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Title: Adherence to antiparkinsonian medication: an in-depth qualitative study

Keywords: Adherence to medication, concordance, Parkinson's disease, symptom control, negotiation

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## Abstract

**Background:** Adherence to prescribed medication is low. It is a major problem as following practitioners' recommendations is strongly associated with good patient outcomes. Little research has been undertaken with people in the early stages of Parkinson's Disease although achieving symptom control depends on regularly timing doses. **Research Questions:** How do people with Parkinson's Disease adhere to prescribed medication, and what are the antecedents of non-adherence to antiparkinsonian medication? **Design:** Exploratory qualitative study using semi-structured interviews **Setting:** Specialist Parkinson's Disease clinic in one National Health Service hospital in England. **Participants:** Fifteen consecutive patients not yet in the advanced stages of Parkinson's Disease living at home and responsible for managing their own medication or managing medication with the help of their carer. **Methods:** Semi-structured interviews with open questions. **Findings:** Levels of non-adherence were high and different types of non-adherence were clearly identifiable. Each respondent demonstrated at least one type and in most cases several different types of non-adherent behaviour. Inadvertent minor non-adherence occurred because patients forgot to take tablets or muddled doses. Minor deliberate deviations occurred when patients took occasional extra tablets or brought forward doses to achieve better symptom control, often to cater for situations that were anticipated as especially demanding. Deliberate major non-adherence was very common and always related to over-use of medication. The experiences of parkinsonism were particular to the individual. The specific circumstances that prompted an episode of non-adherence varied between patients. Nevertheless there was evidence of negotiation between respondents and the Parkinson's Disease nurse specialist. Medication regimes were altered in conjunction during formal consultations and by telephone. **Conclusion:** Non-adherence to prescribed medication for people with chronic conditions is complex and for people with Parkinson's Disease it was possible to identify different types of non-adherence. The possible existence of a typology of non-adherence for people with other chronic conditions merits investigation. Further research is needed to establish whether the findings of this small scale qualitative study can be replicated with a larger, more representative sample and establish how people with Parkinson's Disease might be encouraged to adhere to medication regimes to improve symptom control.

What is known about this topic?

Adherence to prescribed medication is low but is not generally thought to be deliberate.

Parkinson's Disease is the most serious movement disorder in the world and increasing numbers of people are being diagnosed under the age of fifty but little research has been undertaken with people in the early stages, especially in relation to medication management or motivation to adhere to prescribed medication.

What this paper adds

People in the early stages of Parkinson's Disease exhibited very high levels of nonadherence to medication and continually experimented with medication.

Different types of non-adherence were identified and most patients exhibited more than one type. Inadvertent minor non-adherence resulted through simple memory failures. Minor deliberate deviations occurred when patients occasionally took extra tablets or brought forward doses to achieve better symptom control. Deliberate major non-adherence was also very common and always related to over-medication.

The experiences of parkinsonism were particular to the individual and the specific circumstances that prompted an episode of non-adherence varied between patients.

The challenge of controlling parkinsonism illustrates differences in opinion between patient advocates and biomedical scientists. Patient advocates favour a collaborative approach where patient and practitioner negotiate the best way to take medication. In reality, for Parkinson's Disease and possibly for other conditions, there is limited scope for changing the regime in response to patient preference if the medication is to be safe and effective.

## Introduction

The aim of the study was to identify and provide qualitative descriptions of adherence and non-adherence to medication by people with Parkinson's Disease (PD) and establish the antecedents of non-adherent behaviour. People with PD were selected for detailed investigation because they have to cope with complex medication regimes that impose dietary restrictions and may reduce adherence. Adherence may also be reduced by special problems presented by the condition itself and the distressing side-effects of medication. The focus of the study was on people not yet in the advanced stages of PD who were still responsible for managing their own medication or managing it with the help of lay carers.

The effectiveness of medication is influenced by the patient's ability and willingness to take it (Horne and Weinman 1995). Compliance, the extent that the patient's actual use of medication corresponds with the regimen prescribed, is related to success (Aronson 2007). The importance of taking medication as prescribed is clearly illustrated in examples drawn from widely different areas of clinical practice. For example, failure to take oral contraceptives exactly as instructed is very likely to result in unplanned pregnancy (Campbell and Pickard 2007). For numerous other drugs strict compliance is necessary to avoid adverse events that can be very serious. Some antidepressants react dangerously with certain foods (Callingham 1993): maintaining a constant level of antibiotic in the bloodstream is essential to resolve infection (Frost 2007). However, the concept of compliance has fallen from favour because it implies passive behaviour in which the patient adopts the practitioner's instructions unquestioningly, and has additionally been criticised for connotations of paternalism (Barjramovic et al 2004). It has been replaced by the notion of adherence that encourages patients to participate in medication management (Aronson 2007).

