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Swallowing Quality of Life after Zona Incerta Deep Brain Stimulation

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Objectives - The management of Parkinson's disease (PD) has been improved, but management of features like swallowing problems is still challenging. Deep Brain Stimulation (DBS) alleviates the cardinal motor symptoms and improves quality of life, but its effect on swallowing is not fully explored. The purpose of this study was to examine self-reported swallowing specific quality of life, before and after caudal zona incerta DBS (cZI DBS), in comparison with a control group. **Methods** - Nine PD patients (2 women and 7 men) completed the self-report Swallowing Quality of Life questionnaire (SWAL-QOL) before and 12 months after cZI DBS surgery. The postoperative data were compared to nine controls. Median ages were 53 years (range 40-70) for patients and 54 years (range 42-72) for controls. **Results** - No significant differences were found between the pre-, or postoperative scores. The SWAL-QOL total scores did not differ significantly between PD patients and controls. PD patients reported significantly lower scores in the 'burden' subscale and in the 'symptom' scale. **Conclusions** - PD patients selected for cZI DBS showed a good self-reported swallowing specific quality of life, in many aspects equal to controls. CZI DBS did not negatively affect swallowing specific quality of life in this study.

Keywords: caudal zona incerta, Deep Brain Stimulation, Dysphagia, Parkinson's disease, Swallowing quality of life

Abbreviations: PD: Parkinson's disease, DBS: Deep Brain Stimulation, cZI DBS: caudal zona incerta Deep Brain Stimulation, SWAL-QOL: Swallowing Quality of Life questionnaire (SWAL-QOL), STN: Subthalamic nucleus, QOL: quality of life, DHI: Dysphagia Handicap Index,

Introduction

Recent developments in pharmaceutical and surgical management of Parkinson's disease (PD), such as new ways of administering drugs and electrical 'Deep Brain Stimulation' (DBS), have increased the therapeutic options for symptomatic treatment of the disease in general¹⁻³, and for alleviating cardinal motor symptoms, particularly tremor, bradykinesia and rigidity²⁻⁴. However, several signs of PD, like speech and swallowing problems, are still challenging to manage⁵⁻⁸.

Swallowing dysfunction is commonly found in PD, with a prevalence of 82 %, with swallowing

problems often manifested in the oral and pharyngeal phases⁹, but also in the esophageal phase^{6,10}. In comparison to healthy controls, PD patients also show more silent saliva aspiration, as well as more post-swallow pooling, and even in an early stage of the disease, eating habits are affected¹⁰⁻¹². Problems with swallowing impair quality of life (QOL), as restrictions in food intake, and anxiety or avoidance of eating in public have consequences for both the patients and their caregivers¹³⁻¹⁷. PD patients report lower swallowing specific QOL than age-matched controls¹⁸. In the elderly and in PD patients, problems with swallowing may also lead to

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physical health issues like malnutrition, dehydration and pneumonia^{15,19,20}.

DBS in the Subthalamic nucleus (STN) as well as in the caudal Zona Incerta (cZI) have been associated with a positive effect on health-related QOL^{21,22}, but the effect on swallowing and swallowing specific QOL has not been fully explored. In a systematic review of swallowing function and DBS, Troche et al. conclude that there is a need for more studies on these matters, as current reports are heterogeneous and entail methodological issues²³. Several studies have examined swallowing function with STN DBS^{24–27}. Troche et al. found a negative effect of STN DBS with increased penetration and aspiration while the other studies did not report any decrease in swallowing function^{24–27}. The only earlier swallowing study that have investigated swallowing function after cZI DBS found no overall negative effects of the DBS stimulation or the operation²⁸. The effect of DBS on swallowing is a complicated but important matter to address, as DBS brings a clear-cut improvement in cardinal symptoms of PD, but does not seem to have the same pronounced effect on swallowing function²³.

