stated, “I don’t think you have anything to gain by thinking negatively or in a fatalistic view . . . I live one day at a time and stay positive.”

Providing Care

The third cluster pertains to how the adult children reported providing care, their perceptions of caregiving, and their spouse’s involvement in caregiving tasks. Thus, while many of the adult children described caregiving as part of their experience, none identified with being the primary caregiver. They described supplementing caregiving provided by the non-PD parent. They reported performing tasks associated with emotional, physical, financial, household, decision-making, and social support as requested. All participants did not perceive caregiving as a burden, although there were barriers such as the influence of geographical distance, income, and gender on the amount and type of support they or their spouse provided to overcome. One adult child stated,

I think she [PD parent] can count on me to sort of be a rock. . . to always be there, to be available. I won’t be too busy to be available emotionally or to fix things around the house, to have more time to spend with her [PD parent].

At least two of the participants' parents had moved closer to them following the diagnosis of PD. One stated,

[non-PD parent] was the one seeing him head to invalidism, saying, I can't do this by myself and I don't want to live here alone and have him in a nursing home. I volunteered and said, why don't you come here.

The other stated, "my parents actually moved here to be closer to me so I could help." Although one participant reported that he lived the furthest away, he took pride in being able to help a great deal because of other factors in his life, such as, financial and emotional stability compared to the sibling who lived in town.

Participants' narratives also included references to gender as an influence on the type of care they provide. The female participants believed they are more involved by virtue of being a woman. One female participant stated, "I think daughters are the ones that kick in. I think there is a heavier lean on daughters. Women just seem to fall into that role easier." Similarly many of the male participants spoke of and recognized their spouse's support in the care of their PD parent, especially when they were not available due to work or other obligations. They further described the positive influence that their spouse's involvement has on the spousal unit. One male participant stated,

I'm a typical guy. My job has me out of town a lot and my wife steps in and goes over there and helps out. I really appreciate and respect her for what she does and for what she is willing to do.

Future Thinking

Many participants spoke of the ways PD may influence their future. Concerns for the future health of their PD parent, their non-PD parent, themselves, and their family of procreation were addressed. Some participants stated they had not thought about actually getting PD themselves, but spoke of concerns that they may develop a chronic illness of any type. One participant stated,

I haven't actually thought of having PD myself. I don't know why but I haven't, but I have thought about Alzheimer's and various things, and I started thinking what it would be like . . . and how awful it must be for him [PD parent].

The participants, who have children, described valuing their relationship with their own offspring more now that their own parent is ill. They often described looking to the future and hoping their relationship with their children stays healthy and close as they age. One adult child described that,

it [being there for her parent] is a natural progression of child to adult. I like for my children to see that. I hope they will take care of me one day. I like for them to see there's value in that and that's an important part of life. I want them to continue being connected [to me].

Several participants shared concerns about the non-PD parent and future caregiving needs. One participant stated, “He’s going to be getting worse. He’s probably gonna end up in a wheelchair in the near future and she will have a lot more to do than she does now.” Another adult child stated, “Well . . . if he does die, what is she going to do? ...how are we [non-PD parent and adult child] going to deal with that...”

PD’s Progression

In this cluster, the adult children described how difficult it was for them to watch their PD parent experience various symptoms such as anxiety, depression, frustration, lack of sleep, slowness in thought, speech and/or movement, cognitive deterioration, and/or overall progression of the disease. They observed ways PD limited family activities, changed holiday celebrations, and modified the PD parent’s social life and behaviors. They also noted changes in time spent and/or emotional closeness to PD parent that have made it harder as the disease progresses. One adult child stated,

it’s been difficult to see my [PD parent] struggle with a disease that affects the quality of her life. She has tremors. She has the walk. She has got limited mobility and she’s also taking medications that have some side effects. It’s difficult to hear that it affects her sleep. It’s been challenging for me to see that and to watch her have to go through this.

Another adult child explained that the biggest influence on the child has been that he cannot communicate as well with his PD parent anymore. He stated that PD has changed his parent’s speech and slowed his thoughts, and it has even changed his personality.

