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Nutrition impact symptoms and the risk of malnutrition in people with Parkinson's disease: A cross-sectional study

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Abstract

Background: People with Parkinson's disease (PD) often experience symptoms that affect their ability to eat. This may contribute to weight loss and increased risk of malnutrition. The present study aimed to quantify the extent of nutrition impact symptoms (NIS) in the population and a scoring system of NIS was incorporated in the tool used to identify malnutrition.

Methods: In this cross-sectional study, members of the Norwegian Parkinson's Association, with any PD diagnosis and stage of illness, were invited to respond to an online 24-item questionnaire. Questions from two validated questionnaires, comprising the abridged Patient-Generated Subjective Global Assessment (aPG-SGA) and the Radboud Oral Motor Inventory for Parkinson's disease (ROMP), were adapted to an online format.

Results: The questionnaire was sent to 3047 members, of which 508 persons (17%) responded (61% men). In total, 59% were categorised as well-nourished, 34% at risk of malnutrition and 6.5% as malnourished. One quarter of all participants reported symptoms that affected food intake. The most frequent symptoms were constipation (14.2%) and dry mouth (13.4%). Malnourished participants reported a mean ± SD of 3.4 ± 1.4 symptoms versus 0.1 ± 0.3 per well-nourished participant. Malnourished participants had more swallowing problems than well-nourished participants, with a mean ± SD total ROMP score of 15.5 ± 6.0 versus 9.0 ± 2.9 ($p < 0.001$). As the number of points in the ROMP score increased by one, the points in the aPG-SGA score increased with 37% (95% confidence interval = 0.309–0.428).

Conclusions: Risk of malnutrition was largely related to NIS, especially dysphagia in people with PD. Symptoms affecting food intake should be systematically mapped and treated in conjunction with PD to prevent malnutrition.

KEYWORDS

dysphagia, malnutrition, nutrition impact symptoms, Parkinson's disease, PD, PG-SGA

Highlights

- Symptoms affecting the food intake, malnutrition risk and malnutrition are commonly seen in patients with Parkinson's disease (PD).
- The present study highlights the fact that, despite being common, malnutrition may be unrecognised, under-reported and untreated in PD patients.
- The results suggest that swallowing problems in PD are important for the development of malnutrition risk and malnutrition.

- Nutrition impact symptoms and weight loss should be systematically assessed in patients with PD.
- There is a need for more research investigating the relationship between malnutrition and nutritional impact symptoms in PD patients.

INTRODUCTION

It is reported that people with Parkinson's disease (PD) are more inclined to develop malnutrition than others of the same age without the disease. In previous studies,[1–4] between 6.3% and 55.2% of people with PD were found to be at risk of malnutrition, whereas 0.0%–25.5% are malnourished, depending on the disease severity, setting, age and differences in assessment tools. A larger proportion of women than men with PD are reported to experience unintentional weight loss (8.5% vs. 4.3%).[5] Both overnutrition and undernutrition are classified as subtypes of malnutrition. In the present study, the term malnutrition is used to mean synonymous with undernutrition.

Symptoms associated with PD and side effects of medication used to manage the disease may interfere with normal food intake and have been used as explanations for the risk of malnutrition seen in these people.[4,6] These symptoms are often referred to as nutrition impact symptoms (NIS).[7] People with PD often experience drooling and swallowing problems (dysphagia), which affect the act of eating,[8] whereas abdominal cramps, constipation and intestinal pain may contribute to poor appetite.[9] Cognitive decline and dementia may also lead to poor appetite through decreased smell and taste, reduced capacity to prepare meals and self-feeding difficulties.[10] Additionally, stiffness (rigidity), shivers (tremor), slow movements (bradykinesia) and postural instability may increase energy expenditure. People with PD tend to have a higher resting energy expenditure than healthy controls both in dopamine treated (ON) and untreated (OFF) states.[8,11,12] Increased energy expenditure in combination with reduced intake of food as a result of symptoms may lead to persistent deficiencies or imbalances in a person's energy intake. This may eventually lead to weight loss and malnutrition, especially in the late stage of the disease.[8] Studies investigating weight loss in relationship to severity of motor manifestations and appetite change in PD found that almost half of the patients experienced weight loss.[13]

