

## Research Report

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# “DBS means everything – for some time”. Patients’ Perspectives on Daily Life with Deep Brain Stimulation for Parkinson’s Disease

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### Abstract.

**Background:** Deep brain stimulation (DBS) is an established treatment for Parkinson’s disease. However, patients’ own perceptions of the impact of DBS on their daily living is not fully explored.

**Objective:** We aimed to collect and analyse patients’ narratives about their everyday experiences of being on chronic DBS.

**Methods:** Semi-structured interviews with open-ended questions were conducted with 42 patients (11 women) who had been on DBS for a mean of three years. The questions were related to patients’ ordinary daily life and eventual changes, both negative and positive, brought about by DBS. The interviews were transcribed verbatim and analysed according to the difference and similarity technique in grounded theory.

**Results:** From the patients’ narratives the core category ‘DBS means everything – for some time’ was established, and supported by the following categories: 1) Relief from invasive tremor. 2) A rescue from cramps and pain. 3) Easier movement swings and more predictable living space. 4) Hard, but compared to previous suffering, bearable adverse events. 5) Parkinson’s disease is progressing despite DBS.

**Conclusions:** The analysis of the participants’ narratives shed light on patients’ unique perceptions and perspectives of the impact of DBS on their everyday lives. Patients with advanced PD highly appreciated the positive impact of DBS on their daily life even if this impact is limited in time. For the majority, the relief from the severe parkinsonian symptoms, especially tremor and painful cramps, outweighed the side effects of DBS. The study provided information not readily captured by pre-formulated questionnaires and scales.

**Keywords:** Parkinson disease, deep brain stimulation, qualitative research, grounded theory, adverse effects, patient satisfaction, activities of daily living

## INTRODUCTION

Parkinson’s disease (PD) is a common progressive degenerative neurological disorder [1], impacting negatively on quality of life (QoL) [2]. The compromised control of movements is often accompanied

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by, and interacting with, non- motor features such as pain, sleep disturbances, mood changes, and cognitive decline [3]. The rate of disease progression is highly individual, and underscores the individual experiences of living with PD. For the majority of people with PD in early stages of the disease, oral medication is sufficient to control symptoms with improved or preserved QoL. However, in people with more advanced PD when medications are not sufficient to ensure a good QoL, deep brain stimulation (DBS) may be an option. The subthalamic nucleus (STN), globus pallidus internus (GPi), caudal Zona incerta (cZi) and ventral intermediate (VIM) nucleus of the thalamus are all documented brain targets for DBS in PD [4]. The results of DBS are typically evaluated by quantifying specific features and symptoms of the disease using rating scales such as the Unified Parkinson's disease rating scale (UPDRS), and the Parkinson's disease quality of life questionnaire 39 (PDQ 39) [5–7]. Evaluations based on these scales show that the outcome of DBS is generally good, and in a recent review of the literature, Deuschl et al. 2013 [7], considered DBS as one of the most effective treatments of PD. Despite this overall positive outcome, DBS may induce well-documented side effects, such as deterioration of speech and gait [8–10].

PD affects individuals differently depending not only on the stage and the symptom profile of the illness, but also on the patients' age, gender, living and social conditions, profession, interests, hobbies, etc. [11–13]. Similarly, DBS may have different effects on various symptoms, and different implications for patients' needs, expectations and wishes. Therefore, it may be difficult to fully capture the individual impact of PD and DBS by 'only' quantifying changes of symptoms, or by means of pre-formulated QoL questionnaires. In this respect, qualitative methods such as in-depth interviews can be used to shed light on the life of persons with PD who are treated with DBS [13–16]. The aim of this interview study was thus to collect and analyse PD patients' narratives about their own experiences of the impact of DBS on their daily life.

## MATERIAL AND METHODS

### *Participants*

Forty-eight consecutive patients with PD (11 women and 37 men) operated on with DBS at the University Hospital of Northern Sweden were invited to

participate in this interview study. Four patients (one woman) declined to participate and five (2 women) did not reply to the invitation. Subsequently, 39 patients (8 women) agreed to participate. To include additional women, we asked representatives from the Swedish Parkinson Disease Society if they knew of other women treated with DBS from other hospitals, who would be willing to participate in this study. This provided three additional women who were operated on in other centres in Sweden. In total, 42 patients could be interviewed, 31 men and 11 women. The local ethical board at Umeå University approved the study (D.no: 2010-97-31M).

### *Data collection*

Data were collected by the first and last author through qualitative interviews. None of the three authors was involved in the selection, surgery or follow-up of the patients. The majority of the interviews were performed face-to-face in the patient's home or at the hospital. For five patients living in remote areas, the interviews were completed by telephone. The interviews were thematically structured with open-ended questions concerning broad areas in relation to PD and its treatment, including considerations about surgery, and symptoms and daily life after surgery. In this paper we focus on how patients experienced the impact of DBS on their day-to-day life. Sample questions related to this domain included the following: *'Please tell me about an ordinary day, at home and at work, and if and how it might differ from a similar day before DBS'*; *'What eventual changes have been brought about by DBS, in relation to your social life and your relations?'*; *'Have you experienced any side-effects from DBS?; What impact do these eventual side-effects have on your daily life?'* The interviewer facilitated the narrative by follow-up questions, such as *'Please could you give an example?'* and *'What happened then?'* Each interview lasted between 60 – 140 minutes and was digitally recorded and transcribed verbatim.