Thus, as the symptoms progress within the patient, it seems the adult child experiences them vicariously. He or she remembers what his or her parent was once able to do. For many of the participants, the parent with PD held a position of power within his/her place of employment/community and now struggles to maintain power over a disease that robs freedom of movement, speech, and thought. The progression of PD forced many of the participants to negotiate a minefield of biopsychosocial-spiritual changes not knowing which ones were temporary, stress related, or will forever be a part their parent’s illness experience.

Coping Methods

Methods of coping were described by the participants as a salient aspect of their phenomenological experiences. Participants discussed how their beliefs, knowledge, and support received from their non-PD parent and others were effective methods of coping. One example of the role beliefs played was shared by a participant who reported that her PD parent is “gonna get through that bad day not because of her own strength but because the Lord was with her” and that belief helped them cope and eased their anxieties as a family. Other adult children described using their beliefs to help them maintain hope. Another adult child stated that her family’s Christian belief, “increases our hope . . . because we’re believing in something larger than ourselves. It allows you to have a lot more peace in the place that you’re at.”

Some participants valued educational opportunities (e.g., support groups, internet, doctor's appointment, conferences) to learn more about PD. One adult child stated,

I do better if things are explained. I went to the symposium last year that the [local] PD support group had and it was really helpful for us because [we] want to help but yet [PD parent's] not gonna tell us what she needs all the time. So, if we have a doctor or someone to explain . . . this is the way a person that has PD [is affected], this is how you can help them. [it] helps us realize how we can help better.

Support received from the non-PD parent was a frequent mention among all participants. One participant replied,

Honestly, I'd say my mom, she's just very amazing when it comes to handling difficult things. So, I think what gives me hope is that my mom and I can work together to make this as comfortable as it can be.

In most cases this was enhanced by the support received from external systems (i.e., support groups, medical care, and community).

Contextual Experience

The final cluster includes descriptions of how various contextual factors influenced their experience. They spoke in reference to their parents' ages and stage in life, as well as their own age, stage in life, geographic location, family role, gender, and career. The adult children ages 30 and older reported drawing strength from other adult children with aging parents; however, the participants who were ages 29 and younger reported that they did not have peers to whom they could relate as most of their peers' parents were in relatively good health. For example, an older participant (above age 30) noted,

I see some of my same age peers going through the same things with their parents except their parents may not have PD. It may just be the infirmities of old age or Alzheimer's. So, I have the same conversations [about roles reversing] with some of my peers.

This is in contrast with one of the participants who was less than 30 years of age and who stated, "My friends don't really understand. It's just different to look at their [parents]. It can be frustrating."

The age of the PD parent also seemed to influence the PD experience because of expectations of where the parent should be in his/her aging process. For example, one adult child stated,

I was concerned because...she's gone from being very active, what I would consider to be a considerable active empty nester, to what you think

of as somebody in their retirement years and she's not even retirement age yet.

Exhaustive Description

The seven thematic clusters described above seem to capture the essence of the experience of having a parent with PD from the perspective of the adult children interviewed. Overall, as PD imposed family changes and care-giving demands on the adult child's shoulders, the adult children focused on the positive, using coping methods such as finding support from siblings, spouses, and their non-PD parent, relying on their spiritual beliefs, and obtaining knowledge about the disease process. Each participant's experience was unique based on the context of their lives and the progression of the PD in their parent.

Phenomenological Essence

The adult children in this study described how their lives have been and currently are being influenced by having a parent with PD. Many of the adult children reported changes in their family systems, while some reported feeling less emotionally connected to family members others reported feeling even closer. They attributed positive changes and refreshed outlooks on life to the presence of PD. The majority reported caregiving as a salient aspect of their experience. Those who lived geographically closer to their PD parent reported that this influenced both availability and type of caregiving provided. Adult children noticed a role reversal between them and their PD parent in that now their PD parent relies on them for emotional, physical, and financial support. They reported helping with tasks such as household chores, decision making, and social support. They expressed that although they have been placed in a caregiving role, they did not perceive their parent with PD as a burden; rather they saw their changing role as a natural progression of their maturing relationship. Support was reportedly also provided in some instances by the non-PD parent, siblings, and their own spouse. Those who were married shared how their spouses' willingness to help positively influenced their own marriages.

