Symptoms affecting food intake and the risk of malnutrition in people with Parkinson's disease

A cross-sectional study

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Oslo, 15th May 2020

Julie Sørbø Helliesen

Abstract

Background: People with Parkinson's disease (PD) often experience symptoms that affect their ability to eat as well as cardinal symptoms that increase energy expenditure (rigidity, tremor, bradykinesia). These symptoms may contribute to weight loss and increased risk of malnutrition.

Objectives: The aim of this cross-sectional study was to investigate the prevalence of malnutrition risk, malnutrition and nutrition impact symptoms, like dysphagia among people with PD, who are patient members of the Norwegian Parkinson's association.

Methods: All registered patient members at the Norwegian Parkinson's Association were invited to respond to an online 24-item questionnaire via their registered email address. Background questions, as well as questions from two validated questionnaires were adapted to an online format (Nettskjema). The abridged patient-generated subjective global assessment (aPG-SGA) was used to measure nutritional status and The Radboud Oral Motor Inventory for Parkinson's disease (ROMP) was used to measure dysphagia.

Results: The questionnaire was sent to 3047 registered members, of which 508 persons (17%) responded within the deadline (61% men). Of these, 59% were categorized as well-nourished (aPG-SGA A), 34% at risk of malnutrition (aPG-SGA B) and 6.5% as malnourished (aPG-SGA C). Malnourished participants had more swallowing problems than well-nourished, respectively, a mean total ROMP score of 15.5 (6.0) versus 9.0 (2.9) ($p < 0.001$). About half of all participants had difficulty swallowing solids, as well as concerns about these complaints. By adjusting for age and PD duration, the ROMP score was significantly associated with aPG-SGA score ($p<0.001$). A quarter of all participants reported symptoms that affected food intake, and the most frequently reported symptom being constipation (14.2%) and dry mouth (13.4%). On average, 3.4 (1.4) symptoms per malnourished participant were reported, as opposed to 0.1 (0.3) symptoms per well-nourished participant.

Conclusion: Risk of malnutrition seems to be relatively common in people with PD. The prevalence was largely related to a number of self-reported symptoms, especially dysphagia. Symptoms affecting food intake should be systematically mapped in conjunction with PD to prevent malnutrition. Future research investigating the relationship between PD, malnutrition and dysphagia is needed.

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List of abbreviations

PD	Parkinson’s disease
ESPEN	European Society for Clinical Nutrition and Metabolism
SGA	Subjective Global Assessment
PG-SGA	Patient Generated Subjective Global Assessment
aPG-SGA	Abridged Patient Generated-Subjective Global Assessment, Short-form SGA
ROMP	Radboud Oral Motor Inventory for Parkinson’s Disease
BMI	Body Mass Index
DRM	Disease-related malnutrition
PROM	Patient reported outcome measurement
MNA	Mini nutritional assessment
MUST	Malnutrition universal screening tool
IQR	Interquartile range (25th–75th -percentiles)
SD	Standard deviation
MSA	Multi system atrophy
CBD	Corticobasal degeneration
PSP	Progressive supranuclear palsy
GLIM	Global Leadership Initiative on Malnutrition

1 Introduction

Parkinson's disease (PD) is a chronic and progressive condition of the nervous system, leading to dopamine deficiency in the brain. Dopamine is required for voluntary movement, and lack of this neurotransmitter can cause a variety of symptoms (1). The prevalence of PD varies from 100-150 people per 100,000 and it is therefore assumed that about 7-8000 people have PD in Norway. PD debut age is often between 50 and 70 years, and is more frequent among men than women (2). In general, the prevalence of the disease increases with increasing age. Therefore, as the population grows older, the number of people with Parkinson's disease is expected to double by 2040. PD is characterized by the cardinal signs of stiffness (rigidity), shivers (tremor), slow movements (bradykinesia) and postural instability (1). In studies, these symptoms have shown to increase energy expenditure in people with PD (3). Other clinical symptoms of importance are gait disturbances, disturbance in speech (dysarthria), drooling (sialorrhea), cramps, pain, swallowing disturbance (dysphagia), intestinal constipation, sleep disturbances, cognitive decline (bradyphrenia), depression and dementia. Some symptoms, like dysphagia, can affect eating function, hence food intake. Dysphagia is a common finding in PD patients and the prevalence ranges from 35-100% depending on assessment, meaning at least one third of every PD patient (4). If one has an increased energy demand at the same time as a low food intake, it can adversely affect energy balance, which may result in weight loss and an increased risk of malnutrition. Despite knowledge of the Parkinson's symptoms that may affect food intake and the increased risk of weight loss and malnutrition, there has been little attention to this topic in Norway. Little is known about the prevalence of nutrition impact symptoms in PD as well as the relationship between these and the risk of weight loss and malnutrition. The purpose of this thesis will be to investigate the prevalence of nutrition impact symptoms, like dysphagia, and the risk of malnutrition among people with Parkinson's disease in Norway.

1.1 Malnutrition

1.1.1 Definition and diagnosing malnutrition

World Health Organization (WHO) refers to malnutrition as deficiencies, excesses or imbalances in a person's intake of energy and/or nutrients. The term malnutrition covers two

broad groups of conditions. One is 'undernutrition'—which includes stunting (low height for age), wasting (low weight for height), underweight (low weight for age) and micronutrient deficiencies or insufficiencies (a lack of important vitamins and minerals)(5). Malnutrition can also be defined simply as nutritional imbalance (6). However, there is currently no universal consensus on its definition, but Meier & Stratton defines malnutrition as "a state of nutrition in which a deficiency or excess (or imbalance) of energy, protein and other nutrients cause measurable adverse effects on tissue/body form (body shape, size, composition), body function and clinical outcome" (7). On the basis of starvation, disease or aging, European Society for Clinical Nutrition and Metabolism (ESPEN) has chosen to define malnutrition as "a state resulting from lack of uptake or intake of nutrition leading to altered body composition (decreased fat free mass) and body cell mass leading to diminished physical and mental function and impaired clinical outcome from disease" (8). Both overnutrition and undernutrition are classified as subtypes of malnutrition. For the purpose of this thesis, the term malnutrition will be synonymous with undernutrition.

Diagnosing malnutrition is recommended to be a two-step process in the clinical setting (9). First, patients must be screened and identified to be "at nutritional risk" by a validated screening tool. For those at risk, further assessment is then performed to potentially set a malnutrition diagnosis. For the time being, the diagnosis of malnutrition in Norway is based on the diagnostic codes in The International classification of diseases and related health problems (ICD-10) and the national guidelines (10). The Patient Generated Subjective Global Assessment (PG-SGA) category B and C were also recently (2019) added as malnutrition diagnostic criteria (table 1). The national guidelines recommend performing screening of all hospitalized patients for nutritional risk at admission and then weekly with one of the following tools: Mini Nutritional Assessment (MNA), Malnutrition Universal Screening Tool (MUST), Nutritional Risk Screening 2002 (NRS 2002). The PG-SGA is also a recommended tool for screening and assessing malnutrition (11). This tool also exists in a short version, called the abridged PG-SGA (aPG-SGA). For this thesis, the aPG-SGA is used for assessing risk of malnutrition and malnutrition. The most recent criteria for assessing nutritional status is Global Leadership Initiative on Malnutrition (GLIM) (12). Unlike the other screening tools, GLIM takes inflammation into account as a cause of malnutrition, however it has not been validated yet.

Table 1: National diagnostic criteria of malnutrition. Adopted from national guidelines for prevention and treatment of malnutrition by the Norwegian Directorate of Health (10).

	E44.00 Moderate malnutrition	E43.00 Severe malnutrition
1	Weight loss > 10% last 3-6 months or >5% last 2 months	Weight loss > 15% last 3-6 months or >5% last month
2	BMI[b] < 18.5 kg/m^2 (>70 years: BMI < 20)	BMI < 16 kg/m^2 (>70 years: BMI < 18.5)
3	BMI < 20.5 kg/m^2 (>70 years: BMI < 22) and weight loss > 5% last 6 months	BMI < 18.5 kg/m^2 (>70 years: BMI < 20) and weight loss > 5% last 3 months
4	Food intake < 50% last week and acute/chronic inflammatory conditions	PG-SGA[c] Category C
5	PG-SGA Category B	

[a] Malnutrition is diagnosed when one of the five criteria is fulfilled.
[b] Body mass index.
[c] Patient-Generated Subjective Global Assessment.

1.1.2 Etiology and prevalence

The causes for malnutrition are numerous. A distinction is made between malnutrition caused by hunger, for example during war and natural disasters, and malnutrition caused by illness as illustrated in figure 1 (13). The latter one is called disease-related malnutrition (DRM) and is the most common cause of malnutrition in developed countries.

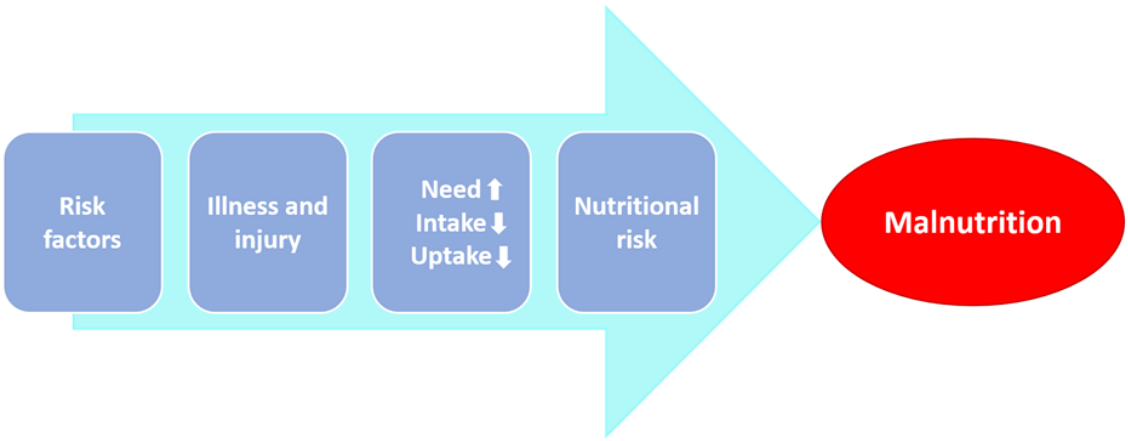


Figure 1. Model of the development of disease-related malnutrition. The arrows symbolize either a reduction (downwards) or an increase (upwards).

DRM can also be classified according to inflammation; DRM without inflammation (e.g. upper digestive obstruction resulting in dysphagia) and chronic DRM with inflammation (e.g. inflammatory bowel disease or cancer resulting in loss of muscle mass). ESPEN also refers to a third malnutrition category without disease that include acute disease- or injury-related malnutrition (e.g. major infections or burns resulting in a proinflammatory state and increased metabolic demand) (figure 2) (8). Available literature does not provide a concrete answer as

to which category PD belongs to. It is convenient to assume that PD patients are at risk of developing malnutrition due to alternative mechanisms; DRM without inflammation and cachexia, a disease-triggered malnutrition in which inflammation is not among the etiologic mechanisms. However, inflammation is also suggested to be more or less central to PD pathogenesis (14). Although the exact etiology of malnutrition remains uncertain, there is inevitability about malnutrition being associated with PD.

Low food intake is an essential problem occurring in DRM, as a disease itself, the medical treatment in combination with the disease or symptoms accompanying a disease (like diarrhea and nausea) can result in a reduced appetite (10). Advanced aging *per se* is commonly known to contribute to DRM without inflammation (8). Malnutrition among the elderly is often a result of inadequate food intake, food choices that lead to dietary deficiencies, illness that causes increased nutrient requirements, poor nutrient absorption, increased nutrient loss, or a combination of these factors (8, 15). The risk of malnutrition is high especially among elderly patients in nursing homes, in hospitals and in homes receiving support from the home-based service in Norway (16). In hospitalized patients, the hospital setting itself can aggravate the situation due to obligatory fasting before medical testing or adverse hospital routines like timing, frequency and palatability of meals (17). In Norway, it is estimated that every third hospitalized patient is malnourished or at nutritional risk (18, 19). The prevalence is even higher among hospitalized elderly ≥70 years ranging from 40-60% (19-21). The prevalence of malnutrition in people with PD has not been assessed on the Norwegian population previously, hence the importance of this topic.

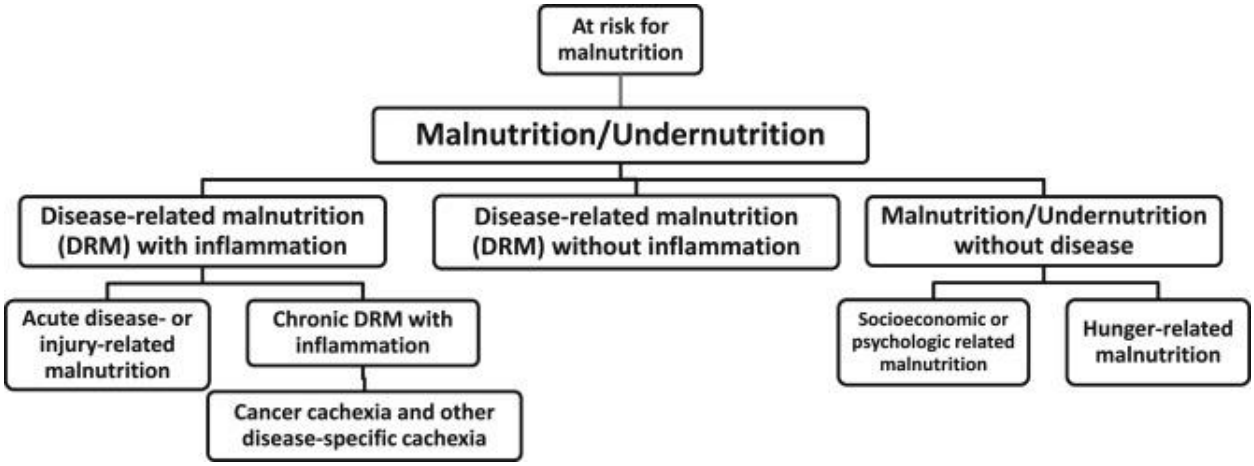


Figure 2: **Diagnosis tree of malnutrition**; from at risk for malnutrition, basic definition of malnutrition to etiology-based diagnoses (8)

1.2 Parkinson’s disease

Parkinson’s disease (PD) is a chronic neurodegenerative disease that results in the gradual loss of neurons due to abnormal deposition of the alpha-synuclein protein especially in the so-called black substance (substrantia nigra) in the brain stem (1). The degeneration mainly results in deficiency of dopamine, a signal substance that is important for maintaining normal motor function (22). The miscommunication between brain and muscles causes movement disturbances. The movement disturbances become more pronounced in prolonged illness (2).

The pattern of the patient's symptoms is diverse and setting a correct diagnosis can be difficult. Parkinsonism is a clinical syndrome in which at least two of four cardinal signs are present: resting tremor, rigidity, bradykinesia and postural changes. Parkinsonism is in most cases caused by PD. However the cause is Atypical Parkinsonism/Parkinson’s plus in about 10-15% of the cases, (23). Atypical PD/Parkinson’s plus is an umbrella term for progressive diseases that present with some of the typical PD symptoms, but that generally do not respond well to drug treatment with Levodopa (24). Examples of these diseases are Progressive supranuclear palsy (PSP), Multi system atrophy (MSA) and Corticobasal degeneration (CBD) (25). The prevalence is estimated to be approximately 300 patients with PSP, 200 patients with MSA and 60 patients with CBD in Norway, and these are considered rare diseases (2).

