Title: 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.

Objective: Our aim was to quantify the extent of nutrition impact symptoms (NIS) in the population and a scoring system of NIS is 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, abridged patient-generated subjective global assessment (aPG-SGA) and 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 categorized as well-nourished, 34% at risk of malnutrition and 6.5% as malnourished. A quarter of all participants reported symptoms that affected food intake. The most frequent symptoms were constipation (14.2%) and dry mouth (13.4%). On average (SD), malnourished participants reported 3.4 (1.4) symptoms as opposed to 0.1 (0.3) per well-nourished participant. Malnourished participants had more swallowing problems than well-nourished, a mean 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% CI 0.309-0.428).

Conclusion: 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: Parkinson's Disease, malnutrition, dysphagia, nutritional risk, weight loss, symptoms, food intake, PG-SGA, aPG-SGA, ROMP

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 studies (1-4), between 6.3% to 55.2% of people with PD were found to be at risk of malnutrition while 0.0% to 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. For this article, the term malnutrition will be 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) while 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. It is shown that people with PD tend to have a higher resting energy expenditure than healthy controls both in dopamine treated (ON state) and untreated state (OFF state) (8, 11, 12). Increased energy expenditure in combination with reduced intake of food due to 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 35-100% is suggested, meaning that at least one third of every PD patient experiences dysphagia (14). Despite being highly prevalent, changes in swallowing function may not initially exercise a decisive impact on food intake due to compensatory eating techniques e.g. sitting right or drinking while eating and adaptive mechanisms developing over time. This way, 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, 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 purpose of this study was therefore to investigate and quantify the extent of NIS. Furthermore, since dysphagia seems to be common in this disease, we wanted to evaluate its association with malnutrition risk in community living people with PD in Norway.

Materials and Methods

This cross-sectional study was conducted from October to November 2019 in cooperation with the Norwegian Parkinson's association (NPA). In Norway there is about 8000 people with PD. In 2019, 3926 of these were members of NPA. The members were highly comparable to the Norwegian PD population with a normal onset of the disease between 50 and 70 years and more men diagnosed than women (2:1)(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 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) recognize the questionnaire as secure. The email contained information about the study and its purpose and that they could withdraw at any point during completion of the questionnaire. After the questionnaire was sent, it was not possible to withdraw. The 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 maximize 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 (October 4th to November 4th in 2019), after which the results were downloaded and analyzed. 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 illustrated 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 categorized: 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 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 to evaluate 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 5-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 IBM SPSS Statistics 25. P-values (2. sided) <0.05 were regarded as 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 Chi-square test, or Fisher's exact test when not all cells had expected values >5. When one category contained ordinal data (2x2 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-square 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 means and standard deviations, and the independent samples t-test was used to explore differences in means. Non-normally distributed data were presented as medians and interquartile range (25th-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), the One-way Anova for parametric test was applied. To investigate differences between each of the continuous variables, a Post Hoc test was performed following the Anova. The Nagelkerke´s R2 was applied to perform a linear 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). Due to the high number of cases it this study, it was purposeful to include these factors as they are logical confounders related to both dysphagia and malnutrition, despite no significant impact on R2. 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 reckon 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 minutes (IQR: 6.0-11.8). Subject characteristics are presented in table 1. The responders were comparable with the NPA members in relation to age (mostly >60 years), gender distribution (more men, 2:1 ratio), proportion of participants with atypical parkinsonism compared to PD (approx. 5-10% atypical), and source of PD sample (mostly community-dwelling).

A total of 62% of the participants were men. Eighty-five percent of participants were 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 BMI were 77.5 (15.8) kg and 25.2 (4.2) kg/m2. Men reported significantly higher mean BMI (25.8, SD: 3.9 versus 24.4, SD: 4.5, $p<0.001$) and higher mean percentage weight loss the past six months (1.1%, SD: 3.0 versus 0.3%, SD: 4.5, $p=0.026$), than women. Weight loss the past year was also slightly higher among men (1.5%, SD: 5.8) than among women (0.5%, SD: 7.8), however not statistically significant ($p=0.098$). According to the BMI cut-offs set by the Norwegian Directorate of Health (60), were 0,8% of the participants under 70 years underweight, 47.0% normal weight and 52.2 % overweight or obese. Among participants 70 years and older, 24.6% were underweight, 52.9% normal weight and 22.5 % overweight or obese.

