



## Feature Article

## Challenges and strategies of medication adherence in Parkinson's disease: A qualitative study



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## ABSTRACT

Little is known about strategies used by people with Parkinson's disease (PD) to facilitate medication adherence in the U.S. The purpose of this study was to describe challenges in adherence to medication regimens and to identify strategies used to facilitate adherence to medication regimens. A qualitative research design was used to interview sixteen community-dwelling people with PD and five caregivers. Data analysis was performed using content analysis. The majority of the participants (81.3%) reported decreased adherence to medication regimens. Seven themes emerged from the data. The main challenges of medication adherence included medication responses, cost of medications, and forgetfulness. Strategies used to facilitate adherence to medication regimens included seeking knowledge about antiparkinsonian medications, seeking advice from family and friends, use of devices, and use of reminders. These findings may be important in formulating interventions to improve adherence to medication regimens for people living with PD.

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## Introduction

As the population in the United States (U.S.) ages, a priority for nurses will be the acquisition of knowledge and expertise in managing chronic conditions common in older adults such as Parkinson's disease (PD).<sup>1,2</sup> PD is a progressive and neurodegenerative condition which results in the loss of dopamine-producing cells in the brain.<sup>3,4</sup> This disease is prevalent among older adults aged 65 and over, affecting at least one million people in the U.S. People with PD develop motor and non-motor symptoms that frequently affect their ability to perform activities of daily living. Due to its progressive nature, management of PD can be challenging to the patient, family, and health care delivery system.

Currently, PD has no cure; however, symptoms can be dramatically reduced with medication. Optimizing adherence to oral antiparkinsonian medication regimens is critical to managing the symptoms of PD and maximizing the therapy response.<sup>5,6</sup> That is, symptom control is best when the patient takes a steady level of antiparkinsonian medications throughout the day. The prevalence of suboptimal adherence in people with PD ranged from 27.3% to 67% in previous population-based studies in the U.S.<sup>6–10</sup> This

suboptimal or non-adherence to antiparkinsonian medications may lead to poor health outcomes and potential increased health care costs in people with PD.<sup>7,11,12</sup>

### Adherence to medication regimens in PD

Medication-taking behaviors can be very complex and multifaceted. People with PD often have complex medication regimens requiring three to four different medications to treat motor and non-motor symptoms. With the progression of the disease, symptom management is likely to become more complex and prescribed medications may be ordered as frequently as every 2–3 hours. People with PD may need greater amounts of time, effort, family support and resources to manage these complex medication regimens due to the increased motor and cognitive impairment associated with the disease.<sup>13</sup> For example, a missed dose of medication may mean that the person's tremor increases, making it more difficult to remove their medication from the container. In more advanced stages, a missed dose may result in having difficulty swallowing the next dose. Taking doses too close to each other might trigger an adverse side effect such as dyskinesia (i.e., excessive involuntary muscle movement).

Prior research investigating medication use among people with PD has focused on identifying the issues related to medication adherence.<sup>6–10</sup> Findings from these studies identified multiple

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associated factors of non-adherence to antiparkinsonian medications, including age, gender, mood disorders, poor cognition, poor symptom control/quality of life, longer disease duration, regimen complexity/polypharmacy, risk-taking behaviors, poor knowledge of PD/education, lack of spouse/partner, low income, and maintaining employment.<sup>8,10,14</sup>

While individualized, specific circumstances prompting non-adherence to antiparkinsonian medication regimens in people with PD has not been studied in the U.S., it has been reported in a qualitative inquiry in the United Kingdom (U.K.). Drey and colleagues<sup>15</sup> conducted a qualitative study exploring different types of non-adherence to medication regimens, including less-use and/or over-use of medications, and forgetting doses or changing the timing of dosing from that prescribed. This study did not explore how people with PD tried to improve adherence to these regimens. Whether or not these findings are relevant to people with PD in the U.S. is unclear given the differences in the health care systems and the different management models of PD between countries.<sup>16</sup>

There is limited research that focuses on identifying the challenges people experience in adhering to medication regimens, and previous research fails to shed light on how people overcome such challenges. Thus, identifying the strategies that people with PD in the U.S. use to facilitate adherence to medication regimens is necessary to develop tailored interventions for better medication adherence and symptom management.

