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| **Title** | |
| Hurt CS, Cleanthous S, Newman SP. Further explorations of illness uncertainty: carers' experiences of Parkinson's disease. Psychol Health. 2017;32(5):549-66. | |
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| Medical management was a central theme in the carers’ discussions of PD. Much of their caring role involved managing medication and medical appointments. Although there was a relatively high degree of certainty that treatment was largely helpful, a considerable amount of uncertainty still surrounded drug treatment.  Future changes in drug regimens were seen as very uncertain with approaches to treatment often being described as trial and error. Most carers felt that their spouse would have to change drugs in the future but what that change may be, and whether there actually was another drug to change to, was uncertain. There was an acknowledgement that Parkinson’s varied greatly between patients and individual response to drugs was equally variable. Most carers were certain that the doctors were doing all they could to manage the condition but it was inevitable that drugs would need to be frequently changed until a good response was achieved.  *“I think it may be the only option to go on trial and error. You know you can double up the tablets and see if it works.” Participant 1 Qcarer*  There was also a lack of certainty around the potential side effects of anti-parkinsonian medication. Carers were unclear whether certain symptoms were caused by drugs, were part of another disease process, were purely psychological, or were due to PD itself.  *“I think that causes considerable confusion [medication], in Parkinson's people, in certain*  *people…. there’s never much said about the confusion side of it, I don’t think. And I think those symptoms sometimes can be very worrying, because you don’t know whether it’s the start of dementia or it is just the drugs.” Participant 10 Qcarer*  There was also concern at the number of drugs some patients were taking and the potential effects on their health.  *“I’m hoping that we can reduce the [name of tablet], ‘cos I suspect it’s not doing anything at all, just damaging his liver.” Participant 12 Qcarer*  When it came to formal support from the hospital carers expressed some uncertainty about whether their spouse was receiving all of the support that should be available to them. Carers described local variation in availability of support (e.g. Parkinson’s nurse visits) and long waits for appointments to see physiotherapists and speech and language therapists. Carers reported sourcing support themselves rather than being informed about available support by the hospital team or GP.  *“We’re becoming aware that perhaps he’s not had um, everything that he should have; not*  *had all the support that he should have had. That um, I’m now not entirely sure that I know*  *what.” Participant 12 Qcarer*  It was widely acknowledged by carers that medical professionals had a high degree of uncertainty when it came to managing PD. For some this resulted in negative feelings of being ‘fobbed off’ and left to help themselves, while others believed that medical staff were doing all they could to try and help patients.  *“…because of the progression of Parkinson's, because it’s so different in everybody, nobody, the best neurologist in the world could not look at [spouse] and tell me what’s gonna happen to him. And they would admit that; they can’t. There’s just no way of knowing.” Participant 13 Qcarer*  *“When we speak to the professionals, the neurologist, whoever, they never really differentiate between it could be because of sensitive bladder because of prostate or it could be a sensitive bladder because of Parkinson's. They just listen and acknowledge but they don’t really define. …we still have checks with the cancer specialist every six months, we ask about the tiredness which really came on with a vengeance with the radiotherapy, and they’re not sure really whether he’s still tired because of that, or whether it’s the Parkinson's. To be honest with you they all seem to pass the buck to each other.” Participant 4 Qcarer*  Some carers questioned how up-to-date medical staff were on recent advances in treatment and how willing they were to be flexible in their approach, incorporating individual patient needs. This inevitably led carers to question whether their spouse was receiving the best available care. In particular carers noted uncertainty around general knowledge of PD and ability to diagnose and manage PD in general practice.  *“I don’t think the GP’s are as educated as they should be. I think there’s a bit of an area there lacking. Because they, they all say well it’s…and you know I know they can’t be specialists in everything but I, I don’t think they are totally aware of…of um, of everything.” Participant 10 Qcarer*  When it came to formal support from the hospital carers expressed some uncertainty about whether their spouse was receiving all of the support that should be available to them. Carers described local variation in availability of support (e.g. Parkinson’s nurse visits) and long waits for appointments to see physiotherapists and speech and language therapists. Carers reported sourcing support themselves rather than being informed about available support by the hospital team or GP.  *“We’re becoming aware that perhaps he’s not had um, everything that he should have; not had all the support that he should have had. That um, I’m now not entirely sure that I know what.” Participant 12 Qcarer*  Some carers expressed a lack of certainty around how often their spouse should expect to see  health professionals (e.g. neurologist, Parkinson’s nurse) and what would prompt a visit.  *“There doesn’t seem to be any specific time, like we see the specialist every six months, there’s no specific time for the Parkinson's Nurse…, I think it must have been about a year…” Participant 12 Qcarer*  Some had attempted exercise but found that co-morbidities made this difficult or were unsure if it was having any beneficial effect.  *“I really don’t know what could be done to improve it. That we’re not already doing. I have no answer to that one.” Participant 18 Qcarer*  Future financial stability was a source of uncertainty for many carers, mainly due to potential nursing costs both at home or in residential care.  *“I’m concerned about if he had to go into a nursing home, how that would be financed” Participant 5 Qcarer*  Many carers were unclear about the services that were currently available to them and mentioned finding out about services accidently rather than being informed.  *“I’m not sure what help I can get to carry out that role. Or even stop carrying out that role. But that’s the big thing isn’t it? If somebody needs medical attention, will it be there?” Participant 6 Qcarer* | |