In addition to the interview, each patient filled in a questionnaire providing socio-demographic information. Patients were also asked to assess the overall outcome of DBS by answering the following question: *'On the whole, how has DBS impacted on your life?'* on a scale from +3 to –3 (+3 = marked improvement; +2 = moderate improvement; +1 = small improvement; 0 = unchanged; –1 = small deterioration; –2 = moderate deterioration; –3 = marked deterioration [17].

## Data analysis

### Qualitative analysis of the interviews

According to inductive qualitative research design [18], preliminary analyses of the transcriptions were conducted in parallel to the interview process. In that way the interviewers could successively refine the questions in subsequent interviews, and learn and reflect during the interview process, and be alert when new aspects were described. The main analysis of the interviews was performed in line with the constant comparison technique in grounded theory [19] and it contained three steps: In a *first step* the researchers separately read and coded the interviews from three patients at a time, and then met to compare and discuss codes and to outline preliminary categories that reflected the content and meaning of the patients' experiences. The interviews of three additional patients were then read, coded and compared. This way of collecting, analysing, and sorting out the data continued until all interviews were completed. During this process the preliminary categories became more explicit and different patterns in the patients' experiences and considerations emerged. In a *second step*, and in order to obtain a better overview, each interview was re-read, summarized and condensed into a case narrative of two-three pages text, reflecting the essentials of the patient's experiences of living with DBS. In the condensed narratives, the patients' stories, their illustrative quotations, as well as the codes and preliminary categories, were organized and sorted in content themes such as 'The path to surgery', 'Living with the DBS device as such', and 'The impact of DBS on daily life'.

The results of the interviews pertaining to 'The path to surgery' and 'Living with the DBS device as such' have been previously published [16, 20]. In the present paper, our focus is on the patients' experiences of 'daily life with Parkinson's disease after surgery'. Thus, in the *third step*, all the 42 condensed narratives were re-read and systematically compared for similarities and differences regarding the theme "daily life with Parkinson's disease after surgery", i.e., utterances and examples describing circumstances, concerns and thoughts related to this theme.

### Statistical analysis of socio-demographics

Descriptive socio-demographic data are presented as mean  $\pm$  SD and range. Clinical characteristics are described in numbers and percentage. Statistical analyses were performed using the SPSS software version 22.0 (SPSS, Inc., Chicago, IL).

## RESULTS

### Demographic data and clinical outcome

Socio-demographic and clinical characteristics are presented in Table 1. Table 2 shows data for each individual patient concerning clinical characteristics including dominant symptom(s) before and after DBS, as well as experienced activity and participation before and after DBS, side-effects of DBS, and examples of quotes illustrating the overall impact of DBS. In summary, the patients' age at interview ranged from 44 to 81 years (mean  $\pm$  SD 64.1  $\pm$  8.2). The duration of PD varied between two and 30 years (mean  $\pm$  SD 11.4  $\pm$  6.2) and at time of interview the patients had been on chronic DBS between

Table 1  
Socio-demographic and clinical characteristics in 42 patients (11 women) with Parkinson's disease at time of interview and at time of surgery

	N = 42
<b>Gender</b>	<b>N (%)</b>
Men/Women	31 (74)/11 (26)
<b>Age</b>	<b>Mean<math>\pm</math>SD (range)</b>
Age at diagnosis	52.6 $\pm$ 10.2 (33-70)
Duration of disease (y)	11.4 $\pm$ 6.2 (2-30)
Age at DBS surgery	61.3 $\pm$ 8.4 (41-79)
Age at interview	64.1 $\pm$ 8.2 (44-81)
Time between surgery and interview (y)	2.8 $\pm$ 1.9 (0.5-8)
<b>Civil status</b>	<b>N (%)</b>
Cohabitant/ Single	29 (69)/13 (31)
<b>Level of education</b>	<b>N (%)</b>
Primary school	9 (21)
High school	17 (41)
University	16 (38)
<b>Employment status at time of DBS/and at time of interview</b>	<b>N / N</b>
Working part or full time	10/6
Sick-listed	15/14
Retired	16/22
Data missing	1/0
<b>Brain targets and laterality of DBS</b>	<b>N (%)</b>
STN bilateral	18 (43)
STN unilateral	1 (2,5)
Zi bilateral	9 (21)
Zi unilateral	13 (31)
GPI bilateral	1 (2,5)
<b>Overall impact of DBS on life*</b>	<b>N (%)</b>
Marked improvement	25 (61)
Moderate improvement	9 (22)
Small improvement	4 (10)
Unchanged	0 (0)
Small deterioration	1 (2,5)
Moderate deterioration	0 (0)
Marked deterioration	2 (5)

Abbreviations: N = Number; y = years; DBS = deep brain stimulation; STN = Subthalamic Nucleus; Zi = Zona incerta; GPI = Globus Pallidus internus. \* = missing data in one patient.