## Adherence

Adherence means that patients follow practitioners' instructions thoughtfully and sensibly, but not unquestioningly (Horne and Weinman 1995). It requires a state of partnership between patient and practitioner to promote maximal benefit from treatment while remaining compatible with what the patient would like and is capable of achieving, given the physical and cognitive limitations imposed by their condition (Barjramovic et al 2004). Non-adherence to medication is not always deliberate (Denois et al 2010) but it is recognised that adherence is compromised if patients need to take a number of different drugs, take them frequently (complexity of the regime), if the drugs impose dietary restrictions, cause distressing side-effects (Chesney 2000) or if communication is poor (Barjramovic et al 2004, Denois et al 2010). Adherence is notoriously poor both for serious, potentially life-

threatening conditions and for chronic illnesses where treatment enhances symptom control (Horne and Weinman 1995, Aronson 2007). To manage medication patients must have a sound understanding of their condition, what their medication is supposed to achieve and how to take it safely and effectively (Barjramovic et al 2004). It has been suggested that for people newly diagnosed with a chronic condition, help and support from „expert. patients more experienced in its management can be beneficial (Tattersal 2002). Good relationships between patient and practitioner are also considered to be very important and this has helped to promote the notion of concordance (Aronson 2007)

## Concordance

Concordance describes a therapeutic alliance between patient and practitioner (Hughes 2004). Although regarded as the ideal situation, especially by those who advocate equality in the patient-practitioner relationship (Elwyn et al 2000), the concept of concordance is not without critics. They have pointed out that practitioners could be placed in a difficult position morally and ethically if they collude in decisions that might result in patients failing to take medication safely and effectively (Kaufman and Birks 2009). The challenge of achieving concordance will vary according to the specific condition and the medication prescribed.

## Parkinson's Disease

In this paper we describe adherence and non-adherence to medication by people with Parkinson's Disease (PD) and seek explanations for non-adherent behaviour. PD is the most serious movement disorder in the world, affecting 0.3% of the population in developed countries and is the second most common neurological condition globally (Lewitt et al 2008). Destruction of cells in the substantia nigra of the brain cause loss of the neurotransmitter dopamine, initially giving rise to movement-related symptoms: stiffness, slowness and rigidity. Eventually non-motor related symptoms develop: impaired sensory and cognitive function and depression (Lang 2009). A high proportion of people with PD eventually develop dementia (Hely et al 2008). PD is a chronic condition for which there is no cure. Patients are prescribed drugs that mimic the action of dopamine. Levodopa taken orally is most frequently prescribed regardless of country or health care system and can improve quality of life for years by reducing stiffness and rigidity (LeWitt et al 2008). However, adherence is poor for younger people with PD and is associated with poor treatment outcomes (Grosset et al 2003). In a that involved 54 patients receiving treatment in one centre, 80% under-used medication either because they failed to take doses within the correct time interval or missed them altogether, on an occasional basis and sometimes for whole days or consecutive days (Grosset et al 2005). A pan-European study

in eight centres that monitored uptake of dopaminergic medication over four weeks using an electronic device attached to medicine bottles reported significant levels of under-medication and established an association with poor treatment outcomes (Grosset et al 2009). Over-use of antiparkinsonian medication has also been described and it has been suggested that compulsion to take tablets excessively might occur because the drugs or the symptom relief they afford have addictive properties (Lawrence et al 2003). No attempts were made to explore why patients under or over-used medication in these studies and their relationship with the practitioner responsible for prescribing medication was not considered. These omissions are significant given the complexity of PD and its control, especially as many people with early-onset PD live at home and have face-to-face consultations with specialist practitioners only a few times a year. Problems are compounded because PD gradually impairs manual dexterity, vision and memory (Rascol et al 2003), all factors that interfere with ability to take drugs.