Dysphagia is a common NIS in PD and a prevalence ranging from 35% to 100% is suggested, meaning that at least one third of PD patients experience dysphagia.[14] Despite being highly prevalent, changes in swallowing function may not initially exercise a decisive impact on food intake because of compensatory eating techniques; for example, sitting right or drinking while eating and adaptive mechanisms developing over time. Accordingly, one can stay at a manageable dietary intake and avoid remarkable weight loss for a relatively long time. Only when frank changes to swallowing and eating become apparent do threats to nutritional, hydration and respiratory health become apparent.[15]

Despite the knowledge about the prevalence of malnutrition and presence of several symptoms that may interfere with food intake, there is limited information about the contribution of NIS to malnutrition in PD. The present study therefore aimed to investigate and quantify the extent of NIS. Furthermore, because dysphagia appears to be common in this disease, we wanted to evaluate its association with malnutrition risk in community living people with PD in Norway.

METHODS

This cross-sectional study was conducted from October to November 2019 in cooperation with the Norwegian Parkinson's association (NPA). In Norway, there are approximately 8000 people with PD. In 2019, 3926 of these were members of NPA with a normal onset of the disease between 50 and 70 years and more men were diagnosed than women (2:1). These characteristics are highly comparable to the Norwegian PD population.[16] Members of any sex, ethnicity, PD diagnosis and stage of illness were considered eligible for inclusion in the study. The study was approved by the Regional Committees for Medical and Health Research Ethics (REC Protocol Approval 2019/865) and the NSD (reference code: 441317, 23.08.2019) and was carried out according to the World Medical Association Declaration of Helsinki (1964). Assessments were based on the Health Research Act §10.

Only members registered with an email address ($n = 3047$) were invited through an information letter to respond to an online 24-item questionnaire designed and distributed using the online questionnaire (nettskjema).[17] Nettskjema is provided by University's Center for Information Technology (USIT) at the University of Oslo and is a secure solution for data collection for small to large amounts of data. The Norwegian Centre for Research Data (NSD) Privacy Ombudsman and Regional Ethical Committees for Health Research (REK) recognise the questionnaire as secure. The email contained information about the study and its purpose and participants could withdraw at any point during completion of the questionnaire. After the questionnaire had been sent, it was not possible to withdraw. Computer

IP addresses were not stored in the system log of questionnaires, and it was therefore impossible to link to single responses. Thus, the study was performed anonymously. To maximise the number of responses, presentations of the study were held on two monthly, regional meetings of the association, encouraging participation. The questionnaire was open for one month (4 October to 4 November 2019), after which the results were downloaded and analysed. A reminder including a video message was sent to all participants after 28 days resulting in a boost in number of participants. The data collection process and background information about the members of the Norwegian Parkinson's Association are shown in Figure 1.

The questionnaire included items from three areas: background information, nutritional status and symptoms. Background information included gender, age, work situation, education level, type of PD-diagnosis, disease duration and medication. The questions regarding nutritional status and symptoms were made up of two previously validated questionnaires, abridged Patient-Generated Subjective Global Assessment (aPG-SGA)[18] and Radboud Oral Motor Inventory for Parkinson's disease (ROMP).[14] The aPG-SGA questionnaire gathers information about height, current weight, weight history, food intake, physical functioning and symptoms affecting food intake. Participants were also given an option of adding free text information if experiencing symptoms affecting food intake other than the ones mentioned in the questionnaire. The online tool had a limitation-function on height and weight: 130–220 cm and 30–180 kg, respectively. After completion, a total score was calculated and the participants were categorised: SGA-A (well nourished), SGA-B (moderately malnourished) or SGA-C (severely malnourished). All questions, except free-text item assessing 'other symptoms than the ones mentioned above', were considered obligatory to answer to be able to continue the questionnaire. This was done to avoid missing values.

The ROMP questionnaire was developed by the Radboud University Medical Centre in Nijmegen, the Netherlands.[19] The questionnaire is regarded as a reliable and valid instrument for evaluating patient-perceived problems with speech, swallowing and saliva control in PD.[14,19] Only the ROMP-swallowing subscale, which has shown high reliability and validity,[14,20] was used in the present study. The subscale consists of seven questions with a five-point Likert scale response option (1 = normal, 5 = worst score). The items probe for choking episodes during oral intake, limitations related to eating and drinking, difficulty swallowing pills, limitations regarding dining with others, concerns regarding swallowing difficulties and the degree of burden the person experiences secondary to their swallowing difficulties.