The motor symptoms presented in classical PD have an impact on total energy expenditure. On one hand, persistent tension in the muscles and efforts to preform movements require extra energy (3). At the same time, many are exhausted of slow movements, chewing problems, difficulty swallowing, and therefore eat less than usual (26). Fatigue is also a common finding that may impact food intake. A study from Akershus University Hospital in Norway found that fatigue was significantly higher in PD patients compared with the general population (27). These aspects can cause insufficient food intake and several research studies had revealed this to be a problem among people with PD (26, 28). Over time, too little energy and nutrients can increase the risk of developing malnutrition, which in turn can lead to reduced general health state, reduced muscle strength and a weakened immune system.

Common symptoms and ailments of Parkinson's disease and a description of how they may affect food intake are listed below. The symptoms include:

- *Tremors, slow movements and muscle stiffness* can interfere with most of the hand functions and make it difficult to hold cutlery and cup/glass, cut food and lead food to the mouth (28).
- *Constipation* due to weakened muscles of the digestive system and/or medications can cause loss of appetite due to one feeling full and unwell, but also cause nausea, vomiting, pain and diarrhea (26).
- *Dry mouth* can be a side effect of drugs making it difficult to chew and swallow food. The taste ability is often impaired or distorted. In addition, reduced or altered salivary secretion causes the protective mechanisms in the oral cavity not to function properly. This increases the risk of tooth decay and oral cavity inflammation (28).
- *Disturbed sense of taste and smell* is caused by both disease and medication. The food does not taste the same as before, which often leads to poor appetite (28).
- *Chewing and swallowing problems* are common in PD. Normal swallowing from the oral cavity to the stomach takes approx. 10 seconds, but with dysphagia this can take considerably longer. PD patients can experience that they are worn out before being fully satisfied after a meal (26).

The prevalence of people with PD in Norway is 110.9 per 100,000 inhabitants according to a prevalence-study conducted in the county of Rogaland (29). The total age-adjusted prevalence was 102.4 per 100,000, and gender-adjusted to be 120.9 per 100,000 men and 89.9 per 100,000 women. Age-adjusted prevalence appears to be higher for rural compared to urban areas. The female gender is associated with lower risk of developing PD and slightly delayed motor onset, however gender appears to have no impact on the severity of PD (30).

PD is viewed as a slowly progressive neurodegenerative disease developed from a complicated interplay of genetics and environment that starts years before receiving the diagnosis. In particular, diagnostic tests allowing definitive diagnosis at early stages of disease do not exist. The presence of corrupted dopaminergic neurons in the midbrain (substansia nigra pars compacta degeneration) and abnormal protein deposits (Lewy pathology) at post-mortem pathological examination is considered the gold standard for diagnosing PD (31).

1.2.1 Malnutrition in Parkinson's disease

Malnutrition is an essential problem, especially in the late stage of PD. Lowering of body mass is seen in 30% of patients, and the risk of malnutrition or malnutrition is seen in 60% and 24% respectively, according to a preliminary report from 2018 (32). Several common symptoms, both motor and non-motor, are associated with an increased risk of weight loss and malnutrition. Results from a review of existing literature that considers the prevalence of malnutrition risk and malnutrition among people with PD are presented in table 2. The prevalence of malnutrition risk varied from 6.3% to 45.3%, and malnutrition from 0.0% to 25.5%. Further information about the review can be found under paragraph 3.5 in this thesis.

Table 2: Prevalence of malnutrition and prevalence of malnutrition risk in PD patients using definitions from different screening tools in the studies

Reference	Study type	PD sample source	Sample size (males)	Mean age, years ± SD[g]	Screening tool[abc]	Malnutrition prevalence among people with PD	
						At risk of malnutrition[e]	Malnourished[f]
Paul SB et al. (2019) (33)	Cohort	Outpatient clinic, Northern India	75 (40)	63.0 (10.5)	MNA	45.3%	12.0%
Roos Ds et al. (2018)(34)	Cross-sectional pilot	Outpatient clinic, Amsterdam, The Netherlands	63 (n/a)[d]	65.9 (8.5)	MUST	6.3%	None
Tomic S et al. (2017)(35)	Cross-sectional	Outpatient clinic, Osijek, Croatia	96 (54)	70.2 (8.6)	MNA	55.2%	8.3%
Kim SR et al.(2016)(36)	Cross-sectional	Outpatients, Seoul, South-Korea	93 (45)	61.2 (10.1)	MNA	26.5%	25.5%
Van Seijn J et al. (2014)(37)	Cross-sectional	Outpatient clinic in Leeuwarden, The Netherlands	102 (54)	76.4 (6.0)	MNA	20.5%	2.0%
Laudisio A et al. (2014)(38)	Cross-sectional	Geriatric day hospital in Rome, Italy	75 (42)	71.5 (7.5)	MNA	35.0%	None
Fereshtenejad SM et al.(2014)(39)	Case-control	Outpatients at the Iran University and Stockholm, Sweden	143 (96)	61.4 (10.5)	MNA	25.9%	2.1%
Sheard JM et al. (2013) (40)	Cross-sectional	Community-dwelling, Brisbane, Australia	125 (74)	69.0 (6.1)	PG-SGA	15.0%	None
Barichella M et al. (2013) (41)	Cross-sectional	Hospitalized in Milano, Italy	208 (141)	67.8 (9.2)	MUST	17.2%	5.0%
Wang G et al. (2010) (42)	Cross-sectional pilot	Outpatient clinic in Ruijin Hospital, Shanghai, China	117 (75)	67.5 (8.9)	MNA	19.7%	1.7%
Jaafar AF et al. (2010)(43)	Cross-sectional	Community-dwelling, North-East England	136 (59)	74.6 (8.9)	MUST	23.5%	8.1%
Barichella M et al. (2008) (44)	Cross-sectional	Outpatients at the neurological institute, Italy in 2004 and follow up in 2007	61 (37)	70.5 (5.5)	MNA	From 22.9% to 34.3%	None/no change

[a] MNA = Mini nutritional assessment, [b] MUST = malnutrition universal screening tool, [c] PG-SGA = Patient-generated subjective global assessment, [d] (n/a) = not available / no answer, [e] Classified as "at malnutrition risk" if: score of 17≤MNA≤23.5, MUST = 1 (medium risk) or SGA-B, [f] Classified as "malnourished" if: score of MNA<17, MUST = 2 (high risk) or SGA-C, [g] Standard deviation (Range)

Increased energy expenditure

The PD symptom triad of tremor, rigidity and bradykinesia are motor symptoms, which can increase energy expenditure. An Italian cross-sectional study aimed to ascertain the relationship between resting energy expenditure (REE), disease duration and BMI (Body Mass Index) in order to determine possible predictors of weight loss in people with PD (3). People with PD tend to have a higher REE than healthy controls both in dopamine treated (ON state) and untreated state (OFF state) (3, 45, 46).

Implementing regular physical activity is recommended and may exhibit potential benefits (47, 48). Physical activity may have a positive impact on disease course and symptoms, such as balance, walking speed, strength and posture. During exercise circulation increases, which improve transportation of medicines to their goal destination for functioning. Increased circulation along with movement of the abdomen promotes digestion, which is often slow due to both illnesses and medications (48). Physiotherapists recommend both high intensity aerobic training as well as anti-Parkinson training. Rock Steady Boxing is an evidence-based, anti-Parkinson specific training used in several countries, including Norway (49). The will powered movements used in boxing to achieve precise punches are a great exercise that counteracts bradykinesia.

Body weight, BMI and weight loss

A negative energy balance will result in decreased body weight. PD is associated with an increased risk of weight loss and lower BMI relative to healthy controls (44, 50-55). Weight loss in PD can occur at any stage, most commonly in later phases (3). An Argentinian study investigated the prevalence of weight loss in PD patients in relation to severity of motor manifestations and appetite change. The results shows that weight loss occurred in almost half of the study population as a consequence of disease progression (56). Individuals with PD experiencing unintended weight loss has been documented to be 52% by Abbot and colleagues (57). In relation to gender, women experience greater weight loss than men (8,5% vs 4,3% respectively) (58). The reason for weight loss in PD is not clear, but it is either a result of reduced energy intake, increased energy expenditure or both. BMI is a marker for nutritional status since it can be used to determine whether a person is underweight, normal weight, overweight or obese (59). The elderly (>70 years) has other cut-offs for BMI (normal

weight ranges from 22-27) as fairly higher BMIs are advantageous in terms of being able to withstand illness and to be able to perform a successful rehabilitation (10, 60). BMI can be used in clinical settings and in research (59).

Dysphagia

Dysphagia is defined as difficulty or discomfort in swallowing, and is often a symptom of disease (61). Common symptoms of dysphagia include choking or coughing, drooling, reduced mastication, difficulty controlling solids or liquids in the mouth, nasal regurgitation, food lodging in the pharynx, and aspiration (matter enters the lungs). Dysphagia is a risk factor for malnutrition, dehydration and pneumonia secondary to aspiration, but can also affect all over quality of life due to social and psychosocial consequences including reduced mental health, self-esteem and social isolation (62-64).

In PD patients, neurogenic dysphagia is a major risk factor for the development of pneumonia, and the most frequent cause of death in this patient group (65, 66). A Japanese cross-sectional study found that one in four independent and one in two dependent individuals (aged 65 years or older) showed suspected dysphagia with perceivable symptoms like coughing, difficulties in swallowing solids and psychological burden (67). Dysphagia can cause discomfort, weight loss because of low caloric intake, difficulties taking pills and oral medication and even dehydration due to avoidance of drinking. Physicians may not be consulted until the patient has reaches an advanced stage of dysphagia causing medical problems (68).

Dysphagia is an expected symptom of neurodegenerative disease (69). Dysphagia is considered a common symptom in PD and the prevalence ranges from 35-100% (4, 70-72). Despite being highly prevalent, dysphagia is chronically under-reported. An episode of aspiration pneumonia is often the time of initial diagnosis (73). When frank changes to swallowing and eating become apparent, the PD patients may still not recognize that they are experiencing difficulties. One explanation to this clinicopathological discrepancy may be due to compensatory and adaptive mechanisms allowing patients to devise their own behavioral adaptation. This way, one can stay at a manageable dietary intake and avoid remarkable weight loss. Given this low recognition, it is essential that clinicians probe deeper than simply asking “do you have trouble swallowing?”. Changes in swallowing function may not initially

exercise a decisive impact at first, but can later pose threats to nutritional, hydration and respiratory health and psychosocial quality of life.

The progressive degenerative of PD may affect swallowing at all stages of PD however, dysphagia is a relatively late clinical problem in course of the disease in spite of early pathological changes in brain structure (73). There are currently no studies on the prevalence of dysphagia and other nutrition related Parkinson's symptoms in the Norwegian population. To treat a potential health problem, awareness of the health problem is essential and that is why this topic is of interest.

Not only are non-motor symptoms like dysphagia affecting nutritional status, but also the motor symptoms, such as tremor, rigidity and bradykinesia. An elevated energy expenditure with simultaneous reduced food intake may lead to a negative energy balance and potentially weight loss and malnutrition. This is part of the reason for believing PD patients are particularly vulnerable to malnutrition compared to the general population.

Gastrointestinal dysfunction

Dysphagia is not the only PD-related symptom affecting nutrition status. The most common non-motor feature of PD is gastrointestinal dysfunction, as illustrated in figure 3, which includes nausea, diarrhea, mouth pain, altered taste sensation, no appetite, vomiting, constipation, dry mouth and altered scent (74, 75). The aforementioned symptoms can all adversely affect food intake, which can lead to weight loss and increased risk of malnutrition.

PD motor and non-motor functions, disease duration and severity are related to nutritional status. Natural aging or illness affects the hunger center in the brain resulting in reduced desire for food, at the same time as one feels full quickly after food intake or even before a meal often in combination with nausea. These symptoms are caused by disturbances in the gastrointestinal tract and may lead to inadequate food intake. If experienced, it is important to compensate by eating small and frequent meals with high nutrient density. Nutritional status assessment should be a standard approach in the PD treatment (76).

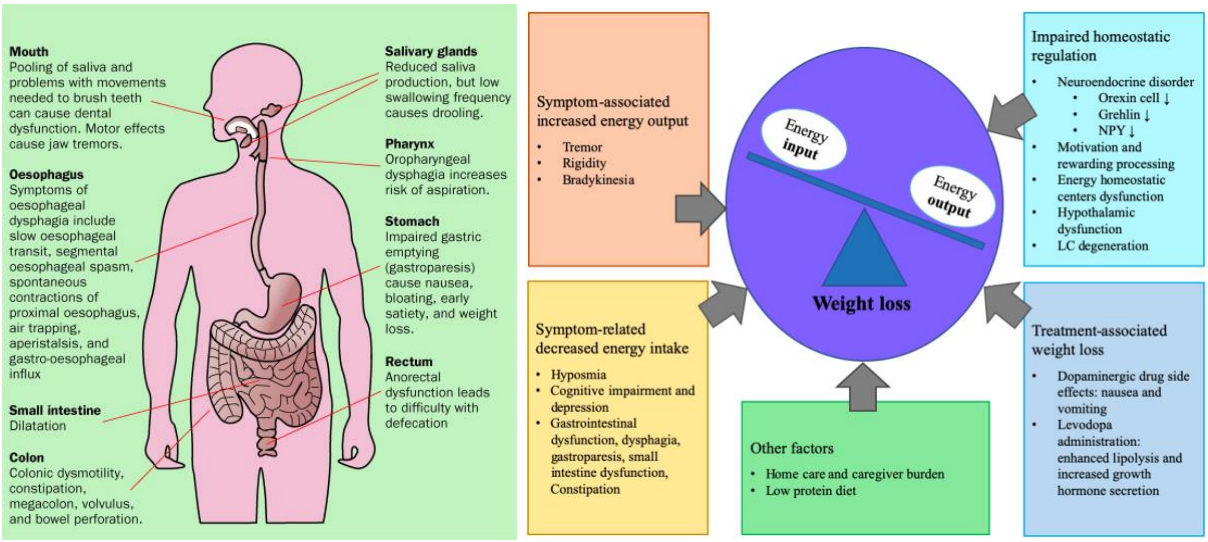


Figure 3. Left: Overview of gastrointestinal dysfunction in PD (74). Right: determinants of weight loss in PD (77)

1.2.2 Nutrition and Parkinson's disease

ESPEN guidelines of neurology

According to ESPEN, nutritional status should be monitored in PD patients, especially in view of changes in body weight and need for supplementation of vitamin D, folic acid and vitamin B12 (strong consensus, 91%). The Hoehn and Yahr scale is a system for describing how the symptoms of PD progress and includes stage 1 (Unilateral involvement only) to 5 (Wheelchair bound or bedridden unless aided) (78). All PD patients with a Hoehn & Yahr-stage above two or weight loss, low BMI, drooling, dementia or signs of dysphagia should be screened for dysphagia in an on-phase (strong consensus, 95%) where a questionnaire or water swallowing test is recommended (strong consensus, 91%). There are also side effects of PD drugs that can affect nutritional status of homocysteine and vitamin D (strong consensus, 95%). For PD patients experiencing high motoric fluctuation, it is recommended to take levodopa (a protein and precursor to dopamine) medication at least 30 minutes before a meal, and these should also follow a protein-distributed diet to maximize the effect of levodopa (strong consensus, 90%)(79). The current evidence and consensus-based guideline from ESPEN addresses clinical questions about best medical nutritional therapy to patients with neurological disorders, including PD (79).

Although one knows that this patient group has a number of ailments and symptoms that can potentially affect food intake, there is less knowledge about how widespread these nutrition-related symptoms are and how they are related to weight loss and malnutrition. For health professionals, this is important knowledge which can help ensure good nutritional status and integrate medical nutrition as a part of the treatment in this patient group (10).