Malnutrition among participants

In total, 59.5% (n=302) were categorized 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 two 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 score of 10.3 (SD: 4.1) (figure 3). None of the participants received a score above 30 which is indicating very high swallowing problems while 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. In contrast, about 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 between the groups was found.

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 with 37% (95% CI 0.309-0.428). The variables included in the model explained 23% of the variance according to Nagelkerke's R2.

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. 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 versus 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, emphasizing 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 this 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 that one or several of the other PD diagnoses were associated with increased malnutrition risk, which has been seen in former studies (23, 24). However, our

results indicated that dysphagia was a considerable contributor to malnutrition since 23% (R2 = 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 believe 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.

About half of the participants experienced some changes in their swallowing function even though none reported a high dysphagia burden. In previous studies, 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 due to 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 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, but we did not find any difference 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 (age >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 presents study where about half (48%) were 70 years or above. 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 also to check for causes other than PD, especially since 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, since olfactory dysfunction is among the earliest nonmotor features of PD (30). If participants had symptoms but did not experience them as a barrier to food intake, 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 discussed that these symptoms precede the PD motor symptoms suggesting they may be present before initial diagnosis (32). As no information about the non-responding participants was available, the reason for non-responding is not known. This is a limitation of the study since these patients could have differed from the ones who were included (selection bias). It is conceivable that people who voluntarily enroll in a health study are not representative of the general population as they are on average 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 emphasizes the importance of systematic symptom assessment and 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 that validated patient reported outcome measures (PROMs)(32) were used. Although a high number of responders the response rate was only 16.7% which

may question the representativity. Despite this it is reasonable to assume the responders were representative of the NPA members and the Norwegian PD population. They were highly comparable in relation to age, gender distribution, proportion of participants with atypical parkinsonism compared to PD and source of PD sample (mostly community-dwelling). It is off course possible that family members or caretakers have answered on the behalf of the person with PD. This may have affected the result as this does not comply with the principle of PROMs i.e. "measurements of any aspect of a patient's health status that come directly from the patient"(32).

Even if it is recognized that the person's own descriptions of physical symptoms and their severity are the primary data for symptom assessment (33), the study may have been prone to bias as self-reported body weight, were collected. Problems are related to participants not knowing their weight (recall bias), lack of weight measures under standardized 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 underreporting in the general adult population, especially in overweight and obese participants (35). Men also tend to overreport their height and weight, while women overreport their height and underreport 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 to measure nutritional status with high validity and reliability. However, the aPG-SGA is mainly validated in community-dwelling cancer patients (18, 39, 40) and in hemodialytic 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 since generic instruments may not be sensitive enough when studying specific phenomena and the severity of the symptoms were 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 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 since about half of the participants had general concerns about dysphagia and a rise in dysphagia was highly associated with decline in nutritional status.

Conclusion

This study explored the nutrition and dysphagia status, as well as symptoms in 508 patients with PD using self-reported data. Malnutrition risk, malnutrition and NIS were prevalent as (1) one in three participants found to be at malnutrition risk, (2) half of the participants reporting to have problems swallowing solids, (3) three in five reporting to have concerns about their swallowing function, (4) one courter of the participants assessed to have symptoms affecting their food intake, and (5) malnourished participants reported 34 times more symptoms than well-nourished. This study highlights the fact that malnutrition is

common in patients with PD and remains unrecognized, under-reported and untreated. Whether identification and proper management of NIS can prevent malnutrition and improve quality of life deserves further exploration.

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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Conflict of Interest:

The authors have no conflict of interest to report.

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Authors contributions

All authors were responsible for the conception and design. JSH were responsible for recruitment, data collection, performed the data analysis, interpreted the data, and wrote the paper. AB analyzed and interpreted data and contributed to the writing process.

RSS contributed to recruitment and data collection and was involved in the writing process. IK and HKB contributed to the writing process. All authors reviewed and approved the final manuscript.

Ethical approval

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).