The adult children who were interviewed in this study witnessed the progression of their parents' PD first hand. They illustrated through their stories the ways PD limited family activities, their parents' social lives, and the way holidays were celebrated. Many reported watching with tremendous difficulty the direct effects of PD on their PD parent as he or she experienced anxiety, depression, frustration, lack of sleep, slowness in thought, speech and/or movement, cognitive deterioration, and/or the overall physical progression of PD. They also noted that while PD had not strained them directly financially, they found it hard to watch PD take a toll on their parents' finances.

As the adult children interviewed in this study spoke of their future, they expressed worrying about their non-PD parent as the disease progressed and eventually the time when their PD parent dies. Some adult children described their thoughts of their future relationships with their own children and reported placing more value on the parent to adult-child dyad because of this experience. They also described thinking about their own future health and the possibility of developing PD or another chronic illness.

Many had already considered what the implications would be for them personally and for their family of procreation if they, like their PD parent became chronically ill.

Adult children described how increased knowledge about PD and the presence of external supports have been helpful to them as they cope with this experience. They described how reading about PD, learning about it formally at symposiums, and receiving information from doctors were all helpful because the more they understood the disease the better they understood their PD and non-PD parents' struggles. They also expressed that support systems such as church, PD support groups, and good medical care helped them to be more informed and prevented them from hiding behind the reality of the disease.

Many believed that their experience was unique based on factors such as their career, their age when their parent was diagnosed, their stage of life, their spiritual beliefs, and their parent's age and stage of life. They reported that their experience was even different from their siblings' experience due to geographic location, sex, and family role. Many described using their beliefs as a way of coping, increasing strength, finding hope, and/or ascribing meaning to the presence of PD.

Discussion

Participant narratives provided us with information about how Parkinson's Disease (PD) had the potential to impact adult children by changing their family system, encouraging them to look at the positives, placing them in a caregiving role, shaping their thoughts and plans for their own future and that of their parent as PD progresses, altering the methods they used to cope, and experiences based on personal context. They serve as a record of their lived experiences, highlighting those that are unique to PD and those that are similar to adult children who have a parent with a different chronic illness.

Researchers have reported that while some parent-child relationships transform with ease upon the intrusion of chronic illness, others experience a more abrupt change in (positive or negative) emotional intimacy (Roberto, 2001). Yet, just as Roberto described, some participants reported that PD was keeping their family emotionally and physically distant. Grandchildren did not want to visit their "invalid" grandparent and so the adult child felt torn between the psychosocial needs and challenges of those two generations. Siblings who used to have a cohesive relationship were now disagreeing over the caregiving decisions related to their PD parent. Participants described that learning how to cope came by watching how their non-PD parent remained emotionally strong and fully committed to the caregiving role.

The caregiving literature is rich with tasks that adult children often perform when a parent becomes ill (although none addressed PD specifically) (Cicerelli, 1983; Lieberman & Fisher, 1995; Stoller, 1983). Common to the literature, participants described providing emotional, physical, and financial support to both their PD and non-PD parent. Despite the sometimes unexpected added responsibility, the participants in this study made it clear through their stories that they willingly taking care of their PD parent out of love, compassion, and the desire to do so. Likewise, researchers have found that caregiving is more than just an obligatory burden (Cicerelli, 1983; Walker & Pratt, 1991). It stems from a preexisting relationship between the parent and the child. The context surrounding their relationship to each parent was such a salient part of all the

participants' stories and became a unique contribution to the literature by capturing the influence that age, stage in life, geographic location, and gender had on their experiences.