Swallowing function can be assessed by using fiber endoscopy, video fluoroscopy, or patient self-reports^{13,16,29}. Traditionally, little attention has been given to patients' subjective experience, even though it has been shown that the feelings and attitudes towards swallowing and eating of patients with PD affect both their eating habits and their mental well-being^{13,16}. However, over the last few years, several self-report assessment scales have been suggested to supplement the clinical examination of swallowing function^{29,30}. Such self-report questionnaires encompass the patients' own perception of their condition, and hence could be argued to reduce possible observer bias.

Several of the self-report questionnaires focus on QOL²⁹. This is favorable, as it is known that PD affects both overall health-related QOL^{31,32} and swallowing specific QOL^{18,33}, and that these two types of QOL measures are related^{13,18}. Both Keage et al.³⁰ and Timmerman et al.²⁹ recommend the

validated 'Swallowing Quality of Life' (SWAL-QOL) questionnaire as a first preference³⁴. SWAL-QOL has been used in swallowing studies for different patient groups as well as for the evaluation of therapeutic effects^{18,35}.

To date, studies examining swallowing function and DBS have not used the SWAL-QOL questionnaire³⁴. Silbergleit et al.²⁴ used the 'Dysphagia Handicap Index' (DHI)³⁶, showing that patients' ratings on the 'functional', 'emotional', and 'total' subscales were improved 12 months after STN DBS, compared to baseline.

A previous preliminary report on swallowing function after cZI DBS by Sundstedt et al.²⁸ included a few swallowing related QOL-questions on 'affected swallowing function'; consistency modification, weight loss, coughing when eating, decreased mealtime pleasure, sticky saliva, and drooling, which indicated that cZI DBS did not noticeably affect the patients' experiences of these aspects. However, there are no additional studies on swallowing function following cZI DBS that include specific swallowing QOL questionnaires.

The purpose of this study was therefore to examine self-reported swallowing specific QOL self-reports in PD patients before and after cZI DBS surgery. The aim of the current study was to describe the change in swallowing specific QOL in patients who have undergone cZI DBS and to compare the SWAL-QOL scores to a control group.

Materials and methods

This prospective descriptive longitudinal study assessed consecutive patients with PD from the Northern region of Sweden. The patients were under clinical evaluation for treatment with DBS at the tertiary referral center at the University Hospital of Umeå. Patients were evaluated for their suitability for inclusion in the study according to clinical evaluation and best clinical practice. Patients were selected for cZI DBS surgery on clinical grounds, based on the assessment of overall motor function and no consideration of swallowing function was taken in the selection

process. The study was conducted in accordance with the Declaration of Helsinki, and was approved by the Regional Ethical Review Boards in Umeå and Gothenburg, Sweden (Approval numbers 08-0934M and 846-15).

Eighteen patients in total were assessed for eligibility for the study. Nine of these patients were not included in the study. Reasons for exclusion were; poor outcome of the neuropsychiatric examination (n=3), use of duodopa instead of surgery (n=1), unilateral DBS (n=3) or alternative DBS target (n=1). Additionally, one patient declined to participate in the 12 months follow up examination.

Nine patients were included in the study; a description of the patients' characteristics is provided in Table 1. Swallowing data were collected as part of a larger, prospective controlled evaluation of the overall motor function following cZI DBS and six of the nine patients were also included in an on-going parallel study by our group. The surgical procedure and the target have been previously described in detail³⁷. All patients underwent bilateral cZI DBS surgery and stimulation frequencies were between 125 and 160 Hz for all patients. The patients visited the tertiary

referral center at 12 months after DBS surgery for examinations of overall motor function as part of an ongoing parallel study, and postoperative examinations regarding swallowing function were also performed at that time.

Nine control subjects without PD, matched for sex and of comparable marital status and age (within three years), were recruited consecutively from patients at the Otorhinolaryngology Department at Sahlgrenska University Hospital in Gothenburg, Sweden. Three controls presented at the otorhinolaryngology clinic with chronic tonsillitis; the remainder presented with vertigo, extirpation of nevus, snoring, salivary stones or chronic rhino sinusitis. Marital status was controlled as the SWAL-QOL subscales; eating desire, communication, and eating duration could be affected by the presence of a partner during meals. Controls without PD were used to enable a comparison of the swallowing specific QOL between PD patients with cZI DBS and controls that were comparable for age and marital status. This comparison was not used to measure the effect of the DBS itself but to describe the swallowing specific QOL in PD patients with cZI DBS.