Protein redistributed diet

Today's focus in relation to nutrition and PD has been on the benefits of a so-called protein redistributed diet. Proteins in food compete with medicines, such as the well-known levodopa medicine, for uptake in the brain. Levodopa is a protein built up of amino acids and a precursor of dopamine with antiparkinsonian properties (80). Amino acids are transported from the bloodstream into the brain via the same transport molecules. Competition can occur between the amino acids, where levodopa becomes the losing party (81). Some may therefore notice a deteriorating of the symptoms after eating a protein-rich meal. Studies have shown that patients who have uneven effect of the medication may benefit from a protein-redistributed diet. The principle of the diet is not to reduce the intake of protein, but redistribute protein during the day (1, 81-83).

The Norwegian Parkinson's association finds that many PD patients tend to change their diet on their own without fully understanding the indications or principles behind a protein-redistributed diet. The change in diet is often related to a lower intake of protein, which increases the risk of consuming too little protein, too little energy, weight loss and eating unilaterally (82). A protein-redistributed diet is best suited for patients who are well-nourished and experiencing uneven fluctuation in medication effect. Protein redistributed diet requires nutritional knowledge. Everyone who changes their diet in this way may benefit from advice and support from health professionals.

1.3 Patient reported outcome measurements

A symptom is a subjective experience, as opposed to disease signs or clinical findings, which are objective signs of the presence of a disease. Examples of symptoms are loss of appetite, fatigue, pain, nausea and swallowing difficulties. Many symptoms cannot be experienced by anyone but the patient themselves (84). Therefore, the best way to collect information about

perceived symptom burden would be to ask the patient directly. The use of a patient reported outcome measure (PROM) in clinical practice has previously shown to be able to narrow the gap between the clinicians' and the patients' views on disease and symptoms (85). PROMs allows understanding burden of disease and patient's quality of life. Systematic use of information from PROMs may lead to better communication, collaboration and decision-making between the therapist and the patient. This way, patients are also more involved in their own treatment. Both the aPG-SGA and the Radboud Oral Motor Inventory for Parkinson's disease (ROMP) used in this study are validated assessments tools using the principle of PROMs. The purpose of using PROMs was to collect information, from patients themselves, about symptoms that can affect nutritional status in PD patients. Patients themselves best describe symptom burden and therefore it was appropriate to ask them directly in a questionnaire.

1.4 The significance of this thesis

In general, there has been little attention the field of nutrition and PD in Norway and few people with nutritional background have worked with these patients. The aim of this study is to investigate the prevalence of malnutrition risk, malnutrition and nutrition impact symptoms in PD patients in Norway. This investigation is an important contribution to the gap in knowledge, and the information may be applied in a clinical setting. If the prevalence of malnutrition risk, malnutrition and nutrition-impact symptoms are revealed to be high in this patient group, both health professionals and relatives would benefit from knowing. Ideally one would rather prevent malnutrition than treating malnutrition. The knowledge gained from this study can be hypothesis forming and provide a basis for further scientific studies.

2 Objectives

The overall aim of this master thesis is to investigate the prevalence of malnutrition risk, malnutrition and nutrition impact symptoms like dysphagia among people with Parkinson's disease, who are patient members of the Norwegian Parkinson's Association.

More specifically, the following research questions were investigated:

1. The prevalence of malnutrition risk and malnutrition in the study population.
2. The prevalence of dysphagia and other nutrition impact symptoms.
3. The relationship between symptoms and malnutrition risk or malnutrition.
4. Potential differences between different Parkinson's diagnosis (Parkinson's disease and the differential diagnoses Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD) with regard to weight loss and malnutrition risk or malnutrition.

3 Materials and methods

3.1 Study design

The project was designed as a cross-sectional study in the form of a web-based survey with informed consent, in cooperation with the Norwegian Parkinson's association. In medical research, a cross-sectional study (also known as a cross-sectional analysis, transverse study, prevalence study) is a type of observational study (86). An observational study draws inferences from a sample to a population where the independent variable is not under the control of the researcher because of ethical concerns or logistical constraints. In a cross-sectional study, data are collected on the specific study population at a single point in time to examine the relationship between disease (or other health-related outcomes) and other variables of interest (exposures). In the present study, a group of PD patients is investigated to see if a condition, like malnutrition, is related to the disease. If malnutrition is related with PD, this would support the hypothesis that PD may be associated with malnutrition.

3.1.1 Data collection

The data collection found place in October and November 2019 (04.10.-04.11). All patient members of the Norwegian Parkinson's association registered with an email address were invited to respond to an online 24-item questionnaire in Nettskjema. General information about the survey (purpose of the study, instructions for responding, investigator, anonymity and the application of data after collection) was included and questions were kept short and focused to reduce the risk of participants abandoning the survey before completion. The survey questions are listed in appendix 6. The questionnaire included items from three categories: background information, nutritional status and swallowing function and were collected by two validated questionnaires: PG-SGA and ROMP (87, 88). Items about participants' background and histories of PD, especially which type of diagnosis, disease duration, and medication were asked. The questionnaire included items about participants' swallowing function, specifically in relation to choking, eating food, drinking liquids, swallowing pills and the psychological strain of dysphagia. To ascertain malnutrition, participants were then asked about their weight history, food intake, symptoms affecting food intake and activities and function. 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 questionnaire was first tested on a smaller pilot group of four (two researchers and two dispatchers working at the Norwegian Parkinson Association). Some minor text edits were made before distributing more broadly. To maximize the number of responses, the web-link to the questionnaire was distributed to people with PD in Norway via an email from the Norwegian Parkinson association, as well as presentations of the study was held on two monthly, regional meetings of the association, encouraging participation. The questionnaire was made available for four weeks in total, after which the results were downloaded and analyzed. The data collection process is illustrated in figure 4.

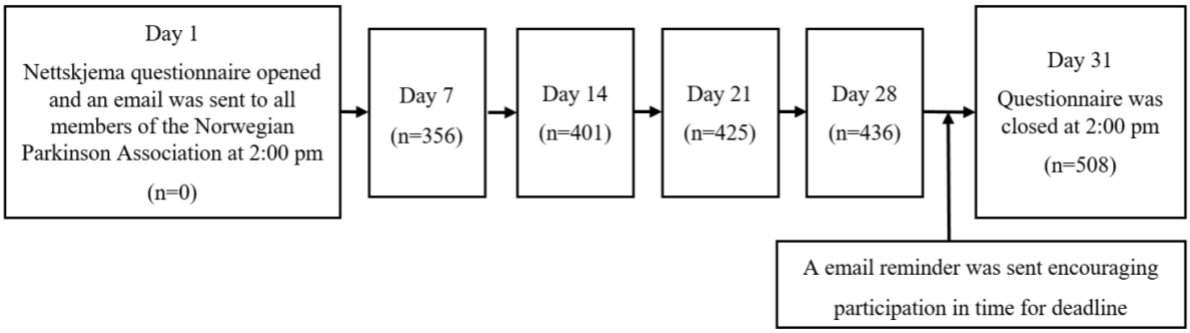


Figure 4: Flow diagram showing the data collection process. The questionnaire was open for one month (October 4th to November 4th in 2019). A reminder including a video message was sent to all participants after 28 days resulting in a boost in number of participants.

3.1.2 The online questionnaire (Nettskjema)

The questionnaire was designed and distributed using the online tool Nettskjema. 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 (89). The NSD Privacy Ombudsman and Regional Ethical Committees for Health Research (REK) recognize Nettskjema as secure. Participants to questionnaires in Nettskjema may be Feide-users, anyone with the link to the survey (fully open surveys) and invited respondent who has an email address. The current questionnaire was fully open, but the link to the survey was only sent to patient members of the Norwegian Parkinson's associations thought their monthly email letter.

The questionnaire did not collect sensitive personal data and was conducted anonymously. The IP address was stored in the system log of Nettskjema, but these are impossible to link to single responses. All eligible participants received written information about the study prior to

participation. After reading the consent form (appendix 5), participants still had the opportunity to withdraw at any point during the questionnaire. However, written informed consent could not be withdrawing after participation. The study was approved by the Regional Committees for Medical and Health Research Ethics (REC Protocol Approval 2019/865) (appendix 1). All study procedures were reviewed and approved by the Division of Clinical Nutrition at the University of Oslo and the faculty of Health Sciences at the Oslo Metropolitan University (OsloMet). The study was also approved by the Norwegian Center for Research Data (NSD) (reference code: 441317, 23.08.2019) (appendix 2). Assessment was made based on the Health Research Act (hforsknl) §10. The study was carried out according to the World Medical Association Declaration of Helsinki (1964).

3.2 Subjects and recruitment

The email invitation containing the participation web-link was sent on October 04th 2019 directly from the group leaders in the Norwegian Parkinson association in order to maintain subject anonymity. The invitation was only sent to members registered as PD patients at the applicable time (n=3047). The master student and researchers had no direct contact with study participants and no identifying information was collected through the questionnaire. The target group were people with a PD diagnosis, both classic and atypical. Participants included were of any sex, ethnicity and stage of illness. The participants had to be in the age gap between 20-100 years old. Participants who did not fulfill the age requirements or was not a patient member of the association registered with an email address did not receive the invitation, which were the exclusion criteria. Background information on members of the Norwegian Parkinson's association are presented in figure 5.

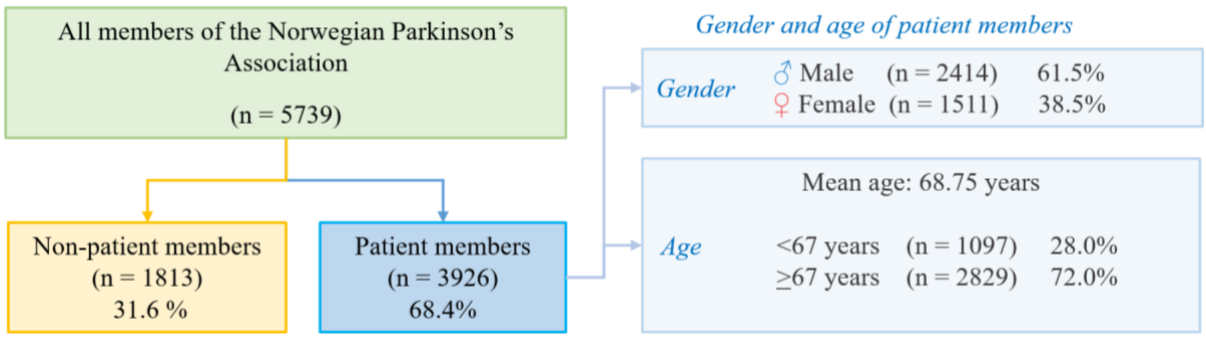


Figure 5: Background data on members of the Norwegian Parkinson's Association. Not all members are registered with an email address. Only patient members registered with an email address were invited to respond to the questionnaire (n=3047).

3.3 Assessment of nutritional status

In this study, only the patient generated component of the PG-SGA, the aPG-SGA, was applied so that the patients could reply to the questionnaire themselves. This was also to maintain the principle of PROMs as mentioned (85). PROM includes measures of symptom, function, health and quality of life. Patients themselves are the ones experiencing the conditions related to health, illness and treatment effects. According to the principle of PROM, patients themselves are most qualified to disclose symptom burden.

3.3.1 Patient Generated-Subjective Global Assessment

The PG-SGA is a validated nutritional assessment tool classifying patient to be well-nourished, moderately/suspected malnourished/at malnutrition risk or severely malnourished. Detsky et.al was the first to introduce SGA in 1987 as a clinical technique, which assessed nutritional status in hospitalized gastrointestinal surgery patients (87). A modified version of the SGA called the PG-SGA was later developed by Ottery et al.(90). The main difference from the SGA is the first four boxes of PG-SGA is self-reported by the patient, and includes symptoms that occur frequently in cancer patients (11). PG-SGA contains additional questions and was designed so that the medical history in SGA (weight history, food intake, symptoms and activity level) could be completed by patients using a check box format. The professional component of the PG-SGA is completed by a health professional and includes and physical examination, diagnosis, age and metabolic stress.

A global rating and total PG-SGA score is awarded based on both components, A scored version of PG-SGA is further developed, incorporating a numerical score in addition to the categorical global rating of well-nourished (PG-SGA A), malnutrition risk or moderately malnourished (PG-SGA B) and malnutrition or severely malnourished (PG-SGA C) (91). The scored PG-SGA is summarized in figure 6. The PG-SGA can not only be used for early detection of malnutrition, but has been described as 4-in-1 instrument capable of screening patients, assessing nutritional status, triaging interventions and monitoring intervention outcomes (92-96). The PG-SGA was originally developed for gastrointestinal surgery patients, but is has later been applied in surgical- and oncological-, and hemodialysis patients (92-95). PG-SGA has also been applied to the elderly (97). In the present study, only the

patient generated component was used i.e. the questions from page 1 (box 1-4). This part is also called the aPG-SGA and described in the next paragraph.