### The challenge of medication adherence for people with Parkinson's Disease

PD is a complicated condition. Symptoms are experienced differently between patients and consequently treatment needs to be highly individualised (Stacey and Galbreath 2008). The challenge for nurses involved in this highly specialist area of care is to ensure that the medication regime is customised to meet the particular needs of the patient while taking into account the progressive nature of the condition (Cook et al 2007). The goal of medication is to balance the problems caused by PD alongside the limitations and side-effects of medication (LeWitt et al 2008). These are considerable.

The half-life of Levodopa is short so it is effective for only a few hours before patients begin to experience fluctuations in motor control with reappearance of stiffness and rigidity. When the drug is working the patient is said to be „on.. The reverse condition (being „off..) reduces normal function and is particularly upsetting if it occurs in public (Rascol et al 2003). Timing is crucial to achieve maximum effectiveness under physically or mentally demanding circumstances (Chaudhuri et al 2007) and to reduce the obvious and stigmatising signs of parkinsonism (Chaudhuri et al 2007). For 15-20% of patients the transition from being „on. to being „off. is rapid and associated with intense anxiety, sweating and tachycardia (Chaudhuri et al 2007). The challenge is to adjust the dose so that sudden fluctuations are avoided. Different dopaminergic drugs or different formulations such as slow-release tablets can be prescribed to reduce fluctuations but difficulties of maintaining a steady level of the drug in the blood are compounded because Levodopa is poorly absorbed and may remain in the stomach for some time after it has been ingested, especially if it is combined with food. Patients are advised to take tablets several hours before meals and if necessary to take several small doses on an empty stomach (Chaudhuri et al 2007). Substances with dopaminergic action occur naturally in plants

and there is a risk that if they are taken in herbal remedies and other complementary treatments, they will interfere with the action of prescribed medication (Poewe et al 2009).

After 4-5 years the effectiveness of Levodopa wanes and patients notice that its effects wear off before the next dose is due (Rascol et al 2003). The frequency of doses can be increased, but this places patients at risk of dyskinesia (inability to control muscular movements, resulting in twitching and in severe cases, uncontrollable flailing movements of the limbs). Dyskinesia usually occurs when the level of Levodopa peaks in the blood. The medication regime becomes increasingly complex as different forms of antiparkinsonian medication are introduced. Side-effects can be disturbing: sudden sleep attacks that can be dangerous for the individual and for other people, for example if driving or handling machinery (Cornella et al 2002), vivid dreams, hallucinations that can occur during the day or night (Arnulf et al 2000), increased libido and compulsive behaviour such as gambling or excessive shopping (Lu et al 2006).

The need for support and the role of the role of the Parkinson's Disease nurse specialist

The role of the Parkinson's Disease nurse specialist (PDS) is well-established in the United States and Europe and is similar in most countries where it has been introduced (Pagoda et al 2009). Their primary function is to provide information and support to people with PD and their carers, especially use of medication, lifestyle counselling and how to cope with the disease (Cook et al 2007, Reynolds et al 2000). In many specialist centres the PDS works alongside the consultant neurologist and patients combine medical and nursing consultations within the same clinic visit (Reynolds et al 2000). There is no evidence that the care provided by the PDS is more cost-effective than that provided by family doctors (Jarman et al 2002) or that the input of the PDS is associated with better patient outcomes (Reynolds et al 2000, Jarman et al 2002). However, patients regard the PDS as an important source of information and emotional support (Reynolds et al 2000).

## Methods

An exploratory qualitative study was undertaken using semi-structured interviews with open questions developed from the existing literature, previous experience undertaking research with people with PD (Fontenla and Gould 2003) and suggestions from experienced practitioners. Informal discussions with the local PDS confirmed that her role was to provide information and emotional support to patients and carers. The interviews were conducted by an experienced male, white data collector with a

background in health services research previously unknown to the respondents and without any particular knowledge of PD. At interview we explored expectations of what medication could achieve, how respondents timed doses, how the recommendations of the PDS were adopted and modified and use of information from additional sources such as patient groups and organisations that might influence adherence. We looked for examples of unsafe behaviour because the findings of a previous study (Fontenla and Gould 2003) suggested that some people with PD continue to drive or work in occupations that involve handling machinery despite the risks of combining these activities with antiparkinsonian medication. We asked about alternative and complementary therapies because of possible interactions with prescribed medication (Poewe et al 2009). Interviews each lasted about an hour, were digitally-recorded with permission and transcribed verbatim. It was not thought appropriate to ask respondents to comment on the veracity of their transcripts because of their poor physical condition and most had obviously were tired by their journey to the clinic. Instead notes of the main points were made during the interviews and the data collector checked to ensure that the respondent agreed with what had been documented.