All statistical analyses were performed using SPSS, version 25 (IBM Corp.). $p < 0.05$ (two-sided) were considered statistically significant. For categorical data, frequencies and percentages were presented. Descriptive analyses were carried out, followed by bivariate analyses between different groups (gender and aPG-SGA category). Group differences were explored using a chi-squared test, or Fisher's exact test when not all cells had expected values >5. When one category contained ordinal data (2 × 2 table) and the expected cell count was not >5 for at least 80% of the cells, the linear-by-linear association test was used instead of the chi-squared test. Continuous data were checked for normality with the Kolmogorov–Smirnov test and interpreted in conjunction with visual inspection of QQ-plots and histograms.[21] Normally distributed data were presented as the mean ± SD, and an independent samples *t*-test was used to explore differences in means. Non-normally distributed data were presented as medians and interquartile range (25th to 75th percentiles) and the Mann–Whitney test was used to explore differences in medians between groups. When investigating mean differences between more than two independent groups (malnutrition groups), one-way analysis of variance (ANOVA) for the parametric test was applied. To investigate differences between each of the continuous variables, a post-hoc test was performed following the ANOVA. Nagelkerke's R^2 was applied to perform a linear

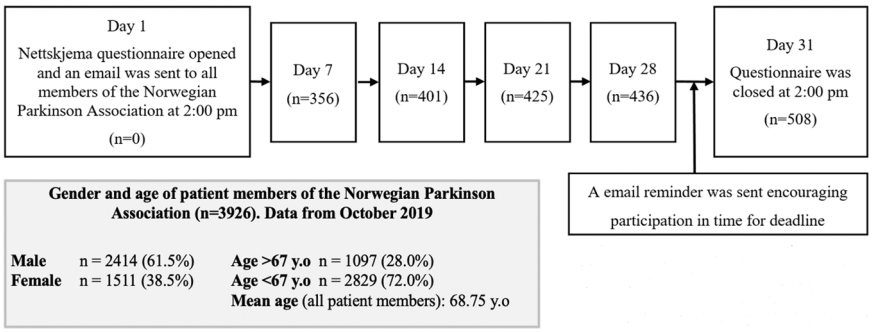

FIGURE 1 Flow diagram showing the data collection process. The questionnaire was open for 1 month (4 October to 4 November 2019). A reminder including a video message was sent to all participants after 28 days, resulting in a boost in number of participants. Gender and age on members of the Norwegian Parkinson Association are also shown.

regression.[22] Multiple linear regression analyses were performed to explore associations with nutritional status. In the regression model, total aPG-SGA score was the dependent variable and total ROMP score was the independent. Possible confounders were also included (age group and PD duration). As a result of the high number of cases in the present study, it was purposeful to include these factors because they are logical confounders related to both dysphagia and malnutrition, despite no significant impact on R^2. Because of the pilot nature of this study, no sample size calculation was performed. Missing values and extreme values were handled in advance by using the limitation-function in the questionnaire so they would not wrongly skew the data.

RESULTS

Subject characteristics

We consider that the majority of the 3047 patient members of the NPA received the mail and had the opportunity to reply. Five hundred and eight participants replied to the questionnaire and were included in the study. Based on this, the response rate was 16.7% and median response time was 8 min (interquartile range = 6.0–11.8). Subject characteristics are presented in Table 1.

In total, 62% of the participants were men. Eighty-five percent of participants were aged 60 years or older. Regarding time since receiving the diagnosis, all groups were well represented, ranging from <1 year to >10 years. Mean ± SD weight and body mass index (BMI) were 77.5 ± 15.8 kg and 25.2 ± 4.2 kg m^{-2}. Men reported a significantly higher mean BMI (25.8 ± 3.9 vs. 24.4 ± 4.5 kg m^{-2}, $p < 0.001$) and higher mean percentage weight loss the past six months (1.1% ± 3.0% vs. 0.3 ± 4.5%, $p = 0.026$) than women. Weight loss the past year was also slightly higher among men (1.5% ± 5.8%) than among women (0.5% ± 7.8%), although it was not statistically significant ($p = 0.098$). According to the BMI cut-offs set by the Norwegian Directorate of Health (60), 0.8% of the participants under 70 years were underweight, 47.0% were normal weight and 52.2% were overweight or obese. Among participants aged 70 years and older, 24.6% were underweight, 52.9% were normal weight and 22.5% were overweight or obese.

