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| **Title** | |
| Drey N, McKeown E, Kelly D, Gould D. Adherence to antiparkinsonian medication: an in-depth qualitative study. Int J Nurs Stud. 2012;49(7):863-71. | |
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| Most respondents provided evidence of trying to adhere to the advice of the Parkinson’s disease specialist nurse. 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)QPwP*  *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) QPwP*    In contrast other respondents did not attempt to take extra doses or re-schedule timing without seeking the Parkinson’s disease specialist nurse’s advice. Another typical comment is reproduced below:  *‘I phone the nurse and she says ‘‘Take an extra two.’’ I always ‘phone her.’ (Respondent 3) QPwP*  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.  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 Parkinson’s disease specialist nurse’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)QPwP*  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.  The inability of the drugs to control the symptoms of progressive Parkinson’s disease 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) QPwP*  *‘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) QPwP*  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.  Respondent 5 had moved all her tablets forwards by 30 min 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 Parkinson’s disease from other people through re-scheduling.  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) QPwP*  *‘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) QPwP*  Respondent 6 concealed his condition from his employers though a regular strategy of extra doses and rescheduled 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  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 Levadopa 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.  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. Occasionally they were used by carers:  *‘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) QCarer*  Although evidence of extremely good relationships with practitioners, especially the Parkinson’s disease specialist nurse, 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 Parkinson’s disease specialist nurse 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 got 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. ‘ QPwP* | |