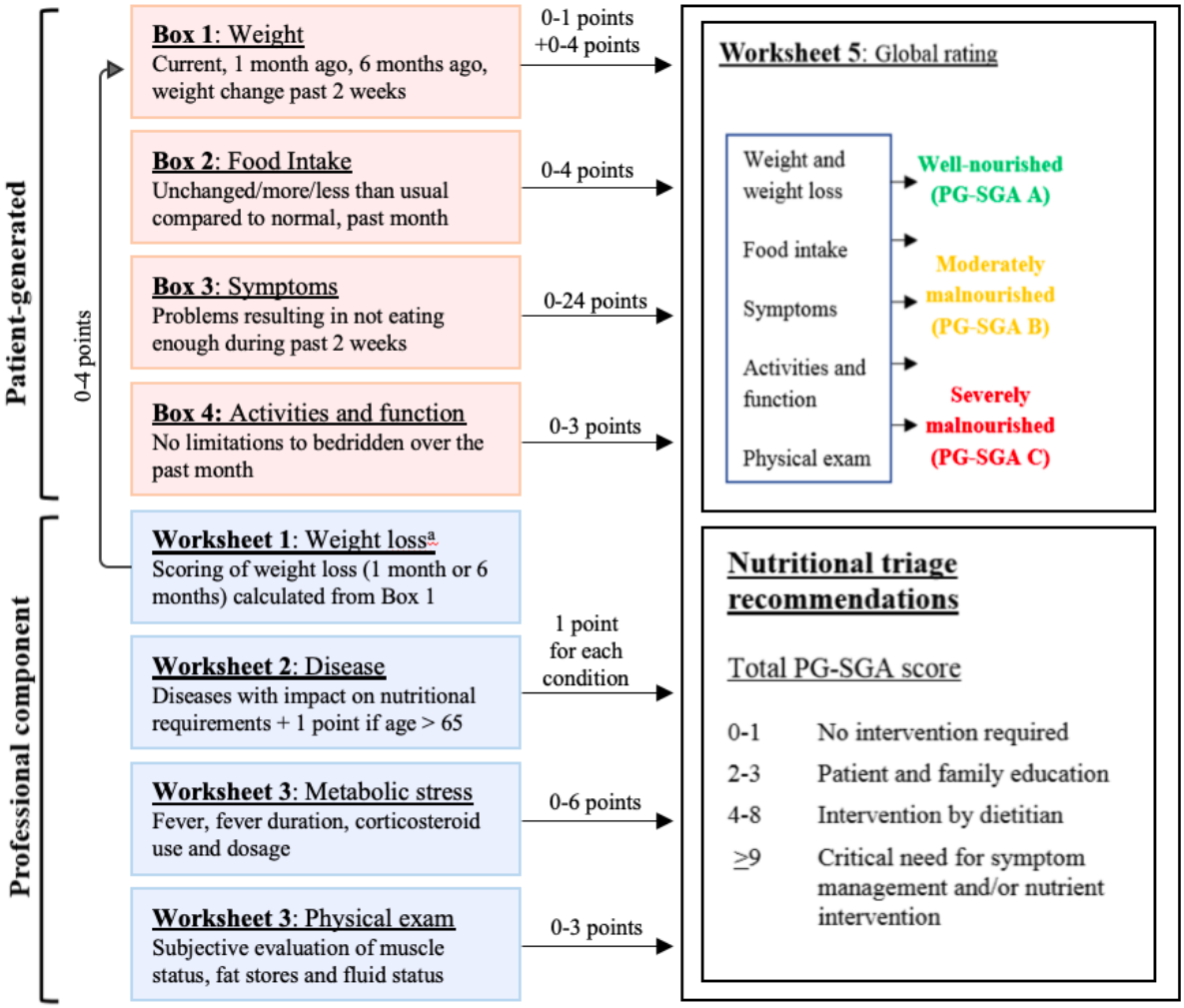
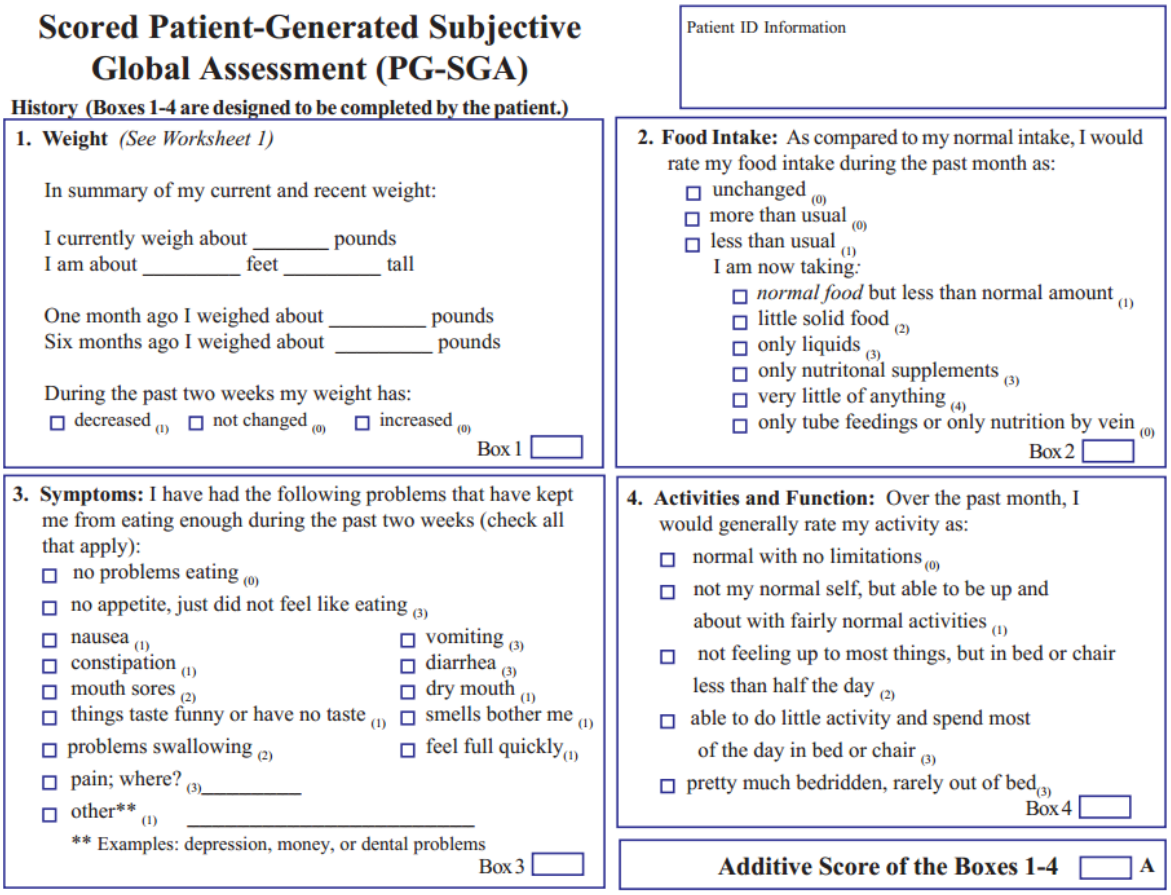


Figure 6. The Patient-Generated Subjective Global Assessment adapted from Ottery et al (90, 98). [a] When calculating the score for weight loss in Worksheet 1, 6-months data is only used if no 1-month data are available.

3.3.2 Abridged Patient Generated-Subjective Global Assessment

The abridged version of the PG-SGA, also known as aPG-SGA, includes the first four boxes from PG-SGA (figure 7) assessing body weight history, food intake, symptoms affecting food intake and physical function. By omitting the physical examination part of PG-SGA, patients can complete the questionnaire without health personnel, which is simple and less time-consuming. For this study aPG-SGA was adapted to Nettskjema and functioned as an online questionnaire (appendix 3). One free text item allowed participants to write symptoms affecting their food intake that was not mentioned in box 3 of the aPG-SGA. Answers that did not receive points if they were either not a symptom or duplicates i.e. one of the symptoms listed in box 3 and already ticked off.

The boxes can be scored as for PG-SGA to a total score, and a categorical division indicates the need for a specific nutritional intervention. A total aPG-SGA-score of 0-1 indicated no need for an intervention, 2-3 require education of the patient and family, 4-8 require a dietetic intervention and a score of ≥9 indicated critical need for an intervention focusing on symptom management and possible nutritional intervention (87). Scoring applicable for this thesis is summed up in table 3.



Scored Patient-Generated Subjective Global Assessment (PG-SGA)

Patient ID Information

History (Boxes 1-4 are designed to be completed by the patient.)

1. Weight *(See Worksheet 1)*

In summary of my current and recent weight:

I currently weigh about _____ pounds
I am about _____ feet _____ tall

One month ago I weighed about _____ pounds
Six months ago I weighed about _____ pounds

During the past two weeks my weight has:
☐ decreased (1) ☐ not changed (0) ☐ increased (0)

Box 1

2. Food Intake: As compared to my normal intake, I would rate my food intake during the past month as:
☐ unchanged (0)
☐ more than usual (0)
☐ less than usual (1)
I am now taking:
☐ *normal food* but less than normal amount (1)
☐ little solid food (2)
☐ only liquids (3)
☐ only nutritonal supplements (3)
☐ very little of anything (4)
☐ only tube feedings or only nutrition by vein (0)

Box 2

3. Symptoms: I have had the following problems that have kept me from eating enough during the past two weeks (check all that apply):
☐ no problems eating (0)
☐ no appetite, just did not feel like eating (3)
☐ nausea (1)
☐ constipation (1)
☐ mouth sores (2)
☐ things taste funny or have no taste (1)
☐ problems swallowing (2)
☐ vomiting (3)
☐ diarrhea (3)
☐ dry mouth (1)
☐ smells bother me (1)
☐ feel full quickly (1)
☐ pain; where? (3)_____
☐ other** (1) _____
** Examples: depression, money, or dental problems

Box 3

4. Activities and Function: Over the past month, I would generally rate my activity as:
☐ normal with no limitations (0)
☐ not my normal self, but able to be up and about with fairly normal activities (1)
☐ not feeling up to most things, but in bed or chair less than half the day (2)
☐ able to do little activity and spend most of the day in bed or chair (3)
☐ pretty much bedridden, rarely out of bed (3)

Box 4

Additive Score of the Boxes 1-4 A

Figure 7. Scoring of the four boxes in PG-SGA, called the aPG-SGA. Adapted from Ottery et al. (98)

The aPG-SGA has never been used specifically on people with PD before, but it has been validated in cancer patients and hemodialytic patients (99, 100). The Norwegian translation of the aPG-SGA is previously used in cancer patients and tested for reliability and validity in Norway (101, 102) and internationally (87). A study by Thoresen et.al completed a validation test of the Norwegian aPG-SGA, which revealed a sensitivity of 96% and specificity of 83% (102). The results show that the aPG-SGA as an easy method for assessment of nutritional status in cancer patients and is therefore suggested as a valid screening tool. Participants in these studies may be relatable to Parkinson's in terms of age and symptoms experienced. In

order to obtain the total score of the aPG-SGA, the four boxes were summed up for each participant, according to the scoring recommendation (figure 7).

Table 3: Categorization and scoring of aPG-SGA[a] in relation to malnutrition

Category name for this thesis	Score	Category indication
Well-nourished (A)	0-1	Patients with no particular nutritional problems and in no need of intervention (0-1 point on aPG-SGA).
Malnutrition risk (B)	2-8	Patients with increased nutritional problems who might benefit from but not in critical need of intervention by a registered dietitian nutritionist (RDN) or other clinicians.
Malnourished (C)	≥9	Patients with a critical need for improved symptom management and/or nutrition-intervention options.

[a] Abridged Patient-Generated Subjective Global Assessment (aPG-SGA), also called the PG-SGA Short form

3.1 Assessment of swallowing disturbances

3.1.1 Radboud Oral Motor Inventory for Parkinson's disease

The ROMP questionnaire was developed by the Radboud University Medical Centre in Nijmegen, the Netherlands to assess the three domains of speech, swallowing and saliva control in PD (88). In the current questionnaire, only questions from the swallowing domain assessing dysphagia was used. The ROMP swallowing component was developed after a review of three already existing assessments: The Dutch version of the Swallowing Quality of Life (SWAL-QOL) questionnaire (103), the Performance Status Scale for Head and Neck Cancer Patients (104), and the Swallowing Disturbance Questionnaire (SDQ) (73). The ROMP questionnaire is the only dysphagia questionnaire which have been translated to Norwegian, and it is also validated and reliable (4, 70, 88). The original ROMP questions are presented in appendix 4. For this thesis, ROMP will be used as the general term for the ROMP swallowing subscale. The ROMP consists of seven questions with a 5-point Likert scale response option (1 = normal, 5 = worst score). The items on the ROMP swallowing subscale 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 bother the patient experiences secondary to their swallowing difficulties. Originally, the total ROMP swallowing score ranges from 7-35. In the current questionnaire, the maximum score was 34 due to one question (question nr.7) only having four response options. Interpretation of the score is illustrated in figure 8.

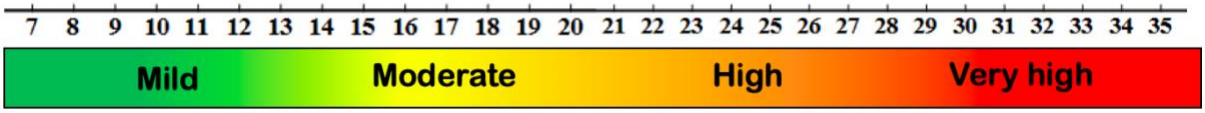


Figure 8: Interpretation of total ROMP swallowing scores in relation to swallowing disturbances. The original ROMP scale ranges from seven (lowest) to 35 (highest) points.

3.2 Literature review on malnutrition prevalence

A search was undertaken for all available years in PudMed, using the following search terms: "prevalence malnutrition" AND "Parkinson's disease". In addition, the search was customized to "best match", a new relevance search algorithm as an alternative to the traditional date sort order. The search conducted on February 6, 2020 resulted in 119 studies for further review by abstract. The review revealed 12 cross-sectional, cohort and case-control studies published between 2008 and 2019 from all over the world. Participants were all diagnosed with idiopathic PD and the sample size varied from 61 to 208 cases and included both outpatients, community-dwelling and hospitalized patients. In all studies, except one (Jaafar AF et al), most of the PD patients included were men, and the mean age ranged from 61 to 76 years. Studies using the following malnutrition screening tools were included: PG-SGA, MNA or MUST. Studies not classifying patients into malnutrition risk/malnutrition categories were excluded. Additionally, the following types of articles were excluded: systematic reviews, intervention studies, guidelines and animal studies. No Norwegian articles were found in this search, so only papers published in English were included.

3.3 Statistical Analysis

All statistical analyses were performed using IBM SPSS Statistics 25. Analysis were performed by the master student, with input from a statistician from OsloMet during one meeting March 2020. P-values (2. sided) <0.05 were regarded as statistically significant. All data were plotted into Excel directly from the electronic database in Nettskjema. Data processing and coding was then completed, including transforming alphabetic variables to numeric variables for further investigation in SPSS. New variables were made in Excel and SPSS including weight loss in percent after six months and after one year, BMI, total score of aPG-SGA and total ROMP-score. Continuous data were checked for normality with the Kolmogorov-Smirnov test and interpreted in conjunction with visual inspection of QQ- plots and histograms (105). Normally distributed data were presented as means and standard

deviations, and non-normally distributed data as medians and interquartile range (25th-75th percentiles). 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 (2xk 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. For continuous variables, the independent samples t-test was used to explore differences in means between groups with normally distributed data. The Mann-Whitney test was used to explore differences in medians between groups with non-normally distributed data. 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. 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). Because of the pilot nature if this study, no sample size calculation was performed. Missing values and extreme values were handled in advance by using the limitation-function in Nettskjema so they would not wrongly skew the data. The questionnaire had a limitation-function on numeric values e.g. one could not answer body weight below 30 kg or above 180 kg. The question on height was also limited to the interval 130-220 cm. All questions, except one free-text item assessing "other symptoms then the ones mentioned above" from box 3 from the aPG-SGA, were obligatory to answer to be able to continue on the questionnaire, which was beneficial for avoiding missing values.

3.4 Contribution

My contribution was developing the questionnaire, participating in the recruitment process, conducting the literature review, promotion of the questionnaire to member of the Norwegian Parkinson's association through email and participation on local member meetings in the Oslo region. In addition, my role was to be an advisor for the study in the field of nutrition, as well as administrating the data collection and statistical analysis of the data from the questionnaire.

4 Results

4.1 Subject characteristics

In total, all 3047 email registered patient members of the Norwegian Parkinson association received the questionnaire. We reckon that all 3047 members had the opportunity to reply of those who received the email invite. Five hundred and eight participants replied to the questionnaire and were included in the study. Based on this, the response rate was 16.7%. Median response time was 8 minutes (IQR: 6.0-11.8). Subject characteristics are presented in table 4.

Seventy-eight percent of participants were between the ages of 60 and 79 years. In relation to gender distribution, 62% of the participants were men. The women were slightly younger than the men were, but not statistically significant (p=0.078). Regarding how long a participant have had a PD diagnose, all groups were well represented ranging from <1 year to >10 years.

Mean (±SD) weight and BMI was 77.5 (15.8) kg and 25.2 (4.2) kg/m2. As expected, men had significantly higher body weight, however also higher BMI than women (p<0.001). Men also reported higher mean percentage weight loss the past six months (1.1%, SD: 3.0) than women (0.3%, SD: 4.5) (p=0.026). Weight loss the past year was also 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), 0,8% were underweight, 47.0% normal weight and 52.2 % overweight or obese, among younger participants under 70 years. Among participants 70 years or older, 24.6% were underweight, 52.9% normal weight and 18.0% overweight or obese.

Table 4: Characteristics of the study participants and differences in 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/m2 (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

4.2 Malnutrition status among participants

4.2.1 Malnutrition risk and malnutrition

In total, 59% (n=302) were categorized as well-nourished (A), 34% (n=173) as malnutrition risk (B) and 6.5% (n=33) as malnourished (C) (Figure 9a). The category at malnutrition risk and malnourished are grouped together and presented as participants were a nutritional intervention may be beneficial as presented in figure 9b. Compared with well-nourished patients, malnourished participants were older but not statistically significant (p=0.095).