While it may seem unusual to be young and having to care for a parent, it is commonly expected for these responsibilities to fall on the daughter and/or daughter-in-law (Bond, Farrow, Gregson, McNamee, & Wright, 1999). The participants' narratives supported Bond et al.'s work finding sisters and daughters-in-law being more involved in the day-to-day caregiving tasks than the brothers and sons. However, a secondary benefit to the caregiving provided by a daughter-in-law was a reportedly closer marital connection between the adult child and his spouse. This finding is also unique to the existing literature and deserving of further exploration.

One salient coping method that participants noted using was relative to their beliefs (e.g., spirituality). Previous researchers also found beliefs may be useful in coping with illnesses such as Alzheimer's disease (e.g., Garcia, 2002), cancer (e.g., Ferrell, Smith, Juarez, & Melancon, 2003; Johnson & Spika, 1991), HIV (e.g., Tuck, McCain, & Elswick, 2001), and even PD (Fowler, 1997; Harkness-Hodgson et al., 2004). It seems that with the intrusion of PD into these adult children's lives they seek out new information to give hope and understanding about an unpredictable and progressive illness. This study confirms that in times of crisis and change, humans may seek out biopsychosocial and/or spiritual knowledge to gain understanding and empower their families (e.g., Harkness-Hodgson et al.).

Remaining positive is also a unique finding in the literature on progressive diseases. The adult children described situations in which the positive aspects of life outshined the challenges of this disease. There was a strong sense from the participants that they did not want their stories to convey a negative tone. One participant repeatedly said, "it [caregiving] has not been a bad thing, really it hasn't...it has brought a lot of good." Overall, it seems PD has brought them some degree of positivism, essential to their coping, which they may not have otherwise noticed or experienced.

Limitations of Study

This study was used to explore the phenomenological experience of having a parent with PD. Investigators took measures to make this study as true to the experience as possible; however, as with all research, this study has its limitations.

The first limitation is related to the investigators' biases. Although measures were taken to minimize investigator bias (e.g., written bias statements, reflexive journals, member checking, peer debriefing), as with all research there is really no way to confirm that biases did not inappropriately inform the data collection and analysis processes. Another limitation of the sample is its lack of diversity. All but one of the participants was from the same region of the country. Eastern North Carolina is part of the rural culture in the South, rich with religious tradition (Smith, Denton, Faris, & Regnerus, 2002). Thus, their geographic location, and the culture that exists, may have influenced the adult children's narratives. Furthermore, all of the participants were Caucasian and middle to upper class, which may make the sample too homogeneous. Varying cultural and socioeconomic perspectives were not widely represented in these narratives. Although generalizability to all cultures and people of diverse backgrounds was not a goal of our study, our intent was that consumers of the information will look to

similarities between themselves, others, and locate commonalities (Boss & Dahl, 2005). As Boss and Dahl stated, “Given the complexity and diversity of a particular family’s experience, phenomenological research is more interested in accurately reflecting a given family’s experience than in generalizing about families” (p. 79).

Lastly, the sample was recruited from a local PD support group. The fact that these families are involved in a support group may mean that they are qualitatively different than those not in support groups. Inherent in that fact is that these families, at least the parents, are already connected to external supports and are seeking knowledge willingly. Adult children whose parent(s) is not involved in a support group may experience the phenomenon quite differently.

Future Research

Additional studies using qualitative research methodology are needed to help appreciate the adult children’s experiences of having a parent with PD. The phenomenological approach to qualitative research should be repeated to compare these results to other adult children who also have experienced this phenomenon. This study was true to the essence of the 7 participants, but it would be interesting to see if similar thematic clusters and the resulting exhaustive description would emerge from a different sample. It would also be important to study sibling relationships among those who have a parent with PD. This research subtly indicated from the adult child’s perspective that his/her experience is different than his/her siblings’ perspectives. More research would help to broaden our understanding and ability to lessen the fracturing of sibling relationships.

Another direction of future research may be to conduct a cross-sectional study comparing adult children who have parents in various stages of PD and track similarities and differences over disease progression. Similarly, researchers may also want to study adult children based on their demographics and stage of life (e.g., race/ethnicity, religious affiliation, marital status, life cycle stage). This research would provide us with a richer understanding of how adult children are influenced by a parent’s PD experience.

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