

Online Supplemental Material (Table 1, Table 2, Table 3)

*Table 1: Additional qualitative data to illustrate the issue of social support*

“Is there family support around post-surgery to help them? Are they ready to deal with any sort of complications? Are you ready to know that you might have to care for your partner full time? Those things again, it is not a, I wouldn’t say formal part, but it is an informal part of the whole process.” (B4)

“So we also look at the family support system: is the spouse going to be there for them if they need it? Are they going to get the kind of support that they feel that they need? I suppose that you could say ‘look, if he is not getting the support he needs now when we are treating him with drugs then he probably won’t be any better.’” (C2)

“I do a collateral interview with the family member, whether it is a spouse or son or daughter, whatever the relation is. That is to get a bit more of the psychosocial perspective on their lives, but it is also important to get collateral just because your patients might not have full insight. You might want to get a second opinion.” (B4)

“Well social support’s very important especially initially, um they’re recovering from brain surgery, for one, and they have to have somebody that’s going to be able to um um be around for them if they get into any problems obviously, like like any kind of operation there’s a recovery period, and uh also [...] we do watch them closely for the first little while after we start stimulation um to make sure that there are no mood swings or changes because uh a depression can develop and we have to be aware of that because this is some-a very real risk.” (E1)

*Table 2: Additional qualitative data to illustrate the issue of changes to the “self”*

And we have seen people get depressed after having gotten rid of their seizures you know. So we still don't know in the long run. This is something perhaps that we should be looking at is how are the patients adapting to the fact that their symptoms have improved. Is that a problem you know? (A2/A3)

One thing that has been said about movement disorders is that uh people have been used to a certain type of role, the sick role. And you more or less remove this from them and that could cause problem adaptating to this new role. (A4)

You know I don't know enough about, I will use the term forced normalization because that is a terms I have been familiar with in the epilepsy field and this obviously refers to patients who, we have had great success in what our intention was, which was secure their seizures, and otherwise their lives fall apart completely. There are lots of theories as to why that might be the case, are their presupposing factors that we should have been cognizant of or could have done something about? Is it just that they are so identified with their sick role that now you have taken away their sense of identity etc.? There are lots of theories about that. (B2)

*Table 3: Additional qualitative data to illustrate the issue of relationship with the other*

One of the funny things, which I am sure you probably already know that has happened in the transplant world, is that the relationship between these two people can become very dependent on the part of the one with Parkinson's. When you do the surgery and make he/she better then the spouse who has had the relationship of looking after him like a second child is now put in the position where he is once again moving around and independent. That has caused some problems. (C2)

Well, it is a challenge for many of them and it can be both positive or negative because as they become better, more active, more functional, their roles kind of shift. So you can imagine that if you have Parkinson's disease you have years of loss, you have a caregiver that plays a certain role. You play a certain role. Then you get this system and then you gain back the things that you did. It can be wonderful in that entire families are doing what they want to do again, but also it can be change in that we have seen marriages break down. The person is suddenly better and doesn't want to be cared for anymore like that. So it is this really big shift in roles that can happen. So socially that always does affect the people around them. I think for the most part that it is positive but, um, there can be some painful growth with that too. (C4)

And certainly at the one year follow-up we have had people say my spouse is not the person I've married, umm their roles have changed significantly from caregiver and, you know, the patient role and even with a very successful surgery you create a lot of change in the family and umm families vary to the degree that they can cope with these changes. (D3)

Yeah now some we fix some and it really does change the sort of marital relationship uh the roles of the caregiver basically over time has taken the leader role and all of a sudden the patient is now back in action and uh they can cause significant marital dynamic issues. (E2)

There was a patient that almost got a divorce afterwards. As uh we've had a few, I think we had at least one real divorce but that was sort of happening well before we actually operated on the guy like it wasn't a big surprise. And then the other one did, we, again, we thought it related to the fact that the wife had been the primary caregiver and the patient actually became somewhat independent and he could just do so much more and so he would just sort of take off in the middle of the day and go do something and she wasn't used to that and they ended up, they worked out their differences, they went through some counseling. (D1)