Table 1 Characteristics of patients and controls

	PD patients (n=9)		Controls (n=9)	
	median	(range)	median	(range)
Age (years)	53	(40-70)	54	(42-72)
Women/men (n/n)	2/7		2/7	
Married or cohabitant	7 patients		7 controls	
Disease duration (years)	10	(5-13)		
UPDRS-III medication off	40	(18-52)		
UPDRS-III medication on	17	(6-45)		
Hoen&Yhar	2*	(2.0-2.5)		
LEDD (mg)	1227	(300-1746)		
Anticholinergic medication	1 patient			
Indication for surgery	On-off fluctuations (4), tremor and wearing off (5)			

PD: Parkinson's disease. LEDD: L-dopa equivalent daily dose. UPDRS-III: Preoperative scores from motor part of Unified Parkinson's disease rating scale, lower scores for better function. Hoehn&Yhar: Scores 1-5p with lower score for better function. *Data missing from three patients

SWAL-QOL

Swallowing specific QOL was assessed preoperatively and 12 months after cZI DBS surgery, with the Swedish version of the SWAL-QOL questionnaire³⁸. This patient-based and disease-specific dysphagia tool is used to assess oropharyngeal swallowing function, and encompasses 44 items related to swallowing, two questions about modification of food textures and one question about patients' overall health. The items are grouped into subscales that address 10 different swallowing related domains: Food Selection (2 items), Burden (2 items), Mental Health (5 items), Social Functioning (5 items), Fear (4 items), Eating Duration (2 items), Eating Desire (3 items), Communication (2 items); Sleep (2 items); and Fatigue (3 items). A total SWAL-QOL score (23 items) and a 'symptom' scale score (14 items) can also be calculated. The full list of items from the English SWAL-QOL has been presented in the review by Keage et al.³⁰.

The results of the SWAL-QOL were linearly transformed from a 5-point Likert scale to ratings between 0 and 100 in accordance with the validation by McHorney et al.^{34,39}. The least favorable state is 0, and the most favorable state is 100. A decrease of 14p from the maximum SWAL-QOL total score (100p) has been suggested as a cut-off⁴⁰, so that a SWAL-QOL total score of 86p or less is considered as a sign of clinically relevant swallowing problems.

Swallowing VA-scale

Patients also rated their own swallowing function using a 100 mm visual analog (VA)-scale preoperatively and again 12 months after cZI DBS. The VA-scale is a response scale, which can be used to measure subjective characteristics or attitudes that cannot be directly measured. Respondents specify their level of agreement with a statement by indicating a position along a continuous line between two end-points. In this study, one end-point of the scale represented 100% functional swallowing and the other end-

point represented total loss of swallowing function.

Study design

Patients evaluated their swallowing function preoperatively and 12 months after cZI DBS at the Department of Otorhinolaryngology, at Umeå University Hospital. The SWAL-QOL questionnaire was administered to the patients, together with information about the study and questions regarding demographic data like sex, age and marital status. The evaluation with the VA-scale was done preoperatively with and without L-dopa medication and postoperatively with and without stimulation (medication on). In this study, those VA-scale scores that were assessed with medication on preoperatively, and with medication and stimulation on postoperatively were used. The observations throughout the overall study were conducted with optimal PD medication.

Statistical analysis

All analyses were performed using SPSS version 20.0 for Mac. Descriptive statistics were provided as medians with ranges. Non-parametric two-tailed tests were used and the significance level was set at 5%. Change over time was analyzed with Wilcoxon Signed Rank test and Sign test. Wilcoxon Signed Rank test and Sign test were also used for comparison between PD patients and controls. McNemar test was used for comparison between the PD study group and controls regarding marital status. Magnitude of group differences was analyzed using estimated effect size. Effect size was calculated according to the formula $r = z/\sqrt{N}$, where N is the number of observation e.g. $N_{\text{observations}} = n_{\text{preop}} + n_{\text{postop}}$ or $N_{\text{observations}} = n_{\text{patients}} + n_{\text{controls}}$. This method complements standard significance testing and yields standardized effect levels regardless of sample size. Thresholds for qualitative descriptors of effect size were small ($r > .10$), moderate ($r > .30$); large ($r > .50$) and very large effect size ($r > .70$).