References

1. Paul BS, Singh T, Paul G, Jain D, Singh G, Kaushal S, et al. Prevalence of Malnutrition in Parkinson's Disease and Correlation with Gastrointestinal Symptoms. Ann Indian Acad Neurol. 2019;22(4):447-52.
2. Roos DS, Oranje OJM, Freriksen AFD, Berendse HW, Boesveldt S. Flavor perception and the risk of malnutrition in patients with Parkinson's disease. J Neural Transm (Vienna). 2018;125(6):925-30.
3. Tomic S, Pekic V, Popijac Z, Pucic T, Petek M, Kuric TG, et al. What increases the risk of malnutrition in Parkinson's disease? J Neurol Sci. 2017;375:235-8.
4. Sheard JM, Ash S, Mellick GD, Silburn PA, Kerr GK. Malnutrition in a sample of community-dwelling people with Parkinson's disease. PloS one. 2013;8(1):e53290.
5. Durrieu G, Llau ME, Rascol O, Senard JM, Rascol A, Montastruc JL. Parkinson's disease and weight loss: A study with anthropometric and nutritional assessment. Clinical Autonomic Research. 1992;2(3):153-7.
6. Foltynie T BRA, Lewis S. Parkinson's disease: your questions answered: Churchill Livingstone; 2003 2003.
7. Kubrak C, Olson K, Jha N, Jensen L, McCargar L, Seikaly H, et al. Nutrition impact symptoms: Key determinants of reduced dietary intake, weight loss, and reduced functional capacity of patients with head and neck cancer before treatment. Head & neck. 2009;32:290-300.
8. Capecci M, Petrelli M, Emanuelli B, Millevolte M, Nicolai A, Provinciali L, et al. Rest energy expenditure in Parkinson's disease: role of disease progression and dopaminergic therapy. Parkinsonism Relat Disord. 2013;19(2):238-41.
9. Helsedirektoratet AE. Nasjonale faglige retningslinjer for forebygging og behandling av underernæring. Oslo: Helsedirektoratet, Avdeling ernæring; 2009. 74 s. p.
10. Keller HH. Improving food intake in persons living with dementia. Ann N Y Acad Sci. 2016;1367(1):3-11.
11. Markus HS, Cox M, Tomkins AM. Raised resting energy expenditure in Parkinson's disease and its relationship to muscle rigidity. Clin Sci (Lond). 1992;83(2):199-204.
12. Levi S, Cox M, Lugon M, Hodkinson M, Tomkins A. Increased energy expenditure in Parkinson's disease. Bmj. 1990;301(6763):1256-7.
13. Abbott RA, Cox M, Markus H, Tomkins A. Diet, body size and micronutrient status in Parkinson's disease. European Journal of Clinical Nutrition. 1992;46(12):879-84.
14. Presotto M, Olchik MR, Kalf JG, Rieder CRM. Translation, linguistic and cultural adaptation, reliability and validity of the Radboud Oral Motor Inventory for Parkinson's Disease - ROMP questionnaire. Arq Neuropsiquiatr. 2018;76(5):316-23.
15. Lindqvist C, Slinde F, Majeed A, Bottai M, Wahlin S. Nutrition impact symptoms are related to malnutrition and quality of life - A cross-sectional study of patients with chronic liver disease. Clin Nutr. 2020;39(6):1840-8.
16. Alves G, Muller B, Herlofson K, HogenEsch I, Telstad W, Aarsland D, et al. Incidence of Parkinson's disease in Norway: the Norwegian ParkWest study. J Neurol Neurosurg Psychiatry. 2009;80(8):851-7.
17. UiO. Hjelp of veiledninger til Nettskjema [web page article]. Universitetet i Oslo; 2019 [cited 2019 27.08.19]. Available from: https://www.uio.no/tjenester/it/applikasjoner/nettskjema/hjelp/.
18. Stoyanoff L, Leung E, Robinson J, Brezden-Masley C, Darling P, Gabrielson D, et al. Validation of the Abridged Patient-Generated Subjective Global Assessment as a Screening Tool for Malnutrition in an Outpatient Oncology Setting. Journal of the American Dietetic Association. 2009;109(9, Supplement):A11.

