|  |  |
| --- | --- |
| **Title** | |
| **Dauwerse L, Hendrikx A, Schipper K, Struiksma C, Abma TA**. Quality-of-life of patients with Parkinson's disease. Brain Inj. 2014;28(10):1342-52. | |
| **Agreement** | **136/381** |
| **Agreed** | |
| For patients, good care means: reducing the disadvantages caused by PD. From the patients’ perspective, good care requires expertise in PD (including empathy) and a multidisciplinary approach including informing and negotiating with the patient. Also competences like listening are very important for patients. A participant, for instance, experiences differences in competencies between the neurologist and Parkinson nurse:  *The neurologist focuses on ‘you should do the exercises like this’ and I have to walk up and down and he says: ‘oh, you are still stiff, well, than we will increase the medication a little bit’. While, with the specialized PD nurse it is possible to talk about: ‘of course it is unpleasant that I am stiff, but currently that is not my main problem. For me it is much worse that I forget things. That I am not able to hold on the connecting thread’ (QPwP)*  They also experience this lack of involvement and support when talking about societal services like: aids and work oriented regulations (such as WIA, IVA and WGA and the WMO in the Netherlands). Many patients are 100% disabled and finding the right help, the right institution and possibilities is difficult. Many regulations are not flexible and cannot be tailored to individual needs. There is contradictory information and patients sometimes feel: *‘You are sent from pillar to post’ (Spouse of man, 66, 2009) Qcarer*. | |