Results

A total of 18 patients were assessed for eligibility, of whom nine were excluded or declined to participate. Characteristics of the PD and control groups are provided in Table 1. There were no significant differences regarding age and marital status between the two groups (age; $\chi^2 = -1.71$, $p = .86$, $r = -.04$, and marital status; $\chi^2 = .000$, $p = 1.00$, $r = .00$).

SWAL-QOL, subscales and swallowing VA-scale

Table 2 shows individual pre- and postoperative scores from the SWAL-QOL questionnaire and the VA-scale. Patients in the PD group reported high SWAL-QOL scores. SWAL-QOL total scores ranged between 83 and 100p preoperatively, and between 82 and 100p 12 months after cZI DBS. Preoperatively, only one patient had a SWAL-QOL total score below 86p, which has been suggested as a cut-off score for clinically relevant dysphagia. After 12 months with cZI DBS, another patient had a SWAL-QOL total score below cut-off.

The individual SWAL-QOL total score improved postoperatively in four cZI DBS patients (median age: 56 year, disease duration: 8 years, and pre-op med on UPDRS III: 16 p) and deteriorated postoperatively in another three (median age: 51 year, disease duration: 7 years and pre-op med on UPDRS III: 27). Two patients reported unchanged SWAL-QOL total score throughout the course of the study (median age: 66 years, disease duration: 10 years and pre-op med on UPDRS III: 31).

Table 3 provides descriptive data and significance testing for different subscales included in SWAL-QOL. In the PD group, there were no significant differences when comparing the preoperative ratings and the rating made 12 months after cZI DBS surgery. Effect sizes were $r = .00-.27$. The median for the preoperative VA-scale score was 94% (range 86-100) and the median for the VA-scale 12 months after cZI DBS was 98% (range 59-100). This difference was not significant ($\chi^2 = .388$, $p > .05$, $r = .09$).

Table 2 SWAL-QOL total score, SWAL-QOL symptom scale score, and VA-scale score

Patient	SWAL-QOL total 0-100%			SWAL-QOL symptom scale 0-100%			VA-scale 0-100 %		
	12 m			12 m			12 m		
	Baseline	postop	Change	Baseline	postop	Change	Baseline	postop*	Change
1	87	95	8	86	77	-9	94	84	-10
2	94	82	-16	91	66	-25	86	59	-27
3	96	88	-8	91	80	-11	91	100	9
4	91	90	-1	95	82	-13	93	96	3
5	98	98	0	86	93	7	98	98	0
6	83	90	7	68	82	14	94	99	5
7	97	100	3	100	100	0	100	98	-2
8	93	100	7	84	95	11	86	89	3
9	100	100	0	100	100	0	94	100	4
Median	94	95	0	91	82	0	94	98	3
Min	83	82	-16	68	66	-25	86	59	-27
Max	100	100	8	100	100	14	100	100	9

SWAL-QOL: Swallowing quality of life questionnaire. VA-scale: visual analogue scale. The higher the score the better the function. *cZI stimulation on, medication on

Table 3 Descriptive data. Wilcoxon signed-rank test for differences before and 12 months after cZI DBS surgery and differences between the PD group with cZI DBS and controls