19. Kalf JG, Borm GF, de Swart BJ, Bloem BR, Zwarts MJ, Munneke M. Reproducibility and validity of patient-rated assessment of speech, swallowing, and saliva control in Parkinson's disease. Arch Phys Med Rehabil. 2011;92(7):1152-8.
20. Kalf J, de Swart B, Bloem BR, Munneke M. 1.155 Development and evaluation of a swallowing severity questionnaire for Parkinson's disease (ROMP-swallowing). Parkinsonism & Related Disorders. 2007;13:S48.
21. Odd O. Aalen AF, Tron Anders Moger, Ida Scheel, Eva Skovlund, Marit B. Veierød. Statistiske metoder i medisin og helsefag. Oslo: Gyldendag Akademisk; 2018.
22. Corporation I. R-Squared Measures ibm.com: IBM Corporation 1989; 2016 [Available from: https://www.ibm.com/docs/en/spss-statistics/24.0.0?topic=model-pseudo-squared-measures.
23. Cereda E, Barichella M, Pedrolli C, Pezzoli G. Low-protein and protein-redistribution diets for Parkinson's disease patients with motor fluctuations: A systematic review. Movement Disorders. 2010;25(13):2021-34.
24. Barichella M, Cereda E, Pezzoli G. Major nutritional issues in the management of Parkinson's disease. Mov Disord. 2009;24(13):1881-92.
25. Lauretani F, Maggio M, Silvestrini C, Nardelli A, Saccavini M, Ceda GP. Parkinson's disease (PD) in the elderly: an example of geriatric syndrome (GS)? Arch Gerontol Geriatr. 2012;54(1):242-6.
26. Umemoto G, Furuya H. Management of Dysphagia in Patients with Parkinson's Disease and Related Disorders. Intern Med. 2019.
27. Igarashi K, Kikutani T, Tamura F. Survey of suspected dysphagia prevalence in home-dwelling older people using the 10-Item Eating Assessment Tool (EAT-10). PLoS One. 2019;14(1):e0211040.
28. Madhavan A. Preclinical Dysphagia in Community Dwelling Older Adults: What Should We Look For? American Journal of Speech-Language Pathology. 2021;30:833-43.
29. Wintzen AR, Badrising UA, Roos RA, Vielvoye J, Liauw L, Pauwels EK. Dysphagia in ambulant patients with Parkinson's disease: common, not dangerous. Can J Neurol Sci. 1994;21(1):53-6.
30. Haehner A, Hummel T, Reichmann H. Olfactory loss in Parkinson's disease. Parkinsons Dis. 2011;2011:450939.
31. Pfeiffer RF. Gastrointestinal dysfunction in Parkinson's disease. Lancet Neurol. 2003;2(2):107-16.
32. Chaudhuri KR, Healy DG, Schapira AH. Non-motor symptoms of Parkinson's disease: diagnosis and management. Lancet Neurol. 2006;5(3):235-45.
33. Ishaque S, Karnon J, Chen G, Nair R, Salter AB. A systematic review of randomised controlled trials evaluating the use of patient-reported outcome measures (PROMs). Quality of Life Research. 2019;28(3):567-92.
34. Stein RJ, Haddock CK, Poston WSC, Catanese D, Spertus JA. Precision in weighing: a comparison of scales found in physician offices, fitness centers, and weight loss centers. Public health reports (Washington, DC : 1974). 2005;120(3):266-70.
35. Maukonen M, Mannisto S, Tolonen H. A comparison of measured versus self-reported anthropometrics for assessing obesity in adults: a literature review. Scand J Public Health. 2018;46(5):565-79.
36. Merrill RM, Richardson JS. Validity of self-reported height, weight, and body mass index: findings from the National Health and Nutrition Examination Survey, 2001-2006. Preventing chronic disease. 2009;6(4):A121-A.
37. Makhija S, Baker J. The Subjective Global Assessment: a review of its use in clinical practice. Nutr Clin Pract. 2008;23(4):405-9.

38. Ottery FD. PG-SGA pt-global.org United States of America: Pt-Global Platform; 2020 [cited 2020 16.04]. Available from: http://pt-global.org/?page_id=13
39. Gabrielson DK, Scaffidi D, Leung E, Stoyanoff L, Robinson J, Nisenbaum R, et al. Use of an abridged scored Patient-Generated Subjective Global Assessment (abPG-SGA) as a nutritional screening tool for cancer patients in an outpatient setting. Nutr Cancer. 2013;65(2):234-9.
40. Abbott J, Teleni L, McKavanagh D, Watson J, McCarthy A, Isenring E. Patient-Generated Subjective Global Assessment Short Form (PG-SGA SF) is a valid screening tool in chemotherapy outpatients. Supportive Care in Cancer. 2016;24.
41. Campbell KL, Bauer JD, Ikehiro A, Johnson DW. Role of Nutrition Impact Symptoms in Predicting Nutritional Status and Clinical Outcome in Hemodialysis Patients: A Potential Screening Tool. Journal of Renal Nutrition. 2013;23(4):302-7.
42. Burgos R, Breton I, Cereda E, Desport JC, Dziewas R, Genton L, et al. ESPEN guideline clinical nutrition in neurology. Clin Nutr. 2018;37(1):354-96.