## Recruitment

Respondents were recruited from the specialist PD clinic of a National Health Service hospital in England. They were eligible to take part if they were responsible for managing their own medication on a day to day basis or managing medication with the help of their carer. This meant that eligible patients had to be living at home and were not yet in the advanced stages of PD. The clinic staff directed the interviewer to consecutive patients who met the study criteria. Data collection took place in private before or after routine six monthly clinic appointments. A carer was present in three cases and with the permission of the respondent, were invited to participate.

## Sample

Typical samples in similar studies have involved 15-30 patients (Noel et al 2005). Thus a decision was taken to interview 15 patients, review the transcripts and either continue or truncate data collection depending on whether saturation had been achieved.

## Analysis



Fifteen interviews were undertaken. Inspection of the data established that saturation had been reached and that respondents' medication regimes, symptoms and the side-effects of medication were typical for people not yet in the advanced stages of PD. Thematic analysis was undertaken where significant units of meaning (phrases, sentences, paragraphs) were highlighted, and interpretative codes created. Patterns, themes and regularities were sought, as well as contrasts, paradoxes and irregularities (Miles and Huberman 1994). Members of the research team read the interview transcripts independently then came together to discuss and agree on emerging themes. Once examples of non-adherence had been identified, we interrogated the data to compare and contrast the information supplied by different respondents to identify why episodes of nonadherence were occurring.

### Ethical issues

Respondents were sent written information about the study by post and an invitation to participate two weeks before their next appointment. Consent was obtained before interview. Respondents were reminded of their right to withdraw from the study at any stage without giving reasons and that their identity would not be disclosed in publications.

### Findings

None of the patients refused to be interviewed. They were aged from 44 to 74 years and had been diagnosed from less than one year up to 17 years. The sample included nine men and six women. Five were not native English speakers. Although none was considered to have yet reached the more advanced stages of PD, there was considerable variation in their physical and mental condition and their levels of disability. Three patients were accompanied by carers on whom they were clearly heavily dependent, including help to take medication. These carers were present during the interview and took part. Only four patients were still in paid employment and of these one worked from home.

Two themes emerged from the data: adherence and negotiation. Adherence addressed how respondents used prescribed medication to control symptoms. Negotiation addressed the strategies used by respondents to agree or attempt to agree on changes to the medication regime with practitioners.

## Adherence

Most respondents provided evidence of trying to adhere to the advice of the PDS. Timing to avoid the sudden return of symptoms and to avoid combining medication with food were constant challenges, as illustrated by the typical excerpt presented below. This extract also demonstrates another common side-effect arising from the medication: drowsiness that interfered with daily activities.

'I have a cup of tea at 7:30. I take the first Sinemet at 8 o'clock. I rest for half an hour then get ready and have breakfast. By 9 o'clock I feel rosier. The morning progresses depending on whether I feel OK or not. Forty minutes before lunch, I take Sinemet again. I don't have such a bad after-shock with the lunch-time dose. An hour or two later I feel sleepy and unable to go out.' (Respondent 12)

However, carefully timing medication could help control symptoms even for those whose condition was becoming more pronounced:

'Before the first medication my movement is usually very, very feeble and very frustrating and disappointing. After the first dose it takes about 15 minutes to half an hour to 45 minutes. It really depends on the day. Suddenly I feel I can move. After they (the tablets) kick in it will last for about two hours. Then I'm as normal as anything, or appear to be normal if I time it well' (Respondent 14)

According to some respondents, extra doses and re-scheduled timing were not attempted without seeking the PDS's advice: 'I phone the nurse and she says "Take an extra two." I always „phone her. (Respondent 3)

Some respondents persevered with medication despite highly disturbing and embarrassing side-effects. For example Respondent 6 had experienced increased libido for about twelve months. His wife had remarked unfavourably on his changed behaviour and he had 'got a bit out of control'. During incidents outside the home, but had continued his treatment and was planning to discuss the problem with the consultant neurologist during his appointment.

## Negotiation

There was evidence that a therapeutic alliance existed between respondents and the PDS. Medication regimes were altered in conjunction with her during formal consultations and by telephone and she supplied information about the condition and the aims of medication.