	PD group (n=9)		Controls (n=9)	Wilcoxon signed-rank test and effect size								
	Before cZI DBS	12m after cZI DBS		PD group before cZI DBS vs. 12 m after cZI DBS			Controls vs. PD group 12 m after cZI DBS					
	Mdn (range)	Mdn (range)	Mdn (range)	ζ	p	r	ζ	p	r			
SWAL-QOL												
Food selection	100 (100-100)	100 (88-100)	100 (100-100)	-.707 ^b	.50	-.17	-.707 ^b	.50	-.24			
Burden	100 ^a (63-100)	88 (63-100)	100 (100-100)	-.850	.40	-.20	-2.23	.03*	-.53			
Mental health	100 (70-100)	100 (85-100)	100 (95-100)	.707 ^b	.50	.17	.000 ^b	1.00	.00			
Social functioning	100 (100-100)	100 (100-100)	100 (100-100)	.000	1	.00	.000	1.00	.00			
Fear of eating	100 (69-100)	97 ^a (75-100)	100 (75-100)	.000	1	.00	-.756	.45	-.19			
Eating duration	75 (50-100)	88 (38-100)	100 (63-100)	.850	.40	.20	-1.37	.17	-.32			
Eating desire	92 (67-100)	100 (58-100)	100 (83-100)	.816	.41	.19	.000 ^b	1.00	.00			
Communication	88 (75-100)	100 ^a (50-100)	100 (100-100)	.687	.49	.17	-.707 ^b	.50	-.18			
Sleep	88 (38-100)	88 (63-100)	63 (50-100)	1.16 ^b	.25	.27	1.62	.11	.38			
Fatigue	75 (42-100)	75 (50-100)	67 (50-100)	.000 ^b	1	.00	.358	.72	.08			
Symptom scale	91 (68-100)	82 (66-100)	98 (86-100)	-.593	.55	-.14	-2.38	.02*	-.56			
SWAL-QOL total	94 (83-100)	95 (82-100)	100 (93-100)	.085	.93	.02	-1.76	.08	-.42			

SWAL-QOL: Swallowing Quality of life. PD: Parkinson's disease. cZI DBS: caudal zona incerta Deep Brain Stimulation. Mdn: median. The higher the score the better the function. Estimated effect size:

$r = \xi / \sqrt{(n_{\text{patients}} + n_{\text{controls}})}$ or $r = \xi / \sqrt{(n_{\text{preop}} + n_{\text{postop}})}$. ^aItem missing from one patient. ^bSign rank test was used due to skewness. *significant difference, $p < .05$.

PD group vs. controls

The comparison between the PD group at 12 months after cZI DBS and the control group, showed that the PD group reported significantly lower scores in the 'burden' subscale and in the 'symptom' scale. The estimates of effect size were $r = -.53$ vs. $r = -.56$.

Regarding the SWAL-QOL total score, the difference of medians between the PD group and the controls did not reach significant levels ($p = .08$). The effect size was $r = -.42$. Other items that did not reach statistical significance, but had effect sizes with $r > .30$, were sleep and eating duration ($p = .11$, $r = .38$ and $p = .17$, $r = -.32$).

Discussion

This is the first longitudinal prospective study on self-reported swallowing specific QOL in PD patients selected for cZI DBS. The study constitutes an expansion of the previously published assessment of swallowing function in PD patients after cZI DBS²⁸. The aim of the current study was to describe the change in swallowing specific QOL in patients who have undergone cZI DBS and to compare the SWAL-QOL scores to those from a control group. The results indicated that both the PD and control groups had high swallowing specific QOL. The individual SWAL-QOL 'total scores' of four patients were somewhat higher after cZI DBS while the scores were slightly decreased in three other patients. The differences were however small

and only one patient reported a score below the cut-off for clinically relevant dysphagia⁴⁰. At group level, the PD patients rated their swallowing specific QOL as equally good preoperatively and 12 months after cZI DBS. This was true for both the SWAL-QOL 'total score' and the subscales. The ratings using the VA-scale were also at the same level preoperatively and 12 months after cZI DBS. These outcomes indicate that cZI DBS treatment does not have a clinically significant negative impact on swallowing specific QOL.

It is well established that PD patients often underestimate their swallowing problems when asked about swallowing function and this could possibly affect the result of the current study^{9,41}. However, the results from the current study are similar to the results from our earlier study, in which swallowing function was examined with a fiber endoscopic evaluation of swallowing function²⁸. In both studies, the PD patients had good overall swallowing function which was not negatively affected by cZI DBS.