Malnutrition among participants

In total, 59.5% ($n = 302$) were categorised as well-nourished (A), 34.0% ($n = 173$) as 'at malnutrition risk' (B) and 6.5% ($n = 33$) as 'malnourished' (C). The category at malnutrition risk and malnourished were considered as a group of participants where nutritional intervention probably would be beneficial, leaving 41% in this category. The participants in these two groups, from now on referred to as 'at malnutrition risk' or 'malnourished', were older than the well-nourished but not statistically significant ($p = 0.095$). Detailed anthropometric measures for all participants and comparison between well-nourished, at risk and malnourished are presented in Table 2. Neither disease duration, nor PD diagnoses were associated with malnutrition.

Symptoms affecting food intake

In total, 24.6% of participants reported one or more NIS the past 2 weeks. Malnourished and at malnutrition risk participants reported on average a higher frequency of NIS than the well-nourished, 3.4 ± 1.4 symptoms per person compared to 0.1 ± 0.3, respectively. The most frequently reported NIS were constipation (14.2%), dry mouth (13.4%) and loss of appetite (10.2%), as shown in Figure 2.

Dysphagia and ROMP scores

Patients generally scored low on the ROMP swallowing subscale with a mean ± SD score of 10.3 ± 4.1 (Figure 3). None of the participants received a score above 30, which indicates very high swallowing problems, whereas 15.7% received a score between 15 and 30, indicating moderate to high problems.[19] When considering the ability to swallow food and concerns about the swallowing problems, 49% and 43%, respectively, reported problems. By contrast, approximately 28% and 21% reported problems swallowing pills or dining with others. On average, malnourished patients scored higher than participants at risk and well-nourished, with a mean score of 15.5, against, respectively, 11.6 and 9.0 ($p < 0.001$). The ROMP question with the highest score was the one regarding choking when eating and drinking; however, no significant difference was found between groups.

When adjusting for age and PD duration, the total ROMP score was significantly associated with increased aPG-SGA score. The outcome of the final multiple linear regression model is presented in Table 3. As the number of points in the ROMP-score increased by one, the points in the aPG-SGA score increased by 37% (95% confidence interval = 0.309–0.428). The variables included in the model explained 23% of the variance according to Nagelkerke's R^2.

DISCUSSION

To the best of our knowledge, this is the largest study to report on the extent of malnutrition in community dwelling people with PD ($n = 508$) and the first to do so in Norway.

TABLE 1 Characteristics of the study participants and differences by gender

	All participants ($n = 508$)	Men ($n = 310$)	Women ($n = 198$)	p value[a]
Weight (kg), mean (SD)	77.5 (15.8)	83.9 (13.9)	67.5 (13.2)	<0.001[c]
Height (m), mean (SD)	1.7 (0.1)	1.8 (0.1)	1.7 (0.1)	<0.001[c]
BMI (kg m^{-2}), mean (SD)[b]	25.2 (4.2)	25.8 (3.9)	24.4 (4.5)	<0.001[c]
Age categories, n (%)	–	–	–	0.078[d]
<49 years	12 (2.4)	5 (1.6)	7 (3.5)	–
50–59 years	64 (12.6)	35 (11.3)	29 (14.6)	–
60–69 years	188 (37.0)	111 (35.8)	132 (66.7)	–
70–79 years	210 (41.3)	132 (42.6)	78 (39.4)	–
>80 years	34 (6.7)	27 (8.7)	7 (3.5)	–
Diagnosis, n (%)	–	–	–	0.087[d]
Parkinson's disease	453 (89.2)	268 (86.5)	185 (93.4)	–
Parkinsonism	39 (7.7)	38 (12.3)	8 (4.0)	–
Other Parkinson diagnosis[e]	16 (3.1)	11 (3.5)	5 (2.5)	–
PD duration[f], n (%)	–	–	–	0.759[d]
<1 year	17 (3.3)	10 (3.2)	7 (3.5)	–
1–3 years	121 (23.8)	69 (22.3)	52 (26.3)	–
3–5 years	116 (22.8)	73 (23.5)	43 (21.7)	–
5–7 years	72 (14.2)	44 (14.2)	28 (14.1)	–
7–10 years	71 (14.0)	45 (14.5)	26 (13.1)	–
>10 years	111 (21.9)	69 (22.3)	42 (21.2)	–
Work situation, n (%)	–	–	–	0.427[d]
Retired	331 (65.2)	213 (68.7)	118 (59.6)	–
Disabled/out of work	97 (19.1)	51 (16.5)	46 (23.2)	–
Working	67 (13.2)	54 (17.4)	13 (6.6)	–
Other	13 (2.6)	9 (2.9)	4 (2.0)	–
Treatment, n (%)	–	–	–	0.211[d]
Tablets only	453 (89.2)	274 (88.4)	179 (90.4)	–
Brain stimulation therapy	43 (8.5)	26 (8.4)	17 (8.6)	–
Duodopa	9 (1.8)	8 (2.6)	1 (0.5)	–
Apomorphine pen/pump	3 (0.6)	2 (0.6)	1 (0.5)	–
Education, n (%)	–	–	–	0.456[d]
Elementary (1st to 10th grade)	40 (7.9)	25 (8.1)	15 (7.6)	–
High school (11th to 13th grade)	134 (26.4)	74 (23.9)	60 (30.3)	–
College (3–5 years)	235 (46.3)	145 (46.8)	90 (45.5)	–
College (>6 years)	67 (13.2)	46 (14.8)	21 (10.6)	–
Other	32 (6.3)	20 (6.5)	12 (6.1)	–