Tables:

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, mean kg (SD)	77.5 (15.8)	83.9 (13.9)	67.5 (13.2)	<0.001[c]
Height, mean, m (SD)	1.7 (0.1)	1.8 (0.1)	1.7 (0.1)	<0.001[c]
BMI[b], mean, kg/m^2 (SD)	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)	
Brainstimulation 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 (1-10th grade)	40 (7.9)	25 (8.1)	15 (7.6)	
High school (11-13th 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)	

[a] Significance level $p<0.05$, [b] Body Mass Index, [c] Independent samples t-test, [d] Chi-square test between men and women, [e] Other Parkinson diagnosis includes: Corticobasal degeneration (CBD), Multiple system atrophy (MSA), Progressive supranuclear palsy (PSP) and Atypical parkinsonism/Parkinson Plus, [f] Time since initial diagnosis

Table 2: Anthropometric measures according to categorization 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)					
six months	0.8 (3.7)	0.0 (2.8)	2.1 (3.8)	4.1 (5.4)	<0.001[c]
one year	1.2 (6.7)	+0.7 (4.3)[h]	3.4 (8.5)	5.9 (8.1)	<0.001[c]
BMI, kg/m2, 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[bl]
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

[a] Measured by the abridged Patient-Generated Subjective Global Assessment (aPG-SGA), [b] Significance level p<0.05, [c] One-way Anova 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-square test for more than two categorical variables (rxc table) [j] Radboud Oral Motor Inventory for Parkinson's Disease (ROMP) [k] Standard deviation, [l] Kruskal Wallis for nonparametric test between more than two independent groups

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

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

[a] Measured by the abridged Patient-Generated Subjective Global Assessment (aPG-SGA)

[b] Measured by applying Radboud Oral Motor Inventory for Parkinson's Disease (ROMP)

[c] Standard error

[d] Significance level $p \leq 0.05$

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

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

Figures:

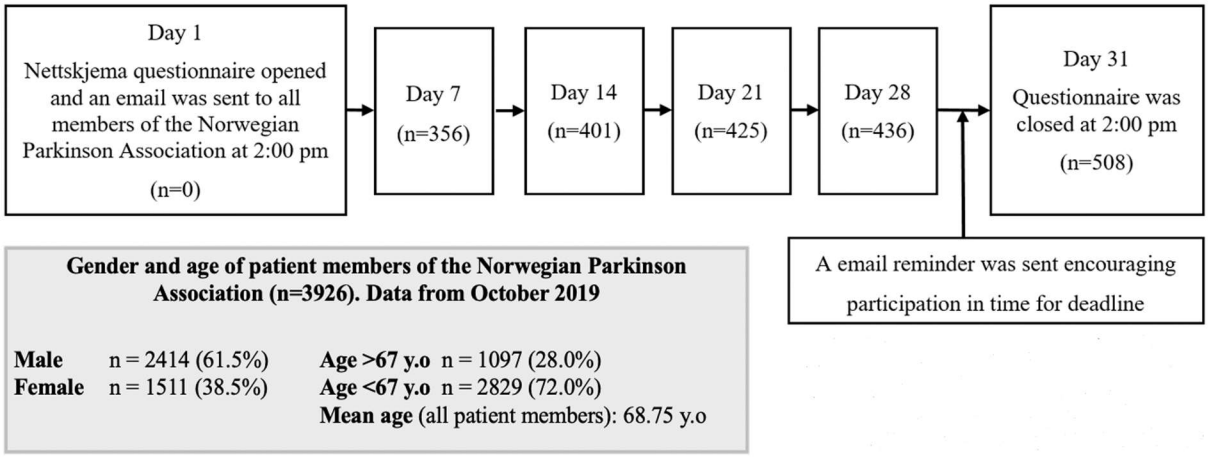

Figure 1: Flow diagram showing the data collection process. The questionnaire was open for one month (October 4th to November 4th in 2019). A reminder including a video message was sent to all participants after 28 days resulting in a boost in number of participants. The figure also includes gender and age on members of the Norwegian Parkinson Association (yellow box).