There are no previous reports on cZI DBS and swallowing specific QOL-questionnaires. Silbergleit et al.²⁴ studied the swallowing function after STN DBS using the DHI, which is another validated QOL questionnaire³⁶. Silbergleit et al. report that patients' ratings on the 'functional', 'emotional', and 'total' subscales on the DHI were improved 12 months after STN-DBS, compared to baseline. These findings are in contrast to the absence of improvement measured by the 'physical' scale of DHI and their clinical examinations with video fluoroscopic examinations of swallowing function. Silbergleit et al. suggest that a placebo effect might improve the patients' self-reports.

Our study is the first to compare swallowing specific QOL in patients with DBS with controls. The controls reported a median SWAL-QOL total score of 100p while the median score in the PD group, 12 months after cZI DBS, was 95p. This indicates that the PD group is comparable to the controls with regard to the SWAL-QOL total score, as the cut-off for clinically significant

dysphagia is 86p⁴⁰. Despite this, the PD group reported a 'symptom' scale score of 82p and a 'burden' score of 88p, while the controls reported 98p on the 'symptom' subscale and 100p on the 'burden' subscale. The interpretation of these results is that while the PD patients report more dysphagia symptoms and suffer more from swallowing problems than the controls, they do not report worse swallowing specific QOL.

As in our study, Carneiro et al. and Leow et al.^{18,33} described SWAL-QOL and compared PD patients to controls. They report a clear deterioration in swallowing specific QOL measured by SWAL-QOL among PD patients (56-90p across subscales). The scores in our study ranged between 75 and 100. Carneiro et al. and Leow et al.^{18,33} also report significant differences between PD patients and controls for all subscales except for the 'sleep' subscale. However, the study by Carneiro et al.³³ has larger power than our study, which may explain some of the differences in the results. Leow et al.¹⁸ also report separate scores from early-stage PD patients, and the scores from that subgroup are similar to the results from our study. This indicates that swallowing specific QOL does not seem to be severely affected in early PD and in PD patients selected to cZI DBS. It is important to remember that our patient group consisted of PD patients selected for cZI DBS, which might affect the outcome of the study, as PD patients selected for DBS may differ from the PD population as a whole²⁸. PD patients in general have worse health related QOL than controls⁴². To our knowledge there are no available studies that report long time health-related QOL pre- and postoperatively in patients with cZI DBS. The current study and the **previous** study by our group are the only available swallowing studies that examine swallowing function and swallowing specific QOL in PD patients with cZI DBS. As both studies are small there is a need for studies with larger sample sizes that include FEES or video fluoroscopy as well as different measures of QOL.

The main limitation of this study is the small number of patients; a total of 18 patients were assessed for eligibility and nine patients could be included in the PD group. When interpreting the results, it is thus important to consider the consequences of low statistical power. In this context, it should be noted that Bonferroni corrections were not used, as this would have further lowered the statistical power. Instead, the use of the statistical concept 'effect size' in the analyses is a strength in our study, as it can highlight non-significant results with high estimated effect size, that needs to be addressed in future research. An additional analytical strength of the study is the prospective longitudinal design with a time frame from a preoperative baseline to a 12 months postoperative end-point as well as the use of controls.

Another limitation is that the patients filled out the SWAL-QOL questionnaire during a period with intense testing and adjustments between on/off medication and between DBS stimulation states. However, the conditions in which the patients completed the questionnaire were the same at the preoperative and postoperative visits.

Conclusion

In conclusion, the main findings from this study are that the patients selected for cZI DBS had a good self-reported swallowing specific QOL preoperatively, and that cZI DBS was shown not to have a negative effect on self-reported swallowing specific QOL 12 months postoperatively. In our sample, the PD patients with cZI DBS were similar to the controls in many of the subscales from SWAL-QOL. The outcomes from this study nevertheless have to be evaluated with caution since the study has a low statistical power, and our findings need to be confirmed in large sample sizes in order to be conclusive.

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