Abbreviation: PD, Parkinson's disease.

[a]Significance level, $p < 0.05$.

[b]Body mass index.

[c]Independent samples t test.

[d]Chi-squared test between men and women.

[e]Other Parkinson diagnosis includes corticobasal degeneration, multiple system atrophy, progressive supranuclear palsy and atypical parkinsonism/Parkinson plus.

[f]Time since initial diagnosis.

TABLE 2 Anthropometric measures according to categorisation of malnutrition by aPG-SGA[a] and mean ROMP score[j]

	All participants ($n = 508$)	Well-nourished ($n = 302$)	Malnutrition risk ($n = 173$)	Malnourished ($n = 33$)	p value[b]
Weight (kg), mean (SD)	77.5 (15.8)	77.7 (14.8)	76.8 (15.1)	78.6 (25.6)	0.766[c]
Weight loss (%), mean (SD)					
6 months	0.8 (3.7)	0.0 (2.8)	2.1 (3.8)	4.1 (5.4)	<0.001[c]
1 year	1.2 (6.7)	+0.7 (4.3)[h]	3.4 (8.5)	5.9 (8.1)	<0.001[c]
BMI (kg m^{-2}), mean (SD)	25.2 (4.2)	25.27 (3.8)	25.2 (4.1)	25.5 (7.6)	0.923[c]
BMI categories, n (%)	–	–	–	–	0.051[i]
Underweight[d]	62 (12.2)	29 (9.6)	24 (13.8)	9 (27.8)	–
Normal[e]	253 (49.8)	156 (84.8)	86 (49.7)	11 (33.3)	–
Overweight[f]	138 (27.2)	88 (29.1)	42 (24.3)	8 (24.2)	–
Obese[g]	55 (10.8)	29 (9.6)	21 (12.1)	5 (15.2)	–
Questions from ROMP[j]	**Mean (SD[k])**	**Mean (SD[k])**	**Mean (SD[k])**	**Mean (SD[k])**	**p value[b,l]**
1. Choking	1.5 (0.9)	1.3 (0.7)	1.7 (1.0)	2.4 (1.3)	<0.001
2. Swallowing fluids	1.4 (0.7)	1.3 (0.5)	1.6 (0.9)	2.2 (1.2)	<0.001
3. Swallowing food	1.6 (0.7)	1.4 (0.5)	1.8 (0.7)	2.2 (1.0)	<0.001
4. Swallowing pills	1.3 (0.6)	1.2 (0.5)	1.5 (0.7)	1.9 (1.0)	<0.001
5. Eat with others	1.3 (0.7)	1.2 (0.5)	1.5 (0.8)	2.1 (1.3)	<0.001
6. Concerns	1.7 (0.9)	1.4 (0.7)	1.9 (1.0)	2.5 (1.1)	<0.001
7. Bother	1.5 (0.7)	1.3 (0.6)	1.7 (0.8)	2.1 (1.0)	<0.001
Overall score seven items	10.3 (4.1)	9.0 (2.9)	11.6 (4.3)	15.5 (6.0)	<0.001

Abbreviations: aPG-SGA, abridged Patient-Generated Subjective Global Assessment; ROMP, Radboud Oral Motor Inventory for Parkinson's disease.

[a]Measured by the aPG-SGA.

[b]Significance level $p < 0.05$.

[c]One-way analysis of variance for parametric test for mean difference between malnutrition groups.