Table 2  
Individual clinical characteristics, overall pre-operative state and outcome after DBS for Parkinson's disease in 42 patients

Patients	DBS - target. <i>a</i>	Age@diagnosis/ age@DBS/ time(y) since DBS. <i>a</i>	Dominant PD Symptom(s) and/or areas of impairment (pre DBS). <i>b</i>	Limited life areas related to activity/ participation/ and emotions due to PD (pre DBS). <i>b</i>	Dominant PD symptom(s) and/or areas of impairment @ time for interview (post DBS). <i>b</i>	Experiences of areas related to activity/ participation and emotions due to PD @ time for interview (post DBS). <i>b</i>	Side-effects attributed to DBS related to the following areas @ time for interview. <i>b</i>	Quotations from patients regarding the impact of DBS. <i>b</i>	Overall outcome of DBS @ interview. <i>c</i>
Mr 1	bil Zi	68/71/2	tremor, cramps	adl, inactive, isolated	0	adl indep, active, socialize	speech, gait, balance	<i>A new chapter in life</i>	+3
Mr 2	bil Zi	59/63/1	tremor	adl, inactive, isolated	slight tremor	adl indep, active, socialize	speech	<i>I can live</i>	+3
Mr 3	bil STN	61/67/2	tremor	adl, inactive, isolated	0	adl indep, active, socialize	speech, balance, gait	<i>Would be dead without DBS</i>	+2
Mr 4	uni Zi	55/59/5	tremor	adl, feeling shame	slight tremor	adl indep, active, socialize	0	<i>Tremor relief</i>	+3
Mr 5	uni Zi	70/79/2	tremor	adl, feeling shame	cramps, balance	adl indep, walking carefully	0	<i>Not alive without DBS</i>	+3
Mr 6	uni Zi	56/64/4	tremor, pain	adl, inactive	balance	adl depend, daily falls	balance	<i>It was a new life</i>	+3
Mr 7	uni Zi	56/67/5	tremor	#	0	#	#	#	-3
Mr 8	bil Zi	60/66/0.5	tremor	adl, isolated	balance, speech	adl indep, active, socialize	speech, balance, gait	<i>Tremor resolved</i>	+3
Mr 9	uni Zi	61/63/1	tremor	adl	tired	adl indep, isolated, inactive	speech, balance, tired	<i>Tremor resolved</i>	+3
Mr 10	uni Zi	65/67/2	tremor	adl, hobbies, driving	0	resumed hobbies, drive car	speech	<i>This is quality of life</i>	+3
Mr 11	uni Zi	57/58/3	tremor	adl, social withdraw	slight tremor	adl indep, active, socialize	0	<i>I got a new life</i>	+3
Mr 12	uni Zi	55/62/3	tremor	adl, social withdraw	slight tremor, off	adl indep, active, socialize	speech, balance	<i>Tremor improved</i>	+1
Ms 13	uni STN	38/41/3	tremor	adl, tired	stress sensitive	adl partly dependent, active	0	<i>It meant everything</i>	+3
Mr 14	uni Zi	66/72/3	tremor	adl	slight tremor	adl indep.	speech, balance	<i>Got everything back</i>	+3
Ms 15	bil Zi	54/67/1	tremor	adl, feeling shame	slight tremor	adl dependent	memory	<i>Got a better life</i>	+2
Mr 16	bil STN	62/67/5	tremor	adl	balance	adl indep, imp. balance	0	<i>DBS meant everything</i>	+3
Mr 17	bil Zi	63/70/2	tremor	#	balance	unable to exercise	speech, balance	<i>Tremor resolved</i>	+1

(Continued)

Table 2  
(Continued)