'The times are being changed subject to what the nurse has to advise today, in order to improve my performance' (Respondent 14)

'I feel rosier taking it after breakfast ... so I „phoned the nurse and she said (take it) about forty minutes before eating. It works better' (Respondent 12)

Respondents' comments suggested that they understood the progressive nature of their condition and that medication was intended to control symptoms, as shown in the typical comments reproduced below:

'It's to do with preventing the progression of symptoms, I think. And the Sinemet is because I got stiff fingers and stuff like that' (Respondent 2)

'I had stiffness in my fingers ... poor handwriting that decreased ability to write, barely legible. It improved with the initial medication I was taking' (Respondent 2)

'At first I thought it was going to cure me until I was told it isn't going to cure. It's going to control the symptoms' (Respondent 5)

Respondents appeared to be satisfied with the amount of information they were offered and were fulsome in their praise of the PDS:

'I think I've had enough (information). I can't always recall stuff anyway, so I ask if I need any more. But I do find the nurse is a lot more helpful than the doctor, for giving information and being honest' (Respondent 4)

It was unusual for information to be sought from other sources. Family doctors were not considered to have enough specialist knowledge. Support groups were avoided because they could be depressing. Those who had attended them disliked seeing other people in more advanced stages of the condition as they were aware that no cure was available and that over time their own deterioration was inevitable. There was no mention of support from expert patients, information leaflets were seldom consulted and not usually by the affected individual:

'At first I didn't realise that with CR you can't have a heavy meal. I read in the literature that with CR you have to avoid heavy meals or a lot of proteins' (Carer of Respondent 9)

Although evidence of extremely good relationships with practitioners, especially the PDS, was apparent throughout the transcripts, there was one paradoxical case where a breakdown in the relationship had occurred. Respondent 7 admitted that when first diagnosed she: 'Just casually popped the tablets whenever it suited my schedule'. The PDS warned her of the risks associated with over-medication so she concealed her activities during subsequent encounters but stored up tablets to cover the night-time period between doses when she experienced insomnia and symptoms returned. Eventually her poor symptom control resulted in an additional prescription:

'I wanted to time it so that I'd still get Sinemet in me when I went to bed to help me sleep all night. I had to argue for it. Now I've got my own little stash, low doses, single dose ones so I can take that if I wake. If I wake between two and four a.m. I'll take an extra pill. '

#### Non-adherence

Interrogation of the data revealed at least one example of non-adherence in each transcript. Three different types were identified: minor, inadvertent non-adherence, minor deliberate nonadherence and major non-adherence. Data from the same respondent frequently revealed the co-existence of more than one type.

#### Minor, inadvertent non-adherence

All the respondents were aware of the need to time doses to prevent the return of symptoms, but most admitted to occasionally forgetting to take medication or becoming muddled about which tablets were due. For some such omissions had become recurrent. Minor episodes of non-adherence arising through under-medication were generally dismissed as of no significance, even when they were repeated. For example Respondent 3 (who according to data contained in an excerpt presented above, claimed never to take extra tablets without first seeking advice) frequently under-medicated. He usually slept during the afternoon and often awoke too late to take his early afternoon tablets. He regarded taking a nap as an effective way of occupying the gap between doses when symptoms might return. Although he realised that this resulted in failure to take his medication in line with the PDS's recommendations, he regarded sleeping as a positive way of coping with his condition and did not think that occasionally omitting his afternoon dose was important. Inadvertent over-medication was also reported. Here respondents were aware of the risks, as illustrated in the typical quotation reproduced below, in which the dangers were exacerbated because the tablets were dispensed in similar packaging and extra tablets were taken at night when the individual was drowsy and in a poorly lit room:

'In the night I realise I'm awake and think I need to take some stuff. The danger is that you can forget you've taken it. One box of drugs looks like another. I'm wary of taking one dose too many'  
(Respondent 8)

None of the respondents reported using aids to help them remember to take their medication such as Dosset boxes or pill counting devices that are frequently recommended by practitioners to reduce accidents (Hughes 2004).

