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| **Title** | |
| **Boersma I, Jones J, Coughlan C, Carter J, Bekelman D, Miyasaki J,** et al. Palliative Care and Parkinson's Disease: Caregiver Perspectives. Journal of palliative medicine. 2017;20(9):930-8. | |
| **Agreement** | **277/695** |
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| Caregivers emphasized a need to be treated as individuals distinct from the patient. This included being properly greeted at office visits and for more questions to be directed at the patient. Some expressed frustration when physicians mainly aimed questions at them during appointments as they felt this put them in a role of simply being the spokesperson of the patient. They stressed it was important for physicians to recognize that they ‘‘are not the ones with the disease’’ and that it should not be assumed that caregivers would know everything that the patient experiences. Despite these concerns, caregivers felt attending neurology appointments with their partner was beneficial to them (i.e., note taking, asking questions, validating information).  This theme referred to caregiver-identified gaps in education and includes resources caregivers have found to be helpful in terms of understanding PD. Despite most caregivers understanding the individual variation in disease progression in PD, participants generally wanted more information about disease progression and what to expect in the future as well as medications and their side effects. Participants also felt unprepared to respond to emergency situations (i.e., falls, cardiopulmonary resuscitation [CPR], psychosis).  This theme described the concerns about the future from the caregiver’s perspective in relation to PD. The most commonly cited concerns related to the following: (1) finances; (2) housing/living situation; and (3) taking care of their spouses in advanced disease. The majority of caregivers we interviewed had advanced directives in place but commented that they would have liked more involvement and guidance from their healthcare teams. Notably, the majority of concerns about the future brought up by caregivers were related to topics not covered in an advanced directive  *‘‘Yeah. And I’m quite worried about side effects and I have to study that. I have to figure out what is the medicine going to do in the long run.’’—Female, 60 Qcarer*  *‘‘More information as to what to expect medically, you know, from the professional. what can you*  *impart to me that can help me a little bit, should something come up? I get afraid that I may not know what to do. And quick, right now, something is going on. What do you do?’’—Female, 60 Qcarer*  *I mean I have to be First Aid, CPR trained. but they don’t teach you some of that stuff for specific issues. And if he does get hurt or have a bad reaction to the medication, worse than some of the one’s he’s had.what do we do?’’— Female, 51 Qcarer*  *‘‘You don’t know what to do. You run into this problem now with insurance. With the insurance don’t want to pay for his medication. The medication is too high. If the Parkinson’s person does not get the medication, it hurts. My husband was very sick. He could not get his medication because the insurance refused to pay for it. So then, that is when you come in as a family and you have to think about that. How are we going to pay for that medication? I forgot which one it was, but it was $500.00. We had to decide how are we going to pay for that medicine.’’—Focus group Qcarer* | |