Patients	DBS - target. <i>a</i>	Age@diagnosis/age@DBS/ time(y) since DBS. <i>a</i>	Dominant PD Symptom(s) and/or areas of impairment (pre DBS). <i>b</i>	Limited life areas related to activity/ participation/ and emotions due to PD (pre DBS). <i>b</i>	Dominant PD symptom(s) and/or areas of impairment @ time for interview (post DBS). <i>b</i>	Experiences of areas related to activity/ participation and emotions due to PD @ time for interview (post DBS). <i>b</i>	Side-effects attributed to DBS related to the following areas @ time for interview. <i>b</i>	Quotations from patients regarding the impact of DBS. <i>b</i>	Overall outcome of DBS @ interview. <i>c</i>
Mr 18	uni Zi	68/71/0.5	tremor	adl, feeling shame	0	adl indep, feel secure	0	Tremor resolved	+2
Ms 19	uni Zi	62/68/5	tremor	adl, social withdraw	slight tremor	adl indep, active, socialize	0	Tremor resolved	+3
Mr 20	uni Zi	57/63/0.5	tremor, stiff	adl, gait	slight tremor	adl indep, active	0	Got another life	+3
Ms 21	bil STN	45/52/3	tremor, cramps	adl, social withdraw	cramps, pain	adl depend, socially active	0	It feels like a new life	+3
Mr 22	bil Zi	40/53/1	tremor, stiff	#	balance, cognition	frequent falls	speech, memory	I has gone downhill	-3
Mr 23	bil Gpi	52/58/3	tremor, stiff, balance	gait, mobility	stiff	adl indep, walk straight	speech	Difficult life without DBS	+2
Ms 24	uni Zi	33/63/0.5	tremor, stiff	gait	balance	frequent falls	balance	DBS is fantastic	+3
Ms 25	bil Zi	58/63/1	tremor, balance, fatigue	adl, gait	gait	adl indep, active, fear of falls	0	No tremor & walk as before	+2
Mr 26	bil STN	47/60/2	tremor, cramps	adl	digestion	indep.	0	Everything is better	+3
Mr 27	bil STN	63/70/3	stiff, tremor, drooling	#	speech, balance	socialize	speech, balance	Could only be better	+2
Mr 28	bil STN	41/57/4	tremor, cramps	adl, work	fatigue	adl indep, need rest	0	Live a normal life	+3
Mr 29	bil STN	53/74/1	on-off, tremor	gait, work	balance, speech	imp. gait, speech	balance, speech	It is a misery	-1
Mr 30	bil Zi	43/50/2	dysk., tremor	adl, work	fatigue, melancholic	#	0	Less dyskinesic	+3
Mr 31	bil STN	40/54/0.5	dysk., tremor	#	#	adl indep, active	0	Fantastic feeling	+3
Mr 32	bil STN	55/64/1	off, freezing	adl	speech, balance	imp. communication	cramps, speech	Improved off periods	+2
Mr 33	bil STN	43/49/1	on-off, cramps, pain	communication	#	active	0	PD more even	+3
Mr 34	bil STN	63/72/4	dysk.	feeling shame	balance, swallowing	active	speech, balance	No dyskinesia	+3

(Continued)

Table 2  
(Continued)

Patients	DBS - target. <i>a</i>	Age@diagnosis/ age@DBS/ time(y) since DBS. <i>a</i>	Dominant PD Symptom(s) and/or areas of impairment (pre DBS). <i>b</i>	Limited life areas related to activity/ participation/ and emotions due to PD (pre DBS). <i>b</i>	Dominant PD symptom(s) and/or areas of impairment @ time for interview (post DBS). <i>b</i>	Experiences of areas related to activity/ participation and emotions due to PD @ time for interview (post DBS). <i>b</i>	Side-effects attributed to DBS related to the following areas @ time for interview. <i>b</i>	Quotations from patients regarding the impact of DBS. <i>b</i>	Overall outcome of DBS @ interview. <i>c</i>
Ms 35	bil. STN	39/54/5	on-off, dysk., cramps	adl, dependent	speech	falls, imp. communication	balance	<i>The best thing done</i>	+3
Mr 36	bil STN	51/59/4	Off	#	speech	adl dependent, imp. speech	0	<i>DBS was a big boost</i>	+2
Mr 37	bil Zi	43/49/1	stiff, cramps	stress sensitive	dysk.	adl indep.	speech	<i>No cramps &amp; less stiff</i>	+1
Mr 38	bil STN	41/53/6	dysk., stiff	adl, isolated	dysk.	adl dependent	speech	<i>DBS was wonderful</i>	+2
Ms 39	bil STN	38/52/4	cramps, pain,	adl, falls, isolated	dysk.	move unaided, socially active	0	<i>DBS helped incredibly</i>	+3
Ms 40	bil STN	35/51/7	dysk., balance	falls	#	adl indep., isolated	#	#	+1
Ms 41	bil STN	53/70/0.5	cramps, pain	#	balance, pain	dependent, isolated	balance	#	#
Ms 42	bil STN	45/52/6	dysk., cramps	adl, inactive	balance	aided gait	speech, balance	<i>PD more even</i>	+3

Abbreviations: DBS = Deep brain stimulation; *a* = Determined from demographic questionnaire, interviews and patient files; *b* = Determined from questionnaire; bil = bilateral; uni = unilateral; PD = Parkinson's disease; STN = subthalamic nucleus; Zi = Zona incerta; Gpi = Globus pallidus internus; adl = activities of daily living; 0 = no side effects/no dominant symptoms; # = no information; dysk. = dyskinesias; imp. = impaired; indep. = independent; +3 = marked improvement; +2 = moderate improvement; +1 = small improvement; 0 = unchanged; -1 = small deterioration; -2 = moderate deterioration; -3 = marked deterioration.