[d]Cut-off <18.5 for persons <70 years and <22 for persons >70 years.

[e]Cut-off 18.5–24.9 for persons <70 years and 22–27 for persons >70 years.

[f]Cut-off 25.0–29.9 for persons <70 years and 27.1–29.9 for persons >70 years.

[g]Cut off >30.

[h]Weight gain.

[I]Chi-squared test for more than two categorical variables (row × column table).

[j]ROMP.

[k]SS.

[l]Kruskal–Wallis for non-parametric test between more than two independent groups.

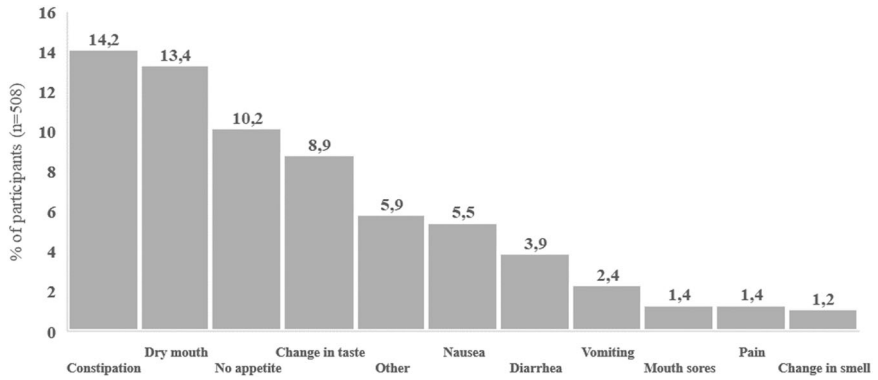

FIGURE 2 Percentage of symptoms affecting food intake among all participants ($n = 508$). Participants could pick several symptoms.

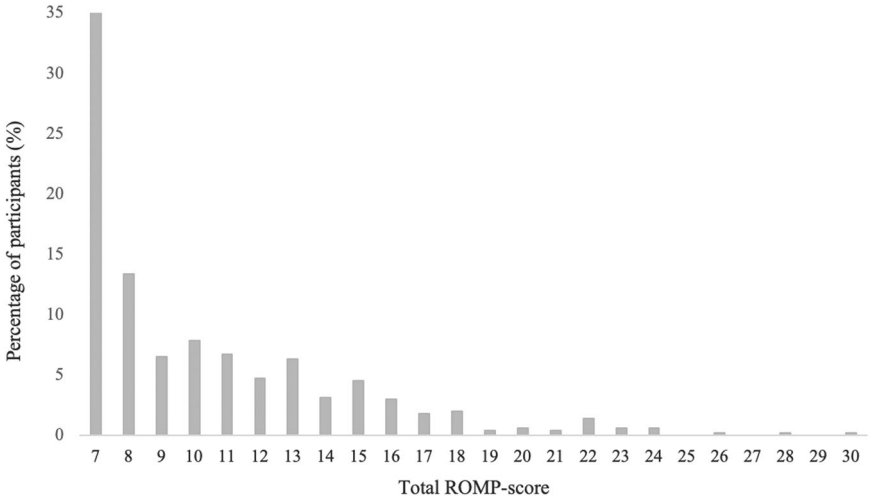

FIGURE 3 Distribution of total ROMP score for participants ($n = 508$) measured by the Radboud Oral Motor Inventory for Parkinson's Disease (ROMP).

TABLE 3 Multiple regression model describing the relationship between aPG-SGA score[a] and ROMP score[b] unadjusted and adjusted for age and PD duration using estimates

	Unadjusted			Adjusted		
Explanation variables[f]	***B* (SE)[c]**	***p* value[d]**	**95% CI[e] for *B***	***B* (SE)**	***p* value**	**95% CI for *B***
ROMP	0.368 (0.030)	0.000	0.309, 0.428	0.367 (0.515)	0.000	0.306, 0.427
Age group	0.317 (0.161)	0.050	0.000, 0.634	0.218 (0.143)	0.129	0.063, 0.499
PD duration	0.157 (0.090)	0.082	0.020, 0.334	−0.016 (0.081)	0.843	0.175, 0.143

Note: $R2 = 0.229$. Dependent variable: aPG-SGA score.

Abbreviations: aPG-SGA, abridged Patient-Generated Subjective Global Assessment; CI, confidence interval; PD, Parkinson's disease; ROMP, Radboud Oral Motor Inventory for Parkinson's Disease.