## Minor deliberate non-adherence

The inability of the drugs to control the symptoms of progressive PD had become clear for most respondents, in several cases quite soon after commencing treatment, as indicated in the typical comments reproduced below:

'It's very obvious now (the tremors). I'm concerned that the medication is not doing what it's supposed to be doing' (Respondent 7)

'I'm worried about the tremors. They're very visible. If I'm standing or walking to the supermarket, it's very obvious. I'm concerned the medication is not doing what it's supposed to be doing' (Respondent 2)

Respondents took extra doses to tide them over unusually demanding activities, especially those that involved outings. Respondent 15, who worked at home, admitted carrying extra tablets when she left the house to 'cover the sudden return of symptoms' while she was out and said she would panic if she discovered that she had forgotten them. Deliberate over-use of medication was also reported in relation to timing and it was common for a dose to be taken early. Respondent 5 had moved all her tablets forwards by 30 minutes to cover her outing to the clinic on the day that her interview was conducted. For those who left home frequently, medication was manipulated to mask the symptoms of PD from other people through rescheduling. Respondent 3 took his first dose very early in the morning so that his long recreational walk would coincide with the time when his medication was working. This also enabled him to strike up conversations with casual acquaintances while appearing what he described as 'normal'. Most respondents appeared to think that taking the odd additional dose or adjusting timing reflected good symptom control and some regularly adopted these practices:

'During the day I'll take 'em as things begin to wear off. It's quite abrupt now. Everything shuts off. It all shuts down. My body clock reminds me about half an hour before ... tinges of symptoms coming. I know I should get ready (to take the next dose)'. (Respondent 10)

## Major non-adherence

Respondents appeared to be unaware or unwilling to acknowledge that major departures from the recommended medication regime did not reflect practitioners' advice. Such departures might occur occasionally to cover a special event, as in the case of Respondent 11, who had used most of his daily ration of tablets to dance at a party. Others had become part of the patient's routine, as revealed in the extract below:

'I'm an early person. I kick off at six o'clock in the morning. They say it should be after meals, before or after meals. I don't eat at six o'clock in the morning, but I'm in the need of 'em (the tablets). So I take two at six. Two more at ten, then at two'. (Respondent 14)

Respondent 6 concealed his condition from his employers though a regular strategy of extra doses and re-scheduled timing because his job involved handling machinery and he feared loss of employment on the grounds of health and safety. His employers were aware that he had a chronic illness, but not what it was, although he had been diagnosed for nine years. He drove to work before the tablets „kicked in. so they would be optimally effective by the time his shift started.

Other extreme examples of major non-adherence, particularly experimentation with nonprescription substances, were deliberately concealed from the PDS because the respondents knew that they were contrary to her advice. There was a feeling that alternative and complementary medications heard about from other people or seen in advertisements might offer hope. Respondent 3 had used homeopathic medicine without ill-effect but found taking it regularly too expensive. However, some respondents reported very severe adverse events that had arisen through taking non-prescription medication. Respondent 4 recalled an episode that had resulted from taking Chinese medicine some years earlier that: 'Nearly killed me ... made me very ill..' The herbal extracts appeared to have contained some chemical that had potentiated the action of his antiparkinsonian drugs, resulting in hallucinations. He had been admitted to a psychiatric unit and it had taken some time for the problem to be identified.

#### Antecedents of non-adherence

Symptoms fluctuated according to real and potential stressors experienced by respondents.

Respondent 13 noticed that his medication seemed less effective if he had 'something on his mind' or had 'slept badly', while Respondent 9's carer had learnt to encourage him to try and relax, stretch or 'say a little prayer' to help reduce stress and the exacerbation of symptoms. However, the same activity did not necessarily result in the same pressure for different respondents. For Respondent 15, leaving the house was a minefield that had to be 'covered' by carrying extra tablets, but Respondent 3 used his outings and the associated exercise to help cope with his condition. Anticipating activities did not always improve coping behaviour. Respondent 3 knew that he would spend most of every afternoon asleep, but made no effort to remind himself to take his early afternoon medication.

Respondent 7 suffered from insomnia on a regular basis, but her solution was to take extra tablets from her hoarded supply, not to try to improve timing during the day. Similarly, ability to anticipate fluctuating symptoms did not necessarily increase ability to time medication or find other ways of improving control and some respondents battled with the 'on/off' transition every day. For example, Respondent 12 described the effect of his first morning dose as an 'after-shock' (anxiety, tachycardia and sweating as his blood levels of Levodopa increased) and a typical morning was like being on a

'roller-coaster' as the drugs took effect. Events that occurred on a daily basis, (being at work, Respondent 6) and special occasions (appearing sociable at a party, Respondent 11) prompted over-use of medication.