Table 3  
The Core category with five categories

Core category	DBS means everything –for some time				
Categories	Relief from invasive tremor	A rescue from cramps and pain	Easier movement swings and more predictable living space	Hard, but compared to previous sufferings, bearable adverse events	Parkinson's disease is progressing despite DBS

six months and eight years (mean  $\pm$  SD  $2.8 \pm 1.9$ ). Twenty-eight patients (67%) had a bilateral procedure: 18 patients had DBS in the subthalamic nucleus (STN); nine in the zona incerta (Zi); and one in the globus pallidus internus (GPi). Fourteen patients (33%) had a unilateral procedure: 13 in the Zi, and one in the STN. The majority of participants were living with a partner and the majority had high school or university education. At the time of surgery 10 patients were able to work half- or fulltime, 15 were full time sick-listed, and 16 had passed retirement age. At time of interview six patients were still working at least half-time whereas 14 were sick-listed and another six had retired (Table 1).

Before surgery, patients had suffered from several symptoms and signs of PD (see Table 2). The most common symptom was tremor, described by 31 (74 %) patients. Tremor was also considered to be the main and most important problem before surgery for 25 of the 42 patients (59.5%) while the remaining 17 (40.5%) patients had had major difficulties with a composite of symptoms including slowness of movement, stiffness, cramps, and dyskinesias. In parallel to their main symptoms before surgery, many patients described symptoms such as stress sensitivity, difficulties to walk and keep balance, pain, sleep disturbance, fatigue, speech disturbance, and/or problems with salivation or swallowing.

At time for interview, when patients were asked about the overall impact of DBS on life, 61% indicated a marked improvement, whereas 32% considered the impact of DBS on their life to be either moderate or small. A small deterioration after DBS was described by 2.5% and a marked deterioration by another 5% of patients (Tables 1 & 2).

Undesirable side effects that were perceived as entirely or partially related to DBS were described by 23 (57.5%) patients. The most common side effects were various combinations of speech, gait and balance difficulties, reported by 11 patients. Five patients indicated worsening of speech only, while four complained about deteriorating balance but had no worsening of speech. In addition, two patients

suspected that deterioration of their memory could be ascribed to DBS. Seventeen patients (42.5%) denied having experienced any kind of deterioration or adverse event after DBS.

### Interviews

At the time of interview the patients had been on chronic stimulation for a mean of almost three years and they had had the disease on average for eleven years. Hence, the majority of patients had had time to experience the significance of DBS for their daily life.

During the interviews the participants appeared to have no difficulties in recalling, and they were detailed in their narratives. They could describe their situation and disease symptoms such as they were before DBS, and they provided a rich account, with many examples, of their experiences of DBS in relation to their current life situation.

The qualitative analysis of the interviews resulted in the core category: '*DBS means everything – for some time*'. The core category contained five categories unfolding the patients' experiences of positive and negative effects of DBS on their day-to-day life. These five categories were: 1) 'Relief from invasive tremor', 2) 'A rescue from cramps and pain', 3) 'Easier movement swings and more predictable living space', 4) 'Hard, but compared to previous sufferings, bearable adverse event', and 5) 'Parkinson's disease is progressing despite DBS' (Table 3). In the following, the core category and categories are presented and illustrated with quotations from the participants. The participants are given fictitious names from Mr. One to Ms. Forty-two, and each individual is presented in Table 2.

#### *Core category: "DBS means everything –for some time"*

This core category summarizes the analysis and the overall message communicated by the patients. When describing the comprehensive significance of DBS, patients often used strong, positive and decisive descriptions of DBS such as, '*life changing*' or '*it is*

a new chapter in life, an easier life'. Ms. Twenty-one, who preoperatively had tremor, painful cramps and was extremely dyskinetic, described the impact of DBS as '*it is unbelievably wonderful, it feels like a new life*'. DBS meant that the symptoms of PD became more even, and also more predictable, and it was therefore possible for the patients to take part in activities they had not been able to manage before, such as personal care, household work, hobbies and social activities. The positive effects of DBS were outlined as so important for the patients that they were prepared to accept troublesome side effects like speech difficulties and deterioration of balance. The patients were also well aware about the fact that the improvements they experienced with DBS were limited in time because the progression of the disease would continue.

#### *Relief from invasive tremor*

Tremor was narrated as a very pervasive symptom that was impossible to escape from and that impacted on almost every aspect of daily life. It resulted in both activity limitations and social isolation, often with confinement to home, as illustrated by a quote from Mr. 1: '*most of the time I lay on the bed trying to fall asleep*'. Since tremor was in many cases abolished, or to a great extent reduced after surgery, DBS meant extensive positive changes of patients' life, described by Mr. 14 as follows; '*I got everything back, it was like day and night*'.

Without or with less tremor, it became easier and less time consuming to manage daily activities requiring fine motor tasks such as eating, drinking and writing, using the mobile phone, the computer, or the camera, and to engage in leisure activities. Mr. 6 was happy to resume his interests and to continue with different building projects and Mr. 10, who, due to tremor, could not play his accordion before the operation, said '*I came home after surgery and put on the accordion and everything was as before, that was fun, it is about quality of life*'. Reduced tremor also meant that patients were less dependent on relatives, and they became more self-sufficient in daily chores and were able to participate in the society more fully.

For the patients who were still working, tremor had threatened their ability to maintain certain fine motor skills required in their job. However, even with a positive outcome after surgery with respect to tremor reduction, for some patients, return to work was not always possible or desired for. A working life with high tempo and demands on productivity was stressful and provoked symptoms. The solution

was therefore often to obtain sick retirement despite a successful surgery. In this process, some patients had required support of their physician in '*taking the fight*' with the social insurance office.