[a]Measured by the aPG-SGA.

[b]Measured by applying ROMP.

[c]SE.

[d]Significance level $p < 0.05$.

[e]Confidence interval (margin of error in effect).

[f]Age group and PD duration were both entered as categorical variables with >2 groups.

Thirty-four percent of the participants were at risk of developing malnutrition and 6.5% were malnourished. The malnourished participants reported more NIS than the well-nourished (mean ± SD = 3.4 ± 1.4 symptoms per person vs. 0.1 ± 0.3, respectively). Additionally, scores on the ROMP-swallowing subscale showed that about half of the participants had problems swallowing solids. A one-point rise in the total ROMP score was associated with a 37% increase in aPG-SGA score, emphasising the importance of dysphagia for development of malnutrition in patients with PD.

The percentage of participants at risk of malnutrition and malnourished (40.5%) in the present study was within the highest range of the results from previous studies showing a prevalence ranging between 6.3% and 55.5%.[1–4] We did not find that disease duration was associated with malnutrition, nor was one or several of the other PD diagnoses associated with increased malnutrition risk, which has been reported in former studies.[23,24] However, our results indicated that dysphagia was a considerable contributor to malnutrition because 23% ($R^2 = 0.229$) of the variation in the aPG-SGA score could be explained by dysphagia when controlling for age and disease duration. One can only speculate which other factors mattered in relation to nutritional status in the present sample, but it is reasonable to consider that other disease-prone factors and geriatric syndromes may have influenced.[25] The use of disease duration as a proxy of disease stage may have been a limitation as Hohn and Yahr staging is more specific when studying a PD population.

Approximately half of the participants experienced some changes in their swallowing function, even though none reported a high dysphagia burden. In previous studies, the prevalence of subjective dysphagia in PD is reported to be higher than in the present study and highest in people with multiple system atrophy (MSA) (73%) and progressive supranuclear palsy (PSP) (83%), probably as a result of additional neuropathology.[26] Also in the present study, participants with MSA and PSP reported a higher median

ROMP score than the other PD diagnoses, but this was not statistically significant. A probable explanation is the very few participants in each diagnostic group. It is also seen that clinical dysphagia often occurs later in the disease course.[26] Participants who have had PD for both a relatively short and long time were well represented in this study, although we did not find any differences between the two groups.

The ROMP question with the highest score was the one regarding choking when eating and drinking. This finding is similar to a previous study in community-dwelling older people (aged >65 years).[27] One in four showed suspected dysphagia and coughing when eating was the most common symptom. They also found increased prevalence of dysphagia with age suggesting age-related physiological changes to impact eating/swallowing functions. This may also have been the case in the present study where approximately half (48%) were aged ≥70 years. Early identification of preclinical dysphagia may be a key in preventing or mitigating malnutrition in both home dwelling older adults people with PD.[28] Furthermore, severe dysphagia should always be evaluated with a swallowing assessment to check for causes other than PD, especially because dysphagia in PD is generally mild.[19,29]

The most frequently reported NIS were constipation (14.2%), dry mouth (13.4%) and loss of appetite (10.2%). The first and latter symptoms were also some of the most reported symptoms in the study by Sheard *et al.*[4] in addition to dysphagia. The percentage of participants with change in smell was unexpectedly low because olfactory dysfunction is among the earliest non-motor features of PD.[30] If participants had symptoms but did not experience them as a barrier to food intake, then these may not be reported in the questionnaire, suggesting the need of more specific instruments than aPG-SGA to measure specific phenomena in a trial. Disturbance of autonomic function of the gastrointestinal tract in PD are well documented,[31] including especially delayed gastric emptying and constipation. It has been proposed that these symptoms precede the PD motor symptoms, suggesting that they may be present before initial diagnosis.[32] Because no information about the non-responding participants was available, the reason for non-responding is not known. This is a limitation of the present study because these patients could have differed from those who were included (selection bias). It is conceivable that people who voluntarily enroll in a health study are not representative of the general population because on average they are healthier. Overall, the frequency of NIS symptoms appears to be relatively high in the present study and may have played an important role for the development of risk of malnutrition and malnutrition in this study. This finding emphasises the importance of systematic symptom assessment and the early identification and treatment of symptoms that may affect nutritional status.[7]