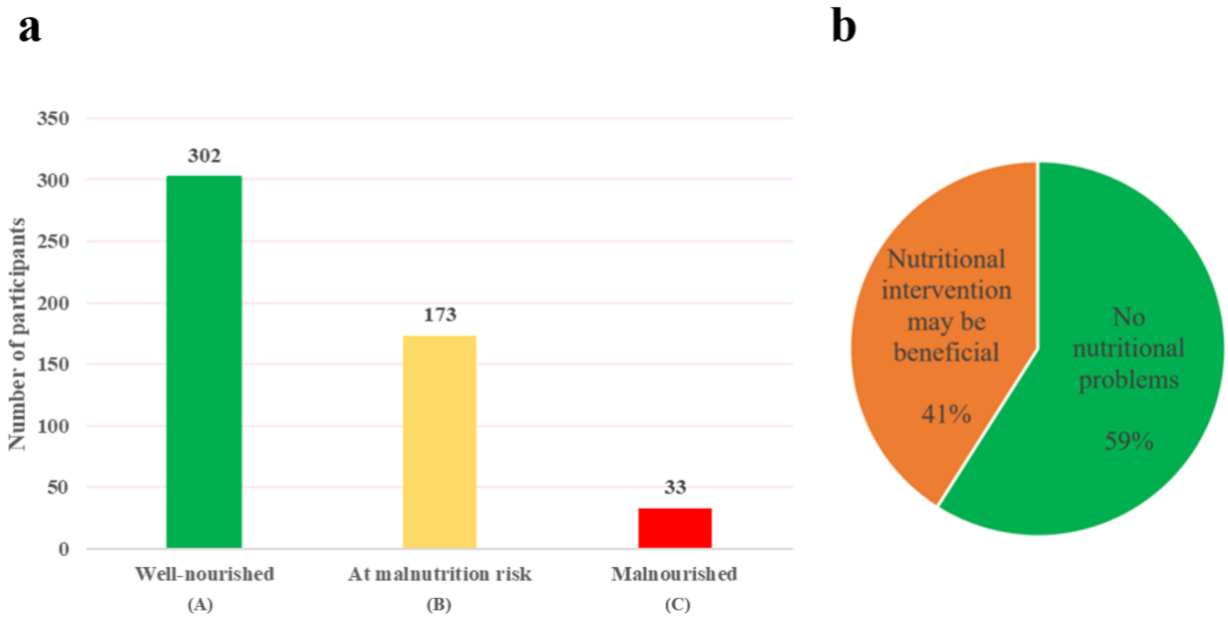


Figure 9. Nutritional status in participants. a) Global rating category measured by the abridged Patient-Generated Subjective Global Assessment (aPG-SGA) (n=508). b) Participants at risk of malnutrition and malnourished are combined into one category were a nutritional intervention may be more or less beneficial.

4.2.2 Anthropometric measures in relation to nutritional state

Generally did malnourished participants have lower body weight and BMI than well-nourished participants. However, of the participants found to be malnourished, 29% were overweight and 10% obese according to BMI. Only 16% of malnourished participants were underweight. On average, the malnourished participant reported 5.9% weight loss during the past year while well-nourished report 0.7% weight gain in the same period. Weight loss the past six months was statistically significantly different between all the malnutrition groups ($p<0.001$). Statistically significant differences were also found for weight loss the past year

for all groups, except between malnutrition risk and malnourished participants. Details for anthropometric measures for all participants and those categorized as well-nourished, malnutrition risk and malnourished are presented in Table 5.

Table 5. Anthropometric measures according to categorization of malnutrition by aPG-SGA[a]

	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)	

[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)

4.1 Weight loss and nutritional impact symptoms

4.1.1 Weight loss

Of the 508 participants, 55 (10.8%) (34 M, 21 F) reported weight loss the past two weeks prior to participation in this study. The greatest prevalence of weight loss was found in participants with other PD diagnoses (18.8%) compared to participants with PD and parkinsonism (10% and 15% respectively), however not statistically significant (p=0.056) (table 6). This result is subject to skewed distribution of cases in each diagnose group. Most men had experienced weight loss, but the difference was minimal (p=0.898). The proportion of participants who experienced weight loss increased in parallel with age group, with the exception of participants aged 60-69 years who had the highest prevalence of weight loss of

all groups. In conclusion of this, weight losers were older than weight stable and weight gaining participants, but not statistically significant (p=0.310). Weight losers also had a longer disease duration, but not statistically significant (p=0.547) as seen in previous studies (56).

In total, 36.4% of weight losers reported decreased appetite compared to 10.3% among non-weight losers (table 7). A significant difference in self-reported food intake was found between all malnutrition groups (p=0.005). Among the weight losers, most participants categorized as well-nourished or at malnutrition risk reported no change in appetite (100% and 62.9% respectively). However, 83.3% of patients categorized as malnourished reported either decreased or increased appetite.

Table 6. Prevalence of weight loss among participants with different Parkinson diagnoses

Diagnosis	Weight loss[a]		
	Yes (n=55)	No (n=453)	
	n (%)	n (%)	P-value[b]
Parkinson's disease	46 (83.6)	407 (89.8)	0.056[c]
Parkinsonism	6 (10.9)	33 (7.3)	
Other Parkinson diagnoses[d]	3 (5.5)	13 (2.9)	

[a] Weight loss the past two weeks according to box 1 of abridged patient generated subjective global assessment (aPG-SGA)
[b] Significance level = 0.05
[c] Pearson Chi-square test for more than two categorical variables
[d] Atypical parkinsonism/Parkinson plus, Multi system atrophy (MSA), Progressive supranuclear palsy (PSP) or Corticobasal degeneration (CBD)

Table 7: Prevalence of change in food intake among weight losers and non-weight losers

Food intake[b]	Weight loss[a]		
	Yes[c] (n=55)	No[d] (n=453)	
	n(%)	n(%)	P-value[ef]
Unchanged	32 (58.1)	369 (81.5)	<0.001
Increased	3 (5.5)	37 (8.2)	
Decreased	20 (36.4)	47 (10.3)	

[a] Weight loss the past two weeks according to box 1 of abridged patient generated subjective global assessment (aPG-SGA)
[b] Item "As compared to my normal intake, I would rate my food intake during the past month as:"
[c] Participants who had lost weight the past two weeks
[d] Participants who had either gained weight or not experienced change in weight the past two weeks,
[e] Significance level = 0.05, [f] Pearson Chi-square test between weight losers and non-weight losers

4.1.1 Symptoms affecting food intake

In total, 75.4% of participants reported no symptoms affecting food intake the past two weeks, whilst 24.6% of reported one or more symptoms. The most frequently reported nutrition impact symptoms were constipation (14.2%), dry mouth (13.4%) and loss of appetite (10.2%) (figure 10). In total, 75.4 % percent reported no problems, where 97% amongst well-nourished, 51% amongst those in malnutrition risk and only 6% amongst malnourished participants reported no problems. Malnourished participants reported more symptoms in average, with a mean of 3.4 (1.4) symptoms per person, whilst well-nourished only reported 0.1 (0.3) symptoms per person (figure 11).

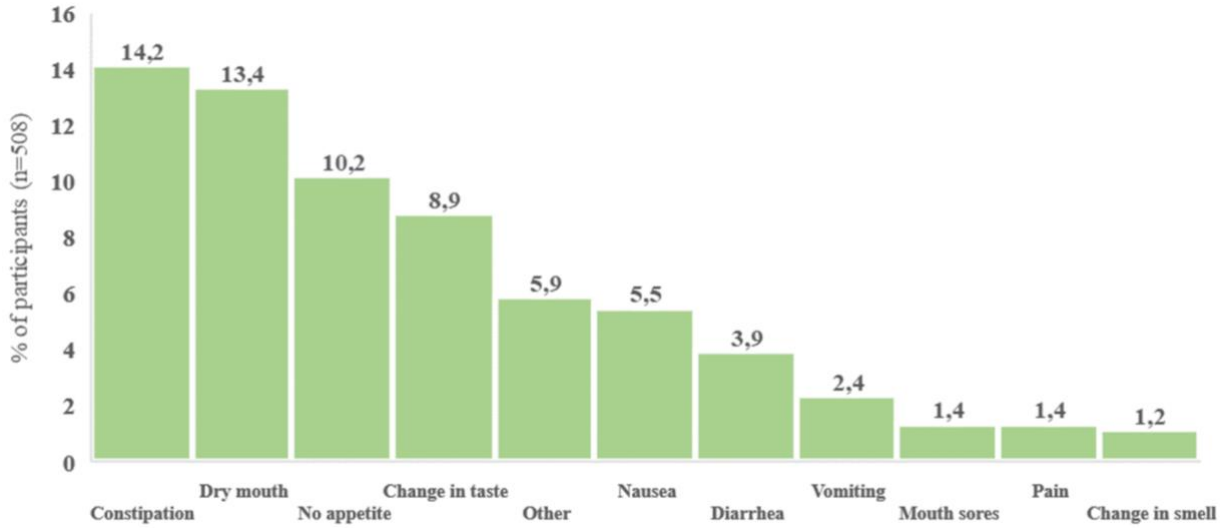


Figure 10. **Prevalence of symptoms affecting food intake** among all participants (n=508). Participants could pick several symptoms.

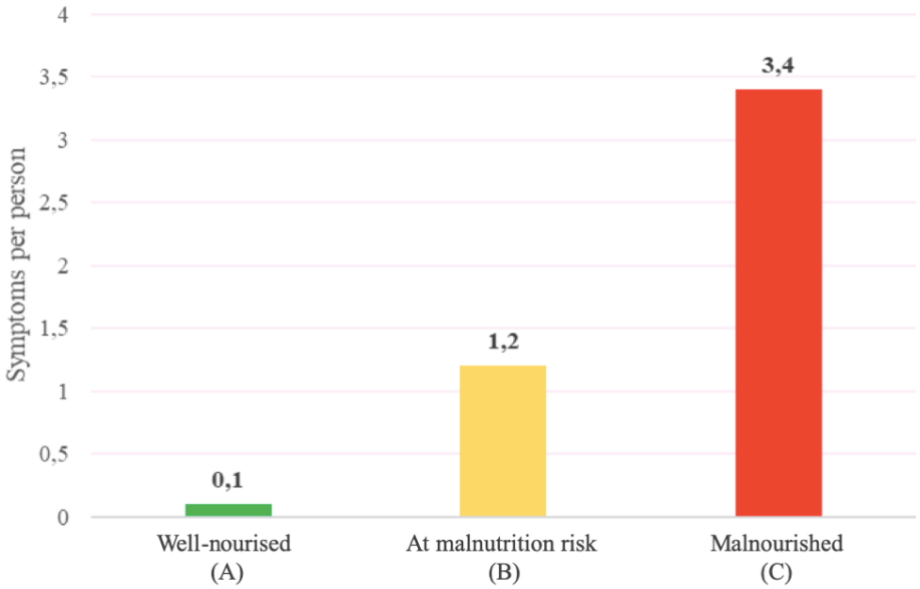


Figure 11: Symptoms per person according to malnutrition category. Global rating category measured by the abridged Patient-Generated Subjective Global Assessment (aPG-SGA) (n=508).

Scoring of replies to the open text item

In total, 76 participants answered the open text item in the aPG-SGA. The review process is presented in figure 12. The total amount of replies that received one point in aPG-SGA were 30 (39.5%). Thirty-eight respondents answered that they had no symptoms while eight gave the same answer as they already had ticked off in the list of symptoms (duplicates).

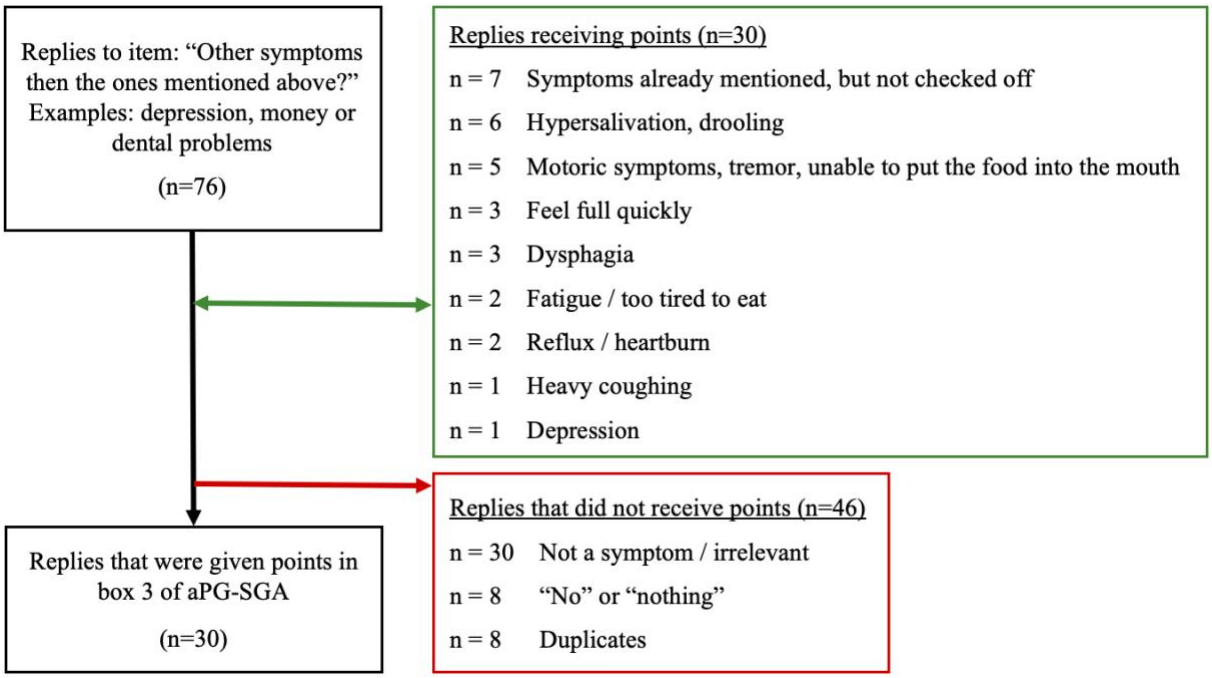


Figure 12: The review process of the open text item in the abridged Patient-Generated Subjective Global Assessment (aPG-SGA) assessing symptoms affecting food intake the past two weeks. Symptoms mentioned were able to receive a maximum of 1 point. Duplicates include symptoms that were checked off in box 3 in addition to being mentioned in the open text item and did not receive point. Examples: no appetite, vomiting, constipation

4.1.2 Dysphagia and ROMP scores

In relation to malnutrition, a statistically significant difference was found between the malnutrition groups for the overall ROMP score ($p<0.001$) (table 8), indicating a higher prevalence of dysphagia among malnourished participants than well-nourished participants. On average, malnourished patients scored higher than both participants at malnutrition risk and well-nourished, with a mean score of 15.5, against respectively 11.6 and 9.0. The difference in total ROMP score was statistically significant ($p<0.001$). The distribution of the total ROMP scores are illustrated in figure 13. Fifty-five percent of participants had a score of seven to nine on the total ROMP, which are considered the three lowest possible scores. None received a score above 30 despite that the maximum possible score was 35.