The improvement of tremor after DBS resulted in a less visible disease. Other peoples' annoying and intrusive attention that had brought about patients' feelings of embarrassment, shame and even guilt before surgery, decreased. Hence, DBS contributed to increased social interactions, and facilitated for patients to take part in activities outside home. Mr. 8, with tremor as his most troublesome symptom said '*before surgery it was a torment to visit and socialize with people and to stay in public places*', '*now [after surgery] it is fun to go shopping, to cook and to meet with people*'.

Ms. 25, who before surgery presented a composite of PD symptoms including difficulties with gait and balance as well as tremor, had reflected on the specific character of tremor relative to other symptoms of the disease in the context of daily living, and formulated the following; '*It's not possible to compensate for tremor as for difficulties with gait and balance where you may use a cane or a wheel chair or actually just sit and wait. It is impossible to escape tremor, it is visible and makes me unsecure*'.

#### *A rescue from cramps and pain*

In most patients with cramps, DBS had a very beneficial impact, despite the variable characters of this often painful state. The location and timing of the cramps as well as factors that triggered them differed between patients and also inflicted various limitations to patients' lives. Mr. 33 had painful foot cramps, that were extremely troublesome to cope with and he described his feeling after surgery as follows: '*all the cramps are gone, I haven't felt anything, my feet are like cotton*'. For Ms. 35 the painful cramps caused a disrupted sleeping pattern, which led to tiredness during the day: '*I had such severe cramps during the night, I don't want that time back, it was painful, I slept no more than two hours each night*'. Painful foot and leg cramps together with distorted feet caused Ms. 39 difficulties in moving around and even if her agonizing cramps did not stop after DBS they decreased significantly. She was then able to move around more freely, '*one important thing that has happened after surgery is that now I dare to walk across the floor, whereas before I had to move along the walls in order to have something to hold on to*'.

One patient was an exception in that DBS did not alleviate her painful foot cramps as she had expected.



Her suffering continued and she was confined to her home, *'then I sit on a chair looking straight ahead; yesterday afternoon it went on from 2 pm until almost 7 pm'* (Ms. 41).

*Easier movement swings and more predictable living space*

DBS had a positive impact on unpredictable and uncontrollable movements, as well as on the swings between the two extremes of either being stiff and totally rooted to the spot, or having excessive uncontrollable movements. Mr. 26 described the change after DBS in this way: *'off-periods are now like child's play when compared to before'*.

Shorter and milder periods of being stiff and slow or dyskinetic made it easier to plan for and participate in daily activities, and these bothersome states also appeared less threatening to the patients' autonomy. Ms. 21 explained: *'Now I can go to the cinema, I sit at the back and it does not need to be a disaster anymore'*. Mr. 32 described a situation before surgery with increasing occasions of freezing preventing him from taking part in activities, especially those outside the house. He said *'The operation helped me with my worst level [of the disease]. Even if I forget my medications, I know that I can get back home without getting stuck [due to freezing]*.

The time when patients could be active increased from a few hours a day to, in some cases, the whole day during which they could resume ordinary daily chores such as shower and dress as well as drive a car or meet with friends. Ms. 35 who before DBS needed a personal assistant around the clock, with only a few hours a day when she could be active on her own, described her preoperative condition as follows: *'I was either like a propeller or totally stiff'*. After surgery she could live independently in her own home.

DBS increased the possibilities for patients to plan for and perform daily chores and hobbies, and for some the improvement of dyskinesia was the major gain after DBS. Mr. 34 explained, *'the by far greatest benefit of DBS is that I can get rid of excessive movements, I still have some as you might see now, but I can live with that'*. Nevertheless, despite the wider living space that was the result of DBS, patients underscored that the improvements were depicted in relation to a very difficult preoperative situation, here illustrated by Ms. 39, who explained: *'now [after DBS] I am able to have a whole day, not like healthy people, but it is a huge difference compared to before DBS'*.

*Hard, but compared to previous suffering, bearable adverse events.*

The relevance of side-effects seemed to differ according to the patients' pre-operative symptoms: the more distressing the preoperative symptoms of PD, the more "acceptable" were eventual side effects of DBS. The perception of side effects was also related to how the side-effects impacted on each patient's needs, wishes, life situation and interests in daily life. Most patients described their symptoms as uncontrollable and very bothersome before surgery and they seemed willing to accept what would be considered during other circumstances as non-negligible adverse events. For Mr. 1, DBS abolished bilateral intense upper extremity tremor but induced difficulties with gait ignition, as well as a slurred speech. However, Mr. 1 concluded: *'there is nothing bad with DBS'* and *'I got a new chapter in life [after DBS]'*. This may seem as an unequivocal contradiction, but overall, the patients appeared very clear about pros and cons of DBS, and were also prepared to tolerate and even ignore apparent side effects from DBS, in the light of its advantages. Mr. 3 was outspoken about this logic. His voice strength decreased dramatically after DBS with difficulties being heard and the need to constantly repeat himself. His balance and gait also deteriorated. Despite the significant impact of these negative side effects on a daily basis he deemed them negligible, compared with his previous constant disabling tremor, and he said: *'nothing could be worse than the shaking I had'* (Mr. 3).