### *Purpose*

The purpose of this study was to describe challenges in adherence to medication regimens and to identify strategies used to facilitate adherence to medication regimens in people with PD.

### **Methods**

An exploratory, descriptive qualitative research design with semi-structured interviews was used in this study. Institutional Review Board approval was obtained and data were collected between July and October of 2013.

### *Participants and setting*

Individuals were eligible for this study if they had a diagnosis of PD and took antiparkinsonian medication(s); managed their own medication on a day-to-day basis; if they were a caregiver involved in management of medications for a care recipient. In addition, all participants had to live in the community; and speak English.

A recruitment flyer was e-mailed to members of the Delmarva PD Alliance, which is composed of PD support groups in and around the state of Delaware. They were invited to participate in a single interview session or audiotaped phone interview. Interested individuals and/or their caregivers contacted the investigators via phone or e-mail. The investigator explained the study and answered any questions that arose during review of the informed consent document. Once they agreed to participate in the study, the principal investigator (PI) and the potential participant and/or caregiver(s) met at a mutually agreeable place to review the study, obtain consent, and to have an in-person interview. Twenty two people contacted the research team and volunteered to participate in the study. Of these volunteers, 16 individuals with PD and 5 family members were eligible and consented. One caregiver volunteer was not eligible to participate in the study as she did not live with her family member with PD and did not directly manage antiparkinsonian medications for the person. One participant with PD and a caregiver participated in a phone interview due to long distance.

### *Data collection: interviews*

The PI conducted digitally recorded, in-depth, semi-structured interviews. Sample interview questions included: a) tell me all the medications you are taking now; b) describe how and when you take your antiparkinsonian medications; c) describe some of your greatest challenges related to taking your antiparkinsonian medications; and d) describe strategies you use that are helpful (also, not helpful) when taking antiparkinsonian medications.

In situations in which a participant with PD had a family member involved in their medication management, the dyad was interviewed together. Interviews ranged from 45 to 70 min and were conducted in a quiet, private place. Field notes were used to record the impression of each interview. Interviews were conducted until informational redundancy was achieved.<sup>17</sup> Interviews were audiotaped using a digital recorder and transcribed verbatim. Each transcript was reviewed while listening to the recording to assure accuracy.

### *Data analysis*

Content analysis was used to describe the challenges and strategies of medication adherence in people with PD, as this is a good fit for analyzing multifaceted, important, and sensitive phenomena.<sup>18,19</sup> The PI and a co-investigator conducted the content analysis independently by coding and creating categories from actual words or phrases used by participants. The investigators compared and discussed their findings until consensus between them was achieved for a final master code list. Master codes were then categorized by the researchers into themes that identified the challenges and strategies of medication adherence in people with PD. The credibility of the data was established by a third researcher (BH) familiar with both the PD population and qualitative techniques who reviewed the master code and resultant seven themes. The confirmability of the data was checked by bringing back the findings to the participants in order to confirm what they said.<sup>17,20</sup>

### **Findings**

#### *Participant characteristics*

Participants of this study included 16 individuals with PD and five family caregivers. Participants with PD included 11 men and five women. The mean age of participants with PD was 68.1 years (range from 53 to 82 years old) and the mean years of education attainment was 18 years (range from 12 to 26 years). All participants with PD were white and native English speakers. There was a wide range in years since diagnosis ranging from six months to 14 years. Participants took at least one antiparkinsonian medication: either carbidopa/levodopa or a carbidopa/levodopa/Catechol-O-methyltransferase combination. Daily levodopa equivalent dose ranged from 200 mg to 600 mg. Eleven of sixteen participants with PD (68.8%) were also taking other antiparkinsonian medications (e.g., dopamine agonist and/or Monoamine Oxidase B [MAO-B] inhibitors). All participating family caregivers were spouses of participants with PD; three were females and two males. The mean age of participating family caregivers was 73.2 years (range from 64 to 80 years old).

All participants in the study discussed how and when they took antiparkinsonian medications. Three participants in this study reported that they have been adherent to antiparkinsonian medications as prescribed. One participant said, "It's been very good; I would say my compliance is 100%." Another participant described that she had not skipped any doses due to the anticipated medication off-time: "I find that I will go months having taken all my

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