Table 8: Mean ROMP score[a] according to malnutrition[b]

Question	All participants (n=508) Mean (SD[c])	Well-nourished (n=302) Mean (SD[c])	Malnutrition risk (n=173) Mean (SD[c])	Malnourished (n=33) Mean (SD[c])	P-value[de]
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] Radboud Oral Motor Inventory for Parkinson's Disease (ROMP)
[b] Measured by the abridged Patient-Generated Subjective Global Assessment (aPG-SGA)
[c] Standard deviation
[d] Significance level = 0.05
[e] Kruskal Wallis for nonparametric test between more than two independent groups

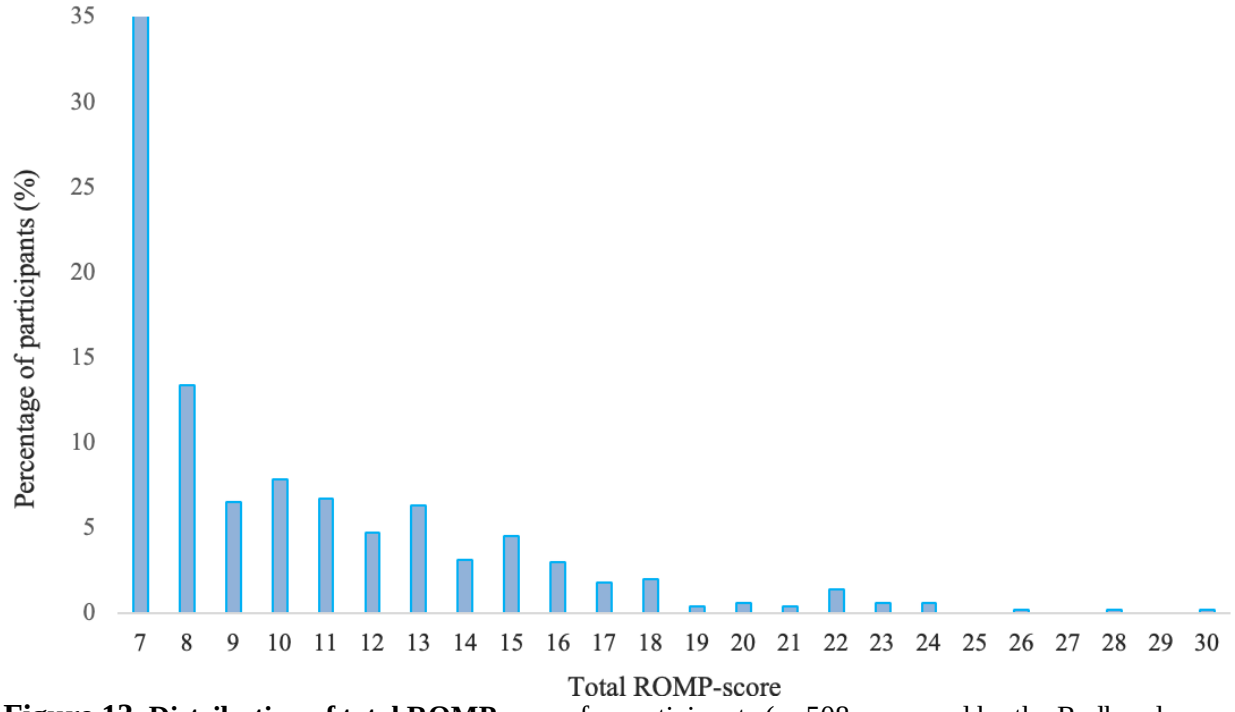


Figure 13: **Distribution of total ROMP-score** for participants (n=508 measured by the Radboud Oral Motor Inventory for Parkinson's Disease (ROMP).

Taken subject to the skewed distribution of cases, a statistically significant difference in ROMP score was found between the PD diagnoses ($p<0.001$). The highest reported ROMP scores were revealed in participants with MSA and PSP and are presented in table 9.

Table 9: Differences in total ROMP[a] score between the PD diagnoses in the study sample

Type of PD diagnosis	**Participants (n=508),** n (%)	**Median total ROMP score**	P-value[bc]
Parkinson's disease	453 (89.2)	9	<0.001
Parkinsonism	39 (7.7)	8	
Atypical parkinsonism/Parkinson plus	10 (2.0)	14.5	
MSA[d]	4 (0.8)	20.5	
PSP[e]	1 (0.2)	22	
CBD[f]	1 (0.2)	8	

[a] Measured by the Radboud Oral Motor Inventory for Parkinson's Disease (ROMP)
[b] Significance level = 0.05
[c] One-way Anova for parametric test for mean difference in ROMP score between the different PD diagnosis
[d] Multi system atrophy
[e] Progressive supranuclear palsy
[f] Corticobasal degeneration

Prevalence of swallowing disturbances for each ROMP item are presented in table 10. In general, patients scored low on the ROMP scale with a mean score of 10.3 and a dose response effect is pervasive. Considering participants´ ability to swallow food and ones concerns about their swallowing disturbances, only 51% and 57% respectively replied that they have no problems with this. In contrast, about 72% and 79% replied that they had no problems swallowing pills or dining with others.

Table 10: Prevalence of swallowing disturbances[a] according to malnutrition[b]

Questions	Alternative	All participants (n=508)	Well-nourished (n=302)	Malnutrition risk (n=173)	Malnourished (n=33)	
		n (%)	n (%)	n (%)	n (%)	
1 Choking	1	349 (68.7)	232 (76.8)	104 (60.1)	13 (39.4)	
	2	89 (17.5)	47 (15.6)	37 (21.4)	5 (15.2)	
	3	39 (7.7)	16 (5.3)	18 (10.4)	5 (15.2)	
	4	21 (4.1)	4 (1.3)	9 (5.2)	8 (24.2)	
	5	33 (6.5)	3 (1.0)	5 (2.9)	2 (6.1)	
2 Swallow fluids	1	334 (65.7)	232 (76.8)	93 (53.8)	9 (27.3)	
	2	151 (27.7)	67 (22.2)	68 (39.3)	16 (48.5)	
	3	9 (1.8)	2 (0.7)	4 (2.3)	3 (9.1)	
	4	6 (1.2)	1 (0.3)	3 (1.7)	2 (6.1)	
	5	8 (1.6)	0 (0)	5 (2.9)	3 (9.1)	
3 Swallow food	1	258 (50.8)	191 (63.2)	59 (34.1)	8 (24.2)	
	2	219 (43.1)	104 (34.4)	101 (58.4)	14 (42.4)	
	3	23 (4.5)	7 (2.3)	10 (5.8)	6 (18.2)	
	4	6 (1.2)	0 (0)	1 (0.6)	5 (15.2)	
	5	2 (0.4)	0 (0)	2 (1.2)	0 (0)	
4 Swallow pills	1	368 (72.4)	252 (83.4)	103 (59.5)	13 (39.4)	
	2	118 (23.2)	46 (15.2)	59 (34.1)	13 (39.4)	
	3	14 (2.8)	2 (0.7)	9 (5.2)	3 (9.1)	
	4	8 (1.6)	2 (0.7)	2 (1.2)	4 (12.1)	
	5	0 (0)	0 (0)	0 (0)	0 (0)	
5 Eat with others	1	399 (78.5)	271 (89.7)	113 (65.3)	15 (45.5)	
	2	56 (11.0)	18 (6.0)	31 (17.9)	7 (21.2)	
	3	41 (8.1)	12 (4.0)	25 (14.5)	4 (12.1)	
	4	11 (2.2)	1 (0.3)	4 (2.3)	6 (18.2)	
	5	1 (0.2)	0 (0)	0 (0)	1 (3.0)	
6 Concerns	1	288 (56.7)	208 (68.9)	73 (42.2)	7 (21.2)	
	2	133 (26.2)	66 (21.9)	56 (32.4)	11 (33.3)	
	3	66 (13.0)	25 (8.3)	34 (19.7)	7 (21.2)	
	4	16 (3.1)	2 (0.7)	7 (4.0)	7 (21.2)	
	5	5 (1.0)	1 (0.3)	3 (1.7)	1 (3.0)	
7 Bother	1	319 (62.8)	220 (72.8)	88 (50.9)	11 (33.3)	
	2	145 (28.5)	73 (24.2)	62 (35.8)	10 (30.3)	
	3	34 (6.7)	5 (1.7)	19 (11.0)	10 (30.3)	
	4	10 (2.0)	4 (1.3)	4 (2.3)	2 (6.0)	P-value[d]
Overall mean score, (SD[c])		10.3 (4.1)	9.0 (2.9)	11.6 (4.3)	15.5 (6.0)	<0.001[e]

[a] Measured by using Radboud Oral Motor Inventory for Parkinson's Disease (ROMP), [b] Measured by the abridged Patient-Generated Subjective Global Assessment (aPG-SGA), [c] Standard deviation, [d] Significance level = 0.05, [e] Kruskal Wallis for nonparametric test between more than two independent groups

4.2 Multiple linear regression analysis

By adjusting for age and PD duration, the ROMP score was significantly associated with increased aPG-SGA score. The outcome of the final multiple linear regression model is presented in table 11. 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). Age also tended to be associated with SGA-score, as it is estimated that SGA-score changes 0.317 units for with each unit increase in age group (p = 0.05), however the association is not significant in the adjusted model. The variables included in the model explained 23% of the variance according to Nagelkerke´s R2.

Table 11: 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

5 Discussion

This is the first study to describe the prevalence of malnutrition and nutritional impact symptoms in Norwegian PD patients. The main findings of this web-based survey comprise the following: (i) The prevalence of malnutrition in PD patients in Norway is similar compared to other European prevalence studies; (ii) One hundred and seventy-three (34.0%) of the participants were at malnutrition risk (B) while 33 (6.5%) participants were severely malnourished (C). The presence of nutritional impact symptoms, especially dysphagia, was associated with malnutrition. The results suggest that there may be an increased risk of malnutrition in individuals with PD, but these findings should be interpreted with caution given the limitations of the study design.

5.1 Methodological considerations

5.1.1 Cross-sectional study design

A cross-sectional study does not allow examining a sequence of events but rather examines associations only at one point of time (86). The design allows a relatively fast and large data collection to be made at little or no expense. The results of a cross-sectional study can act as suggestions on what variables are worth pursuing using experimental methods and for the generation of hypotheses. This design is also useful for public health planning and understanding disease etiology in general. For the present study this implies that a cross-sectional design allows inclusion of a large study sample to study possible associations between malnutrition and nutritional impact symptoms in PD. There exist only a few similar studies in the world and none in Norway, as summarized in the literature search in table 2. The results can be used to generate hypotheses for future research. The information can also be useful for the Norwegian health care system as there is no data on the prevalence of malnutrition in this group as of today, despite the focus on malnutrition.

A major limitation is that, a cross-sectional design cannot provide temporal relationships and therefore not prove causality (106, 107). If the aim is to investigate causal relationships, one must resort to randomized controlled trials. The variables investigated in a cross-sectional study cannot be used to analyze behavior over a period to time, as the design only provide a snapshot of the situation. The timing of the snapshot is not guaranteed to be representative.

Cross-sectional studies are not suitable for the study of rare diseases as a defined population is required for to draw correct conclusions. PD is not considered a rare disease. However, PD develops over time and the course of the disease varies from patient to patient. Exact data on where the patients were in the course of the disease in relation to disease severity were not collected. This design is prone to selection and information bias and confounding (106). When collecting retrospective data, the quality of the data is determined largely on the patient's ability to accurately recall past exposures. Some data that required participants to recall were collected, for example weight six months and one year ago, respectively. Recall bias may therefore have resulted in either an overestimate or underestimate of the association between dysphagia and malnutrition. Collecting exposure data from an objective source like medical records, as well as blinding participants to the study hypothesis may minimize recall bias, but this was not applicable for the present study.

5.1.2 Study population

The sample used in a cross-sectional study and the response rate determine how well the results can be generalized to the population as a whole (106). To be able to generalize the study population should be selected by using a random technique securing a highly representative sample. In Norway, it is estimated that about 8000 people have PD with a normal onset between 50 and 70 years and more men diagnosed with PD by a ratio of approximately 2:1 (2, 108). In the present study respondents were collected by sending the web-based survey to the approximately 3000 patient members of the Norwegian Parkinson association. Among the patient members of the association, there are 62% men and 38% women, and the mean age is approximately 69 years (figure 5). This indicates that the members of the Norwegian Parkinson association is sufficiently representative of the PD population, reserved with some limitations.

Difficulties arise for potential non-participations by persons with more severe cognitive impairment and dementia, which are one of the most prevalent non-motor symptoms in PD (109). To put this in perspective, the prevalence of symptoms, malnutrition and dysphagia may therefore be higher in the total population which also includes hospitalized and institutionalized PD patients. Some relevant participants may also have fallen outside this study like patients who are malnourished and very frail. It is also a possibility that the results have been affected by the fact that non-PD patient (etc. family members and caretakers) could

also respond on PD patients' behalf, which does not comply with the principle of PROMs. The results in this study may have been affected by the lack of non-organized PD patients. One may suggest that sending the survey per post may have included a wider variety of patients, for example the elderly not using computer technology and emails, and thereby a more representative sample. A potential written version of the survey was a matter of cost-effect, but it is unlikely that the participation rate would be significantly increased in relation to the resources it would require.

5.1.3 Internal validity

Validity refers to how accurately a method measures what it is intended to measure (110). The results of high validity research correspond to real characteristics and variations in population as a whole. The internal validity of a study relates to how well a study is conducted i.e. the extent to which the observed results represent the truth in the studied population and are not due to methodological errors (111). The discussions of internal validity in this study therefore primarily focuses on whether the measuring instruments are valid and free of bias. The external validity refers to in which extent the results are generalizable and will be discussed separately. One indicator of validity is high reliability. Reliability refers to the extent to which a measuring procedure yields the same results on repeated trials and relies on the measuring instruments used. The measurements in this study were PROMs (aPG-SGA and ROMP) delivered to the participants by the format of a web-based questionnaire (Nettskjema).

Nutritional assessment by aPG-SGA

In this study the most recent Norwegian version of aPG-SGA (16, 17) was used to identify risk of malnutrition or malnutrition. The aPG-SGA is a validated short form of PG-SGA. The only difference between the two forms is the clinical examination by health personnel which is not included in aPG-SGA. Because of this it is possible for the patients to use aPG-SGA as a PROM where the patients complete the questionnaire themselves which was relevant in the present study. The PG-SGA is considered to be a gold standard for identifying malnutrition and nutritional risk (112). When compared with other nutrition assessment methods, PG-SGA is the fastest, noninvasive and least complicated tool that also has high validity and reliability (92, 94, 113). The sensitivity and specificity describe the accuracy of a screening test and is reported to be high for PG-SGA in the studies (98-100% and 82-97%, respectively). The PG-

SGA is determined to be reliable by a Cronbach coefficient alpha-test (0.64-0.707), suggesting high internal consistency (114, 115). The interrater reliability is found to be between 93-97% suggesting high agreement between different raters (116).

The short version of the PG-SGA (aPG-SGA) is mainly validated in community-dwelling cancer patients (11, 100, 117) and in hemodialytic patients (99). The results from the validation studies revealed sensitivity 90-96% and specificity 68-83% for the aPG-SGA, which is not as high as for the PG-SGA but considered as sufficient. It is clearly a weakness that the aPG-SGA has not been validated in a PD population, but the PG-SGA has been applied to some extent in PD patients before and shown to be well accepted (118). Additionally, as increased age is a major risk factor for PD (119) it may be beneficial to use. The symptoms affecting food intake mentioned in aPG-SGA box 3 are also commonly known in PD, like loss of appetite, constipation, early satiety and problems swallowing (40). The overall impression is therefore that aPG-SGA is able to give a valid indication of malnutrition risk in community-dwelling patients with PD.