For three patients the side effects of DBS overshadowed the gain in symptomatic relief. DBS did indeed meet their expectations with respect to effect on previous symptoms, but they had not foreseen the adverse events that impacted negatively on valuable daily activities or on pursued hobbies and interests, with limitation in social life as a consequence. Mr. 9, enjoyed to meet with friends and go out dancing, and he was very disappointed when he due to impaired balance and tiredness after the operation, was not able to do that any more. Mr. 22 said that less than two month after DBS, the negative impact on his balance and speech had totally prevailed over resolved tremor and now, one year after surgery, his memory also faltered. Mr. 17 enjoyed regular jogging tours before DBS but this was not possible after surgery: *'it's not like jogging anymore . . . I don't fall but it is pulling in one or the other direction. I just have to walk'*. These three men had in common that they in retrospect characterized their preoperative symptoms

as relatively mild and Mr. 22 said: *'I had no worries then [before DBS]'*.

However, it was not always easy for the patients to feel sure about whether a symptom was a DBS related side effect or a sign of the disease progression. A few patients had confirmation of the negative impact of DBS on speech and/or balance following changes in the electrical parameters of the DBS. Mr. 23, explained: *'if they turn up too much on the left side I start to slur, it is impossible to talk. My voice disappears'*. Other patients were more doubtful about the origin of *'what is what'*, i.e., if an impairment was attributed to DBS or to the disease itself. In these cases patients appeared ready to give the treatment with DBS the benefits of the doubt. For example, Ms. 39 explained: *'I have started stuttering after DBS, but that was probably afoot even before surgery'* or Mr. 32 who said: *'my balance is bad but that has nothing to do with DBS, it's due to Parkinson's disease'*.

#### *Parkinson's disease is progressing despite DBS*

Despite variable time duration since DBS surgery and number of years since diagnosis, patients were well aware that DBS 'only' provides a symptomatic relief and that the PD, notwithstanding the surgical treatment, will progress over time. This insight was explicitly expressed by Mr. 10 who said, *'Parkinson's disease has its course and how it ends is an open question; I will travel to France, I have to take the opportunity while I still can'* and *'DBS helps with some symptom but there are others symptoms that will get worse'*. In a similar way Mr. 3 said: *'I understood that it [the disease] will develop on the other side too, so I worked all that I could, I chopped 20 cubic meters of firewood'*.

The notion of PD as a progressive disease and its implication for the outlook on life, was in quite a few cases based on patients' experiences of relatives having, or having had PD. These patients had closely experienced the process of living with PD as a struggle, and this experience triggered their attempts to find a treatment such as DBS, that could alleviate symptoms and postpone difficulties, at least for a period of time. Mr. 27 said *'I watched what happened to my mother, how she got worse and worse and at least I wanted to know if there is something that might hold it back for a while'*.

The impact of DBS on patients' life was almost always narrated in relation to the medical therapy and although patients complained over the inconvenience of frequent daily PD medication they still acknowledged their medication as a cornerstone of

their treatment: *'Medication is still very important to keep me going, but DBS has helped me when I am at my worst'* (Mr. 32).

## DISCUSSION

The aim of this interview study of 42 patients (11 women) treated with DBS for Parkinson's disease was to investigate the patients' own experience of the impact of DBS on their daily life. The main finding was that patients with advanced PD highly appreciated the positive impact of DBS on their daily life even if it is limited in time, and for the majority of them, the relief from the severe parkinsonian symptoms, especially tremor and painful cramps, outweighed the side effects of DBS. This was summarized in the core category that emerged from the interviews: *"DBS means everything – for some time"*.

This core category summarized the patients' experience and implied in essence that after DBS, it became easier, less demanding and less time consuming to plan for, and to perform, daily chores. DBS made it possible to resume activities and interests that had been hard or even impossible to perform before surgery. It decreased patients' energy expenditure and provided them with prerequisites for improved autonomy. However, patients were aware that the improvements were temporary, due to the progressive character of PD.

The core category comprised five categories of which two *'Relief from invasive tremor'* and *'A rescue from cramps and pain'* refer to the amelioration of those symptoms that before operation foremost hampered and limited the patients' possibilities to live a life according to their wishes and needs. The third category *'Easier movement swings, and more predictable living space'* relates to the positive effect of DBS on involuntary movements caused by long-standing levodopa treatment. The fourth category *'Hard, but compared to previous suffering, bearable adverse events'* comprises the patients' experience of DBS-related side-effects and their impact on their daily life; and finally, the fifth category *'Parkinson's disease is progressing despite DBS'*, describes patients understanding and awareness of the progressive character of the disease.