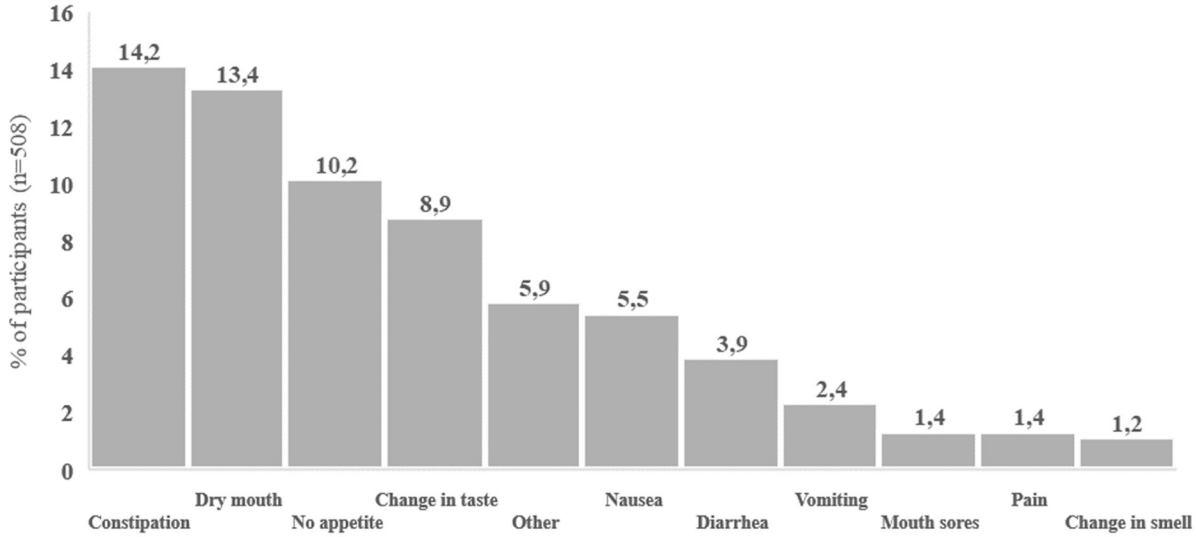

Figure 2. **Percentage of symptoms affecting food intake** among all participants (n=508). Participants could pick several symptoms.

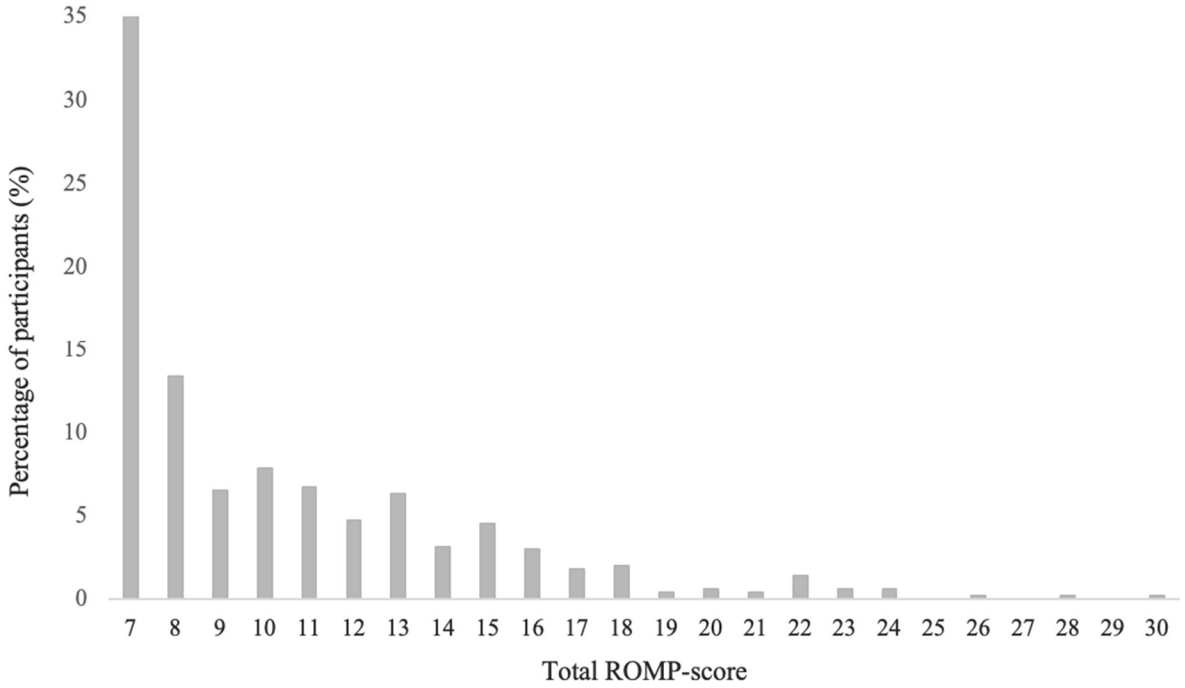

Figure 3: **Distribution of total ROMP-score** for participants (n=508 measured by the Radboud Oral Motor Inventory for Parkinson's Disease (ROMP).