Although the aPG-SGA is revealed to be understandable and easy to complete by participants (120), a few challenges can be noted. The study may have been prone to bias as self-reported data were collected. In the first box of the aPG-SGA, current weight and weight loss is documented. Problems can occur if participants do not know their own weight and do not have ability or do not want to measure weight. Also, if they use a scale at home bias may occur since measurements of weight benefit from standardization. For example, one should measure weight in the morning, fasting, after the first toilet visit. For repeated measurements the same weight scale should be used since variations may be big from scale to scale (121) and standardization is necessary for reliable data. The questionnaire also requests retrospective data (weight six and one year ago), which may affect data accuracy (recall bias). The literature on self-reported weight measures reveals underreporting in the general adult population and the bias is greater in overweight and obese participants than those of normal weight (122). Men also tend to overreport their height and weight, while women overreport their height and underreport their weight (123). If the participants do not specify the correct weight and report a too high or low weight this may lead to a misclassification of malnutrition category since evaluation of nutritional state is based on these data as well as calculation of weight loss.

In box 2 of the aPG-SGA, food intake is assessed. Participants may read and respond quickly to some of the questions, resulting in them not noticing which time period is relevant, which is both food intake now and the past month. The word “only”, used in four of the options, is preventing participants from finding sufficient response options. For example, there are no suitable option for participants who are consuming both solid food and nutritional supplements. In box 3, symptoms that have prevented food intake for the past two weeks is requested. Some participants ticked off the "no problem" option, in addition to ticking off for several symptoms. This may have meant that the participants had symptoms, but that it did not prevent food intake. The assessment of such an answer remains subjective as one could not confirm the response with the participant. Box 3 is also the only box that specifies that one can tick several options and some participants may have overlooked this if reading too quickly. The relatively long recall periods used in both box 2 and 4 caused challenges for the participants. During the past month, participants may have experienced variations that made it impossible for them to select only one response option (120). Since the scoring of aPG-SGA is based on the four boxes, the data must be accurate and correct. To hopefully minimize response errors in the present study, the participants had the opportunity to contact health personnel at the Norwegian Parkinson’s association by email or telephone if anything was unclear.

In summary, the internal validity is strengthened by the use of a nutrition assessment tool applicable to any age that includes, in addition to weight changes, assessment of recent physical function and appetite, and the presence of symptoms that are likely to influence food intake. Limitations are related to the lack of validation of nutritional assessment tools for the PD population. Adapting aPG-SGA to another online format such as Nettskjema can also challenge the validity as this has never been done before.

Dysphagia

In relation to assessing dysphagia, the ROMP was used, which is short in order to ease administrative and patient burden in addition to the psychometric properties being strong. The ROMP provides a reliable and valid instrument to evaluate patient-perceived problems with speech, swallowing, and saliva control in patients with PD (4, 88). Only the ROMP-swallowing subscale was used in the present study, which has also shown high reliability and validity (4, 124). There are few self-assessment questionnaires that evaluate swallowing

function in patients with PD. One of the most comprehensive and popular is the Swallowing Quality-of-life (SWAL-QOL) questionnaire, which is designed for a variety of patients, including patients with neurodegenerative disorders. However, this questionnaire is rather long, consisting of 44 items. The main reason for choosing the ROMP-swallowing subscale was that it can be administered in a short time and even in frail elderly (125), it is originally developed for PD patients and translated to Norwegian.

A validation study on the ROMP subscales found that parameters of the ROMP swallowing subscale presented with Cronbach's alpha 0.87 and Intraclass correlation coefficient (ICC) 0.86, suggesting that this subscale might be less reliable for clinical use than the other subscales (88). However, the parameter-limits were arbitrary, and the parameters are not considered poor. The ROMP was validated on community-dwelling patients with mild to moderate symptoms. Low patient-proxy agreement may justify the creation of a caregiver-rated version of the ROMP as caregivers tend to rate the patients symptoms as more severe than patient's themselves (88). At the same time, this may interfere with the principal of PROMs. As Teisberg and Porter have noted in their work; "value in any field is defined by the customer, not the supplier" (126). Therefore, it is important to measure outcomes from the patient's perspective using PROMs. The patients' self-perception of changes in swallowing may bring implications for clinical practice and future research. If patients can assess their own swallowing burden, this will provide a more accurate assessment of swallowing difficulties as well as an agreement between the patient and the health care provider of the proper treatment. This may contribute to a more accurate dysphagia diagnosis and a more adequate therapeutic plan, improving communicative effectiveness and maintaining swallowing function for a longer time. Consequently, one can improve the quality of life of these patients.

Underreporting of dysphagia in PD is previously documented (73). Many patients are unaware of their own swallowing difficulties due to compensatory mechanisms concealing the true condition. One could include an objective instrumental analysis like Videofluoroscopic Study of swallowing (VFSS) and Fibreoptic Endoscopic Evaluation of swallowing (FEES) for a standardized measure. ESPEN also recommends using these instruments (79), however these are not often available in the clinic. On the other hand, if one should uphold the principle of PROMs, a subjective measurement tool allows patients themselves reporting dysphagia. If patients are not aware of their dysphagia, one may arise

questions whether usage of PROMs is appropriate. Quality of life may be impacted as the severity of dysphagia is likely to increase during the course of the disease. However, if dysphagia is not perceived as a problem for the patient, one can question whether it is in fact the patient themselves can best report symptom burden. A possible solution to this dilemma could be to include an objective measurement method in addition to self-reporting in a questionnaire. This way, one collects more accurate data of swallowing function based on both a subjective and an objective measurement. This was not possible in the present study, but it could be implemented in future studies.

The online questionnaire

A major limitation of the online, anonymous recruitment methodology was the possibility of participants completing the survey more than once. This has to be taken into account as there was no way to return to the participant to confirm or refute duplication, due to the anonymity principle. To minimize the duplicate issue, one had the opportunity to receive a participant receipt after completion of the questionnaire. No identical response forms were detected.

The maximum score of the original ROMP swallowing subscale is 35, however our questionnaire only allows a maximum score of 34. The last question assessing the degree to which one is afflicted or bothered by ones swallowing disturbances only had four response options instead of five. The most severe response option (option 5) was left out due to an upright blunder. This error should not have occurred. However, as it was the most severe response option that is left out, the result is potentially not exaggerated in relation to the question. It is unlikely that a significant portion of participants would select this response option if one is to compare with the response pattern of the other swallowing disturbance questions. A similar type of error was made when entering the aPG-SGA questions concerning previous weight into Nettskjema. Instead of introducing "*My weight one month ago was…*", "*My weight one year ago was…"* was introduced. Fortunately, additional information to the aPG-SGA has introduced that if one does not have access to weight one month ago, one can use weight six months ago instead. On the other hand, it is most advantageous to use the most recent weight as this may indicate more about the severity of a potential weight loss as of today. This may also be more affective to say something about one's prognosis and potentially treat the cause of weight loss before reaching a state of severe

malnutrition. However, the aim of this study was to investigate the prevalence of malnutrition risk and malnutrition, which seems to have been accomplished regardless.

One can discuss whether the length and duration of the questionnaire is significantly related to the response rate. The median response time was 8 minutes (IQR: 6.0-11.8). A questionnaire that is too long can potentially have less thoughtful and thorough answers. Alternatively, the participant will not complete the form as the participants' patience drops the longer the questionnaire is. Additionally, with questionnaires lasting longer than seven to eight minutes, completion rates dropped by five to 20% (127). This is not always the case and will depend on the type of survey, audience, and the relationship of respondents to surveyor. Following this study´s findings, it is ideal to have a questionnaire that is less than 30 questions and/or takes less than 8 minutes to complete. Seeing as the current questionnaire fulfills the latter two criteria, it is unlikely that the study lost potential responders due to the questionnaire length and completion time.

Ethical considerations

Conducing ethically sound studies that are in line with the guidelines remains essential. As mentioned in paragraph 3.1.2, the study is approved by REK and NSD. Despite the ethical approval, there has been a minor violation of anonymity. It was not captured that the master students email address was listed as the responsible person for the Nettskjema questionnaire, making it possible for participants to reach the master student directly through email. Two emails including full names were received from people who were most likely responders to the questionnaire. The first email was a comment that there was a typo in the questionnaire´s headline. The second email included feedbacks that could have been useful and resulting in an even faster and easier questionnaire for the benefit of the participants. However, the questionnaire was standardized and already open for responses, making it impossible to make item changes. This could be partially solved by piloting a larger group and also by including participants with PD. A larger pilot may also have increased the questionnaire's reliability. The questionnaire is not perfect, and some participants may feel that there are no response options that suit their situation perfectly. Further development of the questionnaire would be necessary for it to become more comprehensive. However, such changes are unlikely to have a significant impact on the results for the purpose of this study. It is important to take this

breach of anonymity into consideration, fortunately the names in the emails could not be linked to the responses as all responses remain anonymous in Nettskjema.

5.1.4 External validity and generalization

The external validity of this study refers to the extent to which the results can be accurately generalized to the Norwegian PD population as a whole. Generalizability of the results from this study is challenged by the fact that a patient membership in the Norwegian Parkinson's was necessary for inclusion and the study sample may not be representative of the Norwegian PD population.

The response rate of the questionnaire was only 16.7%. Still, 508 participants were included which is a major strength. The study population is highly comparable to similar studies from all over the world 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) (table 2) (108, 128, 129). Our study sample appears to include variation in population. Cook et al conducted a meta-analysis of internet-based surveys and points out that "Response representativeness is more important than response rate in survey research. However, response rate is important if it bears on representativeness" (130). As no information about the non-responding participants was available, the reasons 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 (131). One other reason for non-response which is specific for web-based surveys is that since the invitation to the questionnaire was sent to participants by email, the spam filter may have caused potential participants to overlook the invitation. The spam filter feature used in current email systems are usually strong and this issue could have affected the response rate in the present study. It is also a potential bias connected to that the one who responded was not the person with PD but their next of kin. Theoretically, all participants that had access to the participation-link could reply to the questionnaire. The link could have been shared with friends, acquaintances or on social media regardless of whether recipients had PD or were members of the association.

In conclusion, overall the study sample appears to be representative of the PD population as well as response rate being sufficient. With the mentioned limitations in mind, the results should be reckoned as generalizable to the Norwegian PD population.

5.2 Discussion of results

5.2.1 Malnutrition risk and malnutrition

The current study resulted in a malnutrition risk diagnosis of 34% of the participants, which is within the range of results of previous studies were ranging from 6.3-55.5% as illustrated in table 2. A study by Sheard et al. used the PG-SGA on a community-dwelling PD population, however revealing a lower prevalence of participants at malnutrition risk (15%) (40). This result may be explained by the fact that the sample size in our study was four times larger, and for this reason, may be more accurate. Additionally, in the study by Sheard et al., the patients had to physically meet up to have a dietitian perform the entire PG-SGA, which could create a barrier for the frailer participants. The most socially isolated and those with higher disease severity are also the least likely to participate in research, regardless of setting. The results may not be generalizable to the wider community-dwelling PD population in which the rates of malnutrition may be higher. The progression of PD is often accompanied by a consequent loss of weight (26, 83). However, it has not been established that nutritional problems occur more frequently among patients who have had the diagnose the longest. This may be important to investigate in future studies.

A weight loss is defined as a decrease in body weight resulting from either voluntary (diet, exercise) or involuntary (often due to illness) circumstances (132). In the present study, the only anthropometric variable that revealed a statistically significant difference between the malnutrition groups was weight loss ($p<0.001$). However, one natural explanation for this result is that the weight loss variable is basis for categorization in the aPG-SGA. An uncertainty lies in potential causes of weight loss and whether the weight loss was voluntary or not. It is conceivable that some of the participants may have had an expected weight loss, such as after an operation or due to comorbidities (metabolic diseases, poorly controlled diabetes, cancer or psychological conditions unrelated to PD). Men experience a greater weight loss the past six months than women as opposite to previous studies (58). One explanation to this is that more men participated in the study and greater variations may have

been included. In relation to diagnosis, the greatest recent weight loss (past two weeks) was found in participants with other PD diagnoses (atypical parkinsonism, MSA, PSP or CBD) (18.8%) than the participants with PD and parkinsonism (10% and 15% respectively). However, the skewness in the distribution of diagnoses makes it difficult to interpret the result. Previous studies have revealed a correlation between disease severity and decreased BMI in MSA (133). MSA patients are suffering from additional neuropathology and symptoms like dysphagia may develop faster than in PD (24). Further investigation of the relationship between nutritional status and MSA would be useful.

The body composition changes as one gets older and studies suggest that people with PD may be exposed to excess adiposity coexisting with depletion of lean body mass (134, 135). This is known as sarcopenic obesity. Sarcopenia is defined as an age-related syndrome characterized by progressive loss of skeletal muscle mass and strength (136). Patients with sarcopenic obesity may have an equally low muscle mass as underweight patients which contributes to functional impairment and poor health-related quality of life (137, 138). By collecting weight and height data, one could investigate how many malnourished patients were classified as overweight and obese. Among the 33 malnourished participants, eight (24.2%) were categorized as overweight and five (15.2%) as obese, while only nine (27.3%) were categorized as underweight. This study highlights the fact that anthropometric measures alone would not have identified all the malnourished participants in this population.

5.2.2 Dysphagia

About half of the participants replied that they had no problems (51%) with their ability to swallow solids and no general concerns (57%) about swallowing disturbances. This indicates that about half of the participants have more or less problems with swallowing solids and the psychological strain this may generate. These results are somewhat similar to a previous study mentioned (67), which revealed that the prevalence of suspected dysphagia in older people (age >65 years) were 25.1% in independent and 53.8% in dependent participants as well as a significant increase with advancing age and care level. In the current study, participants who have had PD for both a relatively short and long time period are well represented in the study sample. Clinical dysphagia in PD often occurs later in the disease course. One has usually had PD for many years before receiving the initial diagnose and this also creates uncertainty about when in the disease course it is common to experience dysphagia. Since most patients

evaluated were classified as well-nourished, one can hypothesize that, if more hospitalized and institutionalized patients were evaluated, patients might have presented with a higher degree of swallowing impairment, as scored by the questionnaire.

In relation to differences between PD diagnoses, a reservation was made in advance of analysis as there were few participants in each diagnostic group. MSA and PSP patients reported a higher median ROMP score than the other PD diagnoses, which indicates a higher swallowing burden. In previous studies, prevalence of subjective dysphagia is reported to be much higher in MSA (73%) and PSP (83%) due to additional neuropathology. Hence, when subjective dysphagia is reported in the early stage of disease, this may be a red flag for MSA and PSP patients and these may require closer follow-up. This is especially when dysphagia is confirmed by endoscopic or radiologic swallowing assessment (139). In addition, 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 (88, 140). Although dysphagia was reported more prevalent for MSA and PSP in this study, there is a large weakness in these data, ie the number of participants in each group. Few participants open up to the fact that coincidences and bias can affect data to a greater extent.

Twenty-three percent ($R2 = 0.229$) of the variation in aPG-SGA score could be explained by the regression model including total ROMP-score, age group and disease duration. This indicated that dysphagia is a considerable contributor to malnutrition. Due to the high number of cases it this study, it is purposeful to include these factors as they are logical confounders related to both dysphagia and malnutrition, despite no significant impact on R2. The majority of variation in the regression model would be explained by other factors which remains unknown. One can speculate which factors matters for the nutritional status in these patients for example elderly people living alone, disease-prone factors and geriatric syndromes. In this study, there is no basis for claiming which other factors may influence this association. but this can be investigated in future studies.

