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| Haahr A, Kirkevold M, Hall EO, Ostergaard K. From miracle to reconciliation: a hermeneutic phenomenological study exploring the experience of living with Parkinson's disease following deep brain stimulation. Int J Nurs Stud. 2010;47(10):1228-36 | |
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| **Agreed** | |
| This made them able to live more spontaneously, not left to plan things ‘in between’ medication times as had been the case before DBS  The hassle seeking to find the right stimulation settings and medicine dosage affected participants’ sense of success in a more negative way than those participants where adjusting to the stimulation went easier.  And participant 7 said: *‘‘I have been really bad. . ..having many Parkinson’s symptoms. Muscle stiffness and everything. I have been in to get the stimulation adjusted, one way and the other. Yes, it has been rough and uphill’’. QPwP*  To some this phase was dominated by a long process of getting stimulation adjusted. Participant 7 said: *‘‘. . .it has been a time of ups and downs. One day I am OK, the next I am not. But it is not that I am depressed. . .I cannot be’’*, *(QPwP)* and participant 6 said: *’’It has been going very slowly and that’s hard when you are impatient, having to wait for a whole week to see what the adjustment did. And then having a new adjustment and then wait another week. It has been like that for six or seven weeks’’. QPwP*  These periods of adjustment kept participants focused on their illness; *‘‘. . .having to go to the hospital every week reminds you all the time, right. You are more focused on how you react all the time (participant 7)’’.* *QPwP*  This was challenging; they could not really go back to living an ordinary life. PD was always in their mind. Participant 4 said: *‘‘I must say, I am sick of talking about Parkinson’s’’. QPwP*  A few participants found their everyday life changed dramatically due to malfunction in stimulation or medication keeping them from engaging in new activities, or leaving usual activities on hold.  Keeping an active daily living. Being physically active helped participants get a sense of the body and gave them the feeling of being able to ‘‘go on’’. An active daily living helped participants re-engage in a social life meeting people and receiving acknowledgement from friends and family. They still had to plan activities though, and had to balance how much they engaged in. Likewise, considerations as to the time and the place of activities played a part.  Medication however, again became a bigger part of everyday life for most participants, even if they tried to use as little medicine as possible. | |