#### *Importance of tremor*

Even if in the literature tremor is not considered as the PD symptom that contributes most to disability [21], or impacts most on quality of life

[2], our patients described it as an intrusive symptom that was very difficult to cope with, aside from causing embarrassment and restricting social life. Tremor was pre-operatively experienced by about 3/4 of our patients (74%), and for 59,5 % of the patients it was the symptom causing most concern before surgery. The amelioration of tremor after DBS enabled patients to resume daily activities, hobbies and also contributed to patients' autonomy. For some patients, relief of tremor as such seemed almost enough, and for them, just to be able to be still was sufficient. One of the patients who had experienced a composite of parkinsonian symptoms including tremor concluded that "... for difficulties with gait and balance, you may use a cane or a wheel chair or actually just sit and wait. But it is impossible to escape tremor..."

Feelings of embarrassment and shame [22] due to the visible character of tremor disappeared after surgery and contributed thus to improved social interactions.

The difficulties related to tremor from the patients' point of view have also been described by others [23, 24], indicating considerable daily problems related to this symptom. The common view in the medical community that tremor is a less problematic symptom does not fit with our patients' depiction of the impact of tremor, or with their expressions of satisfaction when tremor had been relieved by DBS, regardless of effect of DBS on other symptoms of PD.

Pain and cramps are also symptoms that are inherent to advanced PD, and that may be difficult to "escape" from and to cope with. These symptoms caused distress in many of our patients, affecting also their sleep. Pain is often regarded as a "non-motor" symptom that impacts negatively on ADL, wellbeing and quality of life [25]. However, this "non-motor" symptom was considered by our patients as inherent to, or the result of, motor symptoms such as tremor and cramps. Since DBS alleviated motor symptoms and cramps, this in turn relieved the pain in most patients, with positive implications on daily living.

#### *Side effects and expectations*

Almost 60% of our patients experienced side effects, or new unwanted symptoms after surgery, mainly negative affection of speech, balance and gait (Table 2), although some blamed these adverse events on the disease more than on the DBS. It is interesting to note that most patients considered the side effects as the bargain between control of the symp-

toms enabling them to be more active in day-to-day life and the price to pay in terms of slurred speech or balance problems [20].

The extent and degree of side effects varied between patients but on the whole, patients almost always compared the impact of side effects after surgery with the impact of the symptoms of the disease such as they were before the operation: almost invariably, the patients valued more the relief of symptom brought about by DBS, and its positive consequences on their daily life, than the eventual side effects. This was conveyed through the processed interviews and reiterated in patients' answers to the question '*On the whole, how has DBS impacted on your life?*', where all except three patients indicated a positive albeit varying improvement after DBS. This overall improvement was seen independently of brain target or laterality of DBS (Table 2). Ahlberg et al. [26], described a similar pattern in that patients in their study stressed the overall benefits of DBS in terms of increased mobility. Despite the various side effects, their patients felt that they 'had got their life back' [26]. This means that, from the patients' perspective, if they are sufficiently ill and sufficiently suffering from PD symptoms, they would be more prone to "forgive" eventual side effects from DBS in the light of getting rid of their most disabling symptoms. In that respect, it would be interesting to know how side effects would be perceived by patients if they more customarily undergo DBS earlier in the disease process, as has been proposed recently in the so called "Earlystim" study [27]. Interestingly, in our study, 42% of the patients denied having any side effect from the DBS.

#### *Awareness about the disease progress and the limits of DBS*

Our patients disclosed that they were aware that DBS was not a cure and that the disease will continue to progress. This is in contrast to a study by Montel et al. [28], showing that their patients might have had unrealistic expectations and were disappointed by the results of DBS in terms of halting the disease progression.

It seems that our patients had been well informed by their DBS team about what to expect and were well aware that DBS 'only' provided a symptomatic relief and that their illness, notwithstanding the surgical treatment, will progress over time. Hence their understanding and perception of DBS as illustrated by the core category "*DBS means everything – for some time*".

### Advantages of using qualitative methodology

The advantage of using qualitative methodology based on interviews of patients was that this approach elucidated issues and considerations that were relevant to the patients, and that shed light on their daily life with the disease and its treatment from the patient's own perspective. Patients' 'own voice' should be considered, in order to capture their individual needs and preferences which are cornerstones in patient-centred care and prerequisite for good quality in health care [13, 29]. Specifically the use of qualitative methodology including in-depth interviews of patients and partners have been requested by some workers in the field [30–32]. Furthermore, the fact that the present authors were not involved in the surgical or clinical care of the patients may have allowed the participants to be more candid and open in the description of their perceptions and experiences of having DBS.

In our patients, the interviews revealed new information beyond that provided by "established" evaluation scales that are based on pre-formulated questionnaires. An example is the finding that although many participants in our study suffered from side effects of DBS, most of them meant that the reduction of their worst pre-operative symptoms of PD was worth the price despite the new problems with balance and speech.

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### CONFLICT OF INTEREST

Gun-Marie Hariz: No conflict of interests

Patricia Limousin: Received occasional travel grants from Medtronic and St Jude for speaking at meetings

Katarina Hamberg: No conflict of interests

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