The strength of this cross-sectional questionnaire-based study was the high number of respondents and the use of validated patient reported outcome measures (i.e. PROMs).[32] Although there was a high number of responders, the response rate was only 16.7%, which may challenge the representativity. Despite this, it is reasonable to assume that the responders were representative of the NPA members and the Norwegian PD population. They were highly comparable in relation to age (mostly >60 years), gender distribution (more men, 2:1 ratio), proportion of participants with atypical parkinsonism compared to PD (approximately 5%–10% atypical) and source of PD sample (mostly community-dwelling).[16] It is off course possible that family members or caretakers may have answered on behalf of the person with PD. This may have affected the result because this does not comply with the principle of PROMs, that is, 'measurements of any aspect of a patient's health status that come directly from the patient'.[32]

Even if it is recognised that the person's own descriptions of physical symptoms and their severity are the primary data for symptom assessment,[33] the present study may have been prone to bias because self-reported body weights were collected. Problems relate to participants not knowing their weight (recall bias) and lack of weight measures under standardised conditions (in the morning, fasting, after first toilet visit, same weight scale, repeated measures), which is necessary for reliable data.[34] Self-reported weight measures reveals under-reporting in the general adult population, especially in overweight and obese participants.[35] Men also tend to over-report their height and weight, whereas women over-report their height and under-report their weight.[36]

The most recent Norwegian version of the aPG-SGA[18] was used to identifying risk of malnutrition or malnutrition. The aPG-SGA is a shorter version of the SGA,[37,38] which is regarded as a gold standard for measuring nutritional status with high validity and reliability. However, the aPG-SGA is mainly validated in community-dwelling cancer patients[18,39,40] and in haemodialytic patients[41]; therefore, one may raise questions about how accurate it is when used in a PD population. Our aim was to quantify the extent of NIS in the population and a scoring system of NIS is incorporated in the tool used to identify malnutrition. Dysphagia is one of the categories in this tool but, because generic instruments may not be sufficiently sensitive when studying specific phenomena and the severity of the symptoms was not accessed, we choose to use the ROMP-swallowing subscale, which has shown high reliability and validity in person with PD.[14] The online format of the questionnaires may also have been a source of bias as the original aPG-SGA and ROMP questionnaire are in paper format.

Clinical consequences

According to ESPEN guidelines of clinical nutrition in neurology, it is recommended to monitor nutritional status and provide nutritional therapy in people with PD.[42] Our findings verify these recommendations by showing that NIS and the presence of malnutrition risk are relatively common. This indicates that optimal symptom management may be important for preventing development of malnutrition in people with PD. ESPEN guidelines also recommend conducting regular screening for dysphagia in patients with PD. Our results support this recommendation because approximately half of the participants had general concerns about dysphagia and a rise in dysphagia was strongly associated with a decline in nutritional status.

CONCLUSIONS

The present study explored nutrition and dysphagia status, as well as symptoms, in 508 patients with PD using self-reported data. Malnutrition risk, malnutrition and NIS were prevalent because (i) one in three participants found to be at malnutrition risk; (ii) half of the participants reporting to have problems swallowing solids; (iii) three in five reporting to have concerns about their swallowing function; (iv) one quarter of participants were assessed to have symptoms affecting their food intake; and (v) malnourished participants reported 34 times more symptoms than well-nourished participants. This study highlights the fact that malnutrition is common in patients with PD and remains unrecognised, underreported and untreated. Whether the identification and proper management of NIS can prevent malnutrition and improve quality of life deserves further exploration.

AUTHOR CONTRIBUTIONS

All authors were responsible for the conception and design. Julie Sørbø Helliesen was responsible for recruitment, data collection, performed the data analysis, interpreted the data and wrote the paper. Asta Bye analysed and interpreted data and contributed to the writing process. Ragnhild Stenshjemmet Støkket contributed to recruitment and data collection and was involved in the writing process. Ida Kristiansen and Hilde Kristin Brekke contributed to the writing process. All authors reviewed and approved the final manuscript submitted for publication.

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CONFLICTS OF INTEREST

The authors declare that there are no conflicts of interest.

ETHICAL STATEMENT

The study was in accordance with national law, institutional ethical standards and the 1964 Helsinki Declaration and its later amendments. The Regional Committee for Medical and Health Research Ethics, Middle Norway approved the study 2019/865.The study was also approved by the NSD (441317, 23.08.2019).

TRANSPARENCY DECLARATION

The lead author affirms that this manuscript is an honest, accurate and transparent account of the study being reported. The reporting of this work is compliant with STROBE guidelines. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

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