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| **Title** | |
| Habermann B, Shin JY. Preferences and concerns for care needs in advanced Parkinson's disease: a qualitative study of couples. J Clin Nurs. 2017;26(11-12):1650-6. | |
| Agreement | 153/981 |
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| **Agreed** | |
| These issues ranged from having difficulty swallowing pills that required taking medicines with applesauce, to being on a mechanically processed diet to being supervised by the spouse while eating.  The theme of unmet needs describes areas where either the person with PD or spouse felt they needed help or additional resources that they were not accessing or unable to access. There were two categories of unmet needs. The first was inadequate financial resources and the resultant financial strain. Both spouses and person with PD discussed this need. A few examples:  *Spouse #12: “I recorded for one year that $36,000 was what we paid for in cash out of pocket. We have probably gone through over $200,000 of our savings”.*  *Spouse #7: “We have gone through our savings. We are in the process of applying for Medicaid. But that is a very long process.” (Had been involved in the process for over six months)*  Another area of concern was how little information people had to help them plan for the future and make informed decisions. This was expressed by both people with PD and spouses. In some cases, participants directly asked their physician what to expect next and how will the disease progress. But more often than not, these conversations did not yield any information. Participants reported being told disease progression is unique that they could not predict. Most people with PD accepted this type of response, but for spouses it was often frustrating since it did not help them with planning or making decisions. A couple of examples:  *Spouse #6: “Let's talk doctor. I can take it. If my wife had cancer, you would have that kind of dialogue. Can you tell me so that I can plan? More importantly can't you tell me so I can get my kids prepared?”*  *Spouse #8: “I have sleepless nights wondering what will happen with him …. It isn't discussed. I wish the doctor would just tell me.”*  This lack of prognostic information resulted in many of the couples not making any plans or decision relative to the future. More than half of the couples had no plans in place relative to advance directives, wills or any other legal documents or power of attorney for healthcare. When asked about this, the most frequent response related to not knowing when and how the disease would progress farther, therefore, they did not know how or what to plan. | |