## Discussion

The findings demonstrate that practitioners face considerable challenges when they encourage people with PD to take medication safely and effectively (Kaufman and Birks 2009). These findings might have implications for the medication management for people with chronic conditions more generally as they question the widely held assumption that there is scope for patients and practitioners to negotiate how medication could be taken.

### Medication management for people with Parkinson's Disease

Non-adherence appeared to be very frequent and as in earlier studies and previous reports of people in the early stages of PD revealed through pill counts, electronic devices or self-report to practitioners, it was highly complex (Grosset et al 2005, 2006, 2009). Moreover, contrary to existing opinion (Denois et al 2010), much of it was not accidental. Our data are probably more trustworthy than data from studies that rely on self-report to practitioners because the interviewer had no clinical knowledge and was unable to react verbally or non-verbally to information that might have caused a practitioner to register disapproval, either intentionally or otherwise. Although pill counting and electronic devices provide more objective data than self-report, they are unable to deliver the rich and detailed information obtained in our study, where it was possible to explore the context in which medication was taken and to probe respondents about challenges to symptom control to meet the demands of specific occasions, to collect additional information about side-effects, unsafe behaviours and other sources of information that might have influenced individual participants. Under-medication was important, as previously established, but over-medication also appeared to be the major problem, especially as it was often intentional. In other instances individuals either did not recognise, or would not acknowledge, that they were practising non-adherence. The very high levels of non-adherence that we report could have been inflated by the timing of data collection in relation to the patients' medical and nursing review when their medication regime would be updated. Interviews conducted a few weeks after a new medication regime had begun to take effect or in the mid-point between clinic appointments might have provided alternative insights. However, each patient was asked not only about events that affected the demand for medication every day but also about special events and occasions and these were the ones that revealed very high levels of non-adherence not directly related to progressively worsening symptoms.

Overall the data indicated that although they were broadly familiar with their treatment goals, patients' understanding was not necessarily sophisticated enough to manage their condition. In particular, they did not appear to understand that to achieve symptom control, doses must be timed evenly throughout the day to maintain steady levels of the therapeutic agent. Attempts to control symptoms involved endlessly manipulating the timing of doses in relation to planned activities and how well the individual was feeling on a particular occasion. Constant over-medication contributed to the premature return of symptoms and exacerbated the need to bring forward the next dose or to take extra tablets in a spiral of increasingly poor control.

A second novel finding to emerge from our study was the existence of different categories of non-adherent behaviour. Most patients indulged in at least two and sometimes additional types of non-adherence. Moreover, patients who strove to be adherent regarding particular aspects of taking medication could nevertheless be non-adherent in others. However, the circumstances that resulted in a particular type of non-adherent behaviour taking place appeared to be highly idiosyncratic, reflecting the uniqueness of Parkinsonism to the individual, the uniqueness of the factors that influence the fluctuation of symptoms for a particular individual and probably also individual physiological responses to the drugs. Deliberate non-adherence, especially major non-adherence, seemed to be greater among patients who had been diagnosed for longer, suggesting that the 'expert patient' concept (Tattersal 2002) is not helpful in the management of PD.

In the United Kingdom and many other countries, the management of PD falls mainly to highly specialist practitioners, whose expertise is in short supply. Increasing the availability of the service is not an option in the current economic climate, especially as there is no evidence that input from a PDS has direct impact on patient outcomes (Reynolds et al 2000, Jarman et al 2002). The solution may lie in making the existing service more responsive to patients' needs. This might be achieved by increasing patients' awareness of their medication-related behaviour and its impact on symptom control. Very little research in this area has been undertaken. However, there is some evidence that keeping diaries to document the occurrence of symptoms in relation to timing of antiparkinsonian medication might increase adherence (Hauser et al 2000) and the approach is acceptable to patients (Hauser et al 2006).



## CONCLUSION

The findings of this in-depth interview study revealed different patterns of non-adherence by people taking antiparkinsonian medication, especially deliberate and planned over-use of medication that was concealed from practitioners and had serious implications for future health. The findings of this study should be replicated with a larger sample in other centres and between clinic appointments when drug regimens are not in such urgent need of review. Although the study was restricted to a specific patient group who require very specialist care, the findings are of interest to all nurses as they will encounter people with PD in other clinical settings. Moreover, PD is one of many common chronic conditions affecting people in middle age and the older population. Similar in-depth studies might reveal other surprising findings in relation to medication management of people with other long-term conditions.

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