5.2.3 Nutritional impact symptoms other than dysphagia

The most frequently reported nutrition impact symptoms 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 (40) in addition to swallowing problems. The frequency of symptoms appears to be relatively high in the present study. This

is not unexpected given the presence of increased malnutrition risk due to loss of appetite, altered eating function and higher energy expenditure. The prevalence of change in smell was unexpectedly low, seen as olfactory dysfunction is among the earliest nonmotor features of PD (141). 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 prevalence of for example change in smell may be higher. Disturbance of autonomic function of the gastrointestinal tract in PD are well documented (74) 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 (prodromal phase) (142). Early prevention and treatment of symptoms may therefore be applicable on a general basis. It is natural that malnourished participants reported more symptoms as the symptoms mapped are a part of the basis for the malnutrition categorization in the aPG-SGA. The use of various measuring tools for nutritional impact symptoms may also have affected study outcomes.

5.2.4 Clinical consequences

According to ESPEN guidelines of clinical nutrition in neurology, it is recommended to monitor nutritional status and provide nutritional therapy (79). The results of this study suggest that the presence of malnutrition risk and nutritional impact symptoms, like dysphagia is relatively common in the Norwegian PD population. This may also be an indication that symptom management is not optimal as of today. Since there are no previous data on the prevalence of nutritional impact symptoms in the Norwegian PD populations, it remains unknown to what extent such symptoms are followed up and treated in this patient group. Proper symptom management may lead to malnutrition risk patients maintaining optimal nutritional status for a longer time. Avoiding malnutrition would be beneficial in relation to fewer infections, hospitalizations and lower mortality (10). ESPEN also recommends conducting regular screening for dysphagia in patients with PD. As about half of the participants in this study had general concerns about dysphagia, it may indicate that these patients do not know where or how to get help in dealing with these problems. The findings are also verifying the need for establishing nutritional therapy to ensure optimal nutritional status and symptom management for these patients in the future.

6 Conclusion

This thesis explored the nutrition and dysphagia status, as well as symptoms in 508 patients with PD using self-reported data. Malnutrition risk, malnutrition and nutrition impact symptoms were prevalent, with

- One in three participants found to be at malnutrition risk
- Half of the participants reporting to have more or less problems swallowing solids
- Three in five reporting to have concerns about their swallowing function
- One courter of the participants assessed to have symptoms affecting their food intake
- Malnourished participants reported 34 times more symptoms than well-nourished

This study highlights the fact that malnutrition is fairly common in patients with PD and remains unrecognized, under-reported and untreated in PD patients despite unintentional weight loss and presence of nutrition impact symptoms. This study also states that one must not be underweighted to be malnourished as both overweight and obese participants were categorized as malnourished. The results of the multiple regression also suggested that an increase in ROMP score (dysphagia) was associated with an increase in aPG-SGA score, however this relationship requires further investigation. Nutrition impact symptoms and weight loss should be systematically assessed in patients with PD. Today's knowledge on nutritional needs in PD patients is insufficient. Whether identification and proper management of nutritional impact symptoms can prevent malnutrition and improve quality of life deserves further exploration.

Screening for malnutrition at regular intervals by the health professionals who have the most contact with these patients in a community setting would be beneficial. It would also provide appropriate referrals for nutrition-related care, like a dietitian. The nutrition impact symptoms should also be monitored and treated in order to potentially avoid malnutrition, which is a more difficult condition to treat when first established. A take home message and goal will therefore be prevention rather than treatment. In conclusion, there is a need for more research investigating the relationship between malnutrition and nutritional impact symptoms in PD patients.

7 Future perspectives

This work has contributed to increase knowledge about the prevalence of malnutrition risk, malnutrition and nutrition impact symptoms among people with Parkinson's disease in Norway. It also highlights the necessity for further research to elucidate the relationship between malnutrition, nutritional impact symptoms and the Norwegian PD population. This study also allows the generation of new hypotheses.

Enlighten of this subject can contribute to further investigation and research of this topic and potentially implement health initiatives. The national guidelines for prevention and treatment of malnutrition (10) by the Health directorate include some key points to convey to health personnel, which embrace:

- To assess nutritional status
- To give people at nutritional risk targeted nutritional treatment
- To document nutritional status and measures in patient journals and epicrisis
- To pass on the documentation to the next level of care

This also applies to the PD population, as nutrition impact symptoms as well as increased energy expenditure is a reality. With a greater understanding of PD patients' nutritional impact symptoms and malnutrition status, it will be possible to improve the dietary treatment of these patients in the future. This regards actions like correction of medication that counteract symptoms increasing energy consumption (rigidity, tremor, bradykinesia), while supplementing with nutritional measures if food intake is low. There exists little knowledge about nutrition and PD in Norway today. A topic that is somewhat mapped is the protein redistributed diet. The danger of having limited nutritional information available is that patients may start this diet without adequate guidance. A common misconception is that one has an adequate protein intake distributed throughout the day, and not to eat less protein, which is the opposite of what is recommended to prevent malnutrition. Increasing the information on nutrition and PD, as well as guidance from a dietitian, may help modify such dietary restrictions (ie, liberalize the patient's diet). As the focus on exercise and activity increases in the PD population, it is important that the field of nutrition keeps up with this development.

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9 Appendices

Appendix 1. REK approval

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Ingrid Dønåsen	22845523	24.06.2019	2019/865 REK sør-øst B
			Deres dato:	Deres referanse:
			30.04.2019	

Vår referanse må oppgis ved alle henvendelser

Asta Bye
OsloMet - storbyuniversitetet

2019/865 Men hva gjør vi med maten? - et prosjekt for å kartlegge ernæringsproblemer hos personer med parkinsonisme

Forskningsansvarlig: OsloMet - storbyuniversitetet
Prosjektleder: Asta Bye

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst B) i møtet 12.06.2019. Vurderingen er gjort med hjemmel i helseforskningsloven (hforsknl) § 10.

Prosjektleders prosjektbeskrivelse
Dette er en tverrsnittstudie som skal kartlegge symptomer som kan påvirke matinntaket, hos personer med Parkinsons sykdom i Norge. Internasjonal forskning tyder på at personer med denne sykdommen har en rekke plager og symptomer som potensielt kan påvirke matinntaket. Det er imidlertid mindre kunnskap om hvor utbredt disse ernæringsrelaterte symptomene er og hvordan de faktisk er relatert til vekttap eller underernæring. Det er heller ikke tidligere gjort slike studier blant personer med sykdommen i Norge. Overordnet hensikt med studien er derfor å undersøke hvor mange som har symptomer som vi vet har betydning for matinntaket og om det er en sammenheng mellom forekomsten av disse symptomene, vekttap og underernæring. Kunnskap om dette er viktig for å videre studier som kan undersøke betydningen av kosthold og ernæring for personer med Parkinsons sykdom.

Vurdering
Prosjektet har som formål å undersøke forekomst av ernæringsrelaterte problemer og risiko for underernæring blant personer med Parkinsons sykdom. Data samles inn via en nettbasert spørreundersøkelse som skal sendes ut til medlemmer av Norges Parkinsonforbund, det vil si ca. 3500 personer. Det forventes en svarandel på ca. 10%. Spørreskjemaet kan fylles ut av personen selv eller av en pårørende. Innsending av besvarelse anses som samtykke.

Informasjon til deltakerne
Komiteen har noen merknader til informasjonen som gis til deltakere før besvarelse av spørreskjemaet:

- Deltakere refereres til ParkinsonNet via en lenke dersom de har behov for å komme i kontakt med helsepersonell etter å ha svart på spørreskjemaet. Fagpersonene som listes på siden er fysioterapeuter, logopeder og ergoterapeuter. Komiteen anser dette som positivt, men mener at deltakerne også bør informeres om hvem de kan kontakte dersom de har behov for kontakt med annet helsepersonell, som for eksempel lege eller klinisk ernæringsfysiolog.
- Det må fremgå at både personer med Parkinsons sykdom (brukere), pårørende og voksne barn av brukere kan besvare undersøkelsen.

Besøksadresse:
Gullhaugveien 1-3, 0484 Oslo

Telefon: 22845511
E-post: post@helseforskning.etikkom.no
Web: http://helseforskning.etikkom.no/

- Det må også stå at REK har vurdert og godkjent prosjektet, samt hva som er REK-referansen.

Komiteen ber også om at det avklares med Personvernombudet at teksten er i tråd med personopplysningsloven av 2018 (GDPR).

Spørreskjema
Komiteen har også en merknad til spørreskjemaet:

- I spørsmål 6 bør forkortelsene forklares, selv om man forventer at målgruppa kan disse begrepene.

Utover dette har komiteen ingen innvendinger til prosjektet og det godkjennes dermed på følgende vilkår:

1. Informasjonen om prosjektet som gis til deltakerne (Forespørsel om deltakelse i forskningsprosjektet) må revideres i tråd med komiteens kommentarer.
2. Spørreskjemaet må revideres i henhold til komiteens merknad.

Reviderte dokumenter med markerte endringer skal ettersendes REK til orientering via e-post til post@helseforskning.etikkom.no

Vedtak
REK har gjort en helhetlig forskningsetisk vurdering av alle prosjektets sider. Prosjektet godkjennes med hjemmel i helseforskningsloven § 10, under forutsetning av at ovennevnte vilkår oppfylles.

I tillegg til vilkår som fremgår av dette vedtaket, er godkjenningen gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknad og protokoll, og de bestemmelser som følger av helseforskningsloven med forskrifter.

Vi gjør samtidig oppmerksom på at etter ny personopplysningslov må det også foreligge et behandlingsgrunnlag etter personvernforordningen. Det må forankres i egen institusjon.

Tillatelsen gjelder til 01.08.2021. Av dokumentasjonshensyn skal opplysningene likevel bevares inntil 01.08.2026. Forskningsfilen skal oppbevares atskilt i en nøkkel- og en opplysningsfil. Opplysningene skal deretter slettes eller anonymiseres, senest et halvt år fra denne dato.

Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder «*Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse og omsorgssektoren*».

Sluttmelding og søknad om prosjektendring
Dersom det skal gjøres vesentlige endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende endringsmelding til REK.

Prosjektet skal sende sluttmelding på eget skjema, senest et halvt år etter prosjektslutt.

Klageadgang
REKs vedtak kan påklages, jf. forvaltningslovens § 28 flg. Eventuell klage sendes til REK sør-øst B. Klagefristen er 18. august 2019. Dersom vedtaket opprettholdes av REK sør-øst B, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering, jf. forskningsetikkloven § 10 og helseforskningsloven § 10.

Komiteens avgjørelse var enstemmig.

Til informasjon bytter REK søknadsportal i sommer. Den nye portalen vil være klar i august.
Se våre hjemmesider under «Aktuelle meldinger» for oppdatert informasjon.

Med vennlig hilsen

Ragnhild Emblem
Professor, dr. med.
leder REK sør-øst B

Ingrid Dønåsen
Rådgiver

Kopi til: groj@oslomet.no
OsloMet ved øverste administrative ledelse post@oslomet.no

Appendix 2. NSD approval

NSD NORSK SENTER FOR FORSKNINGSDATA

NSD sin vurdering
Prosjekttittel

Men hva gjør vi med maten? - et prosjekt for å kartlegge ernæringsproblemer hos personer med parkinsonisme
Referansenummer

441317

Registrert

23.08.2019 av Asta Bye - abye@oslomet.no

Behandlingsansvarlig institusjon

OsloMet - storbyuniversitetet / Fakultet for helsevitenskap / Institutt for sykepleie og helsefremmende arbeid

Prosjektansvarlig (vitenskapelig ansatt/veileder eller stipendiat)

Asta Bye, abye@oslomet.no, tlf: 97568595

Type prosjekt

Studentprosjekt, masterstudium

Kontaktinformasjon, student

Julie Sørbøe Helliesen, j.s.helliesen@studmed.uio.no, tlf: 94258222

Prosjektperiode

01.08.2019 - 01.08.2026

Status

13.09.2019 - Vurdert anonym

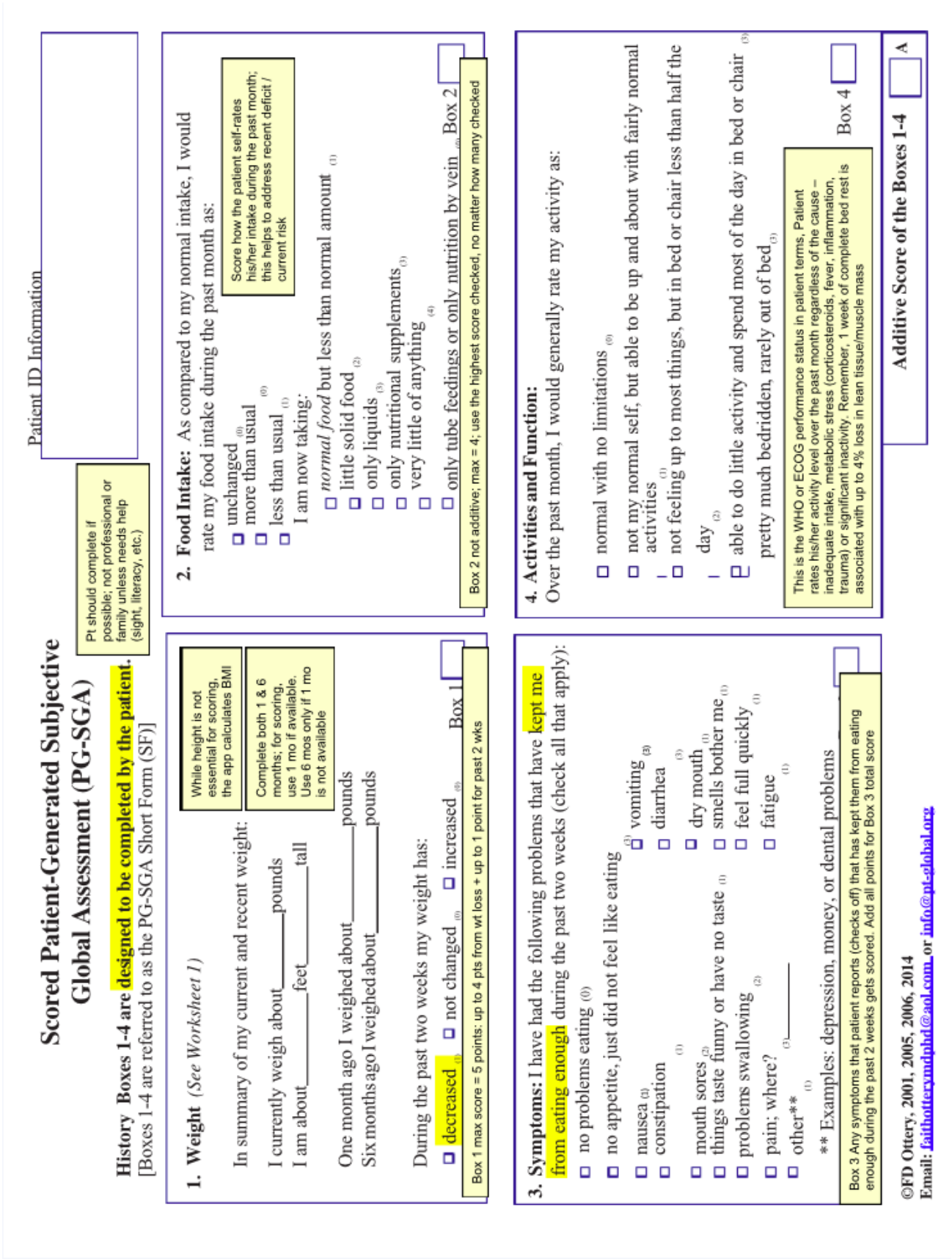
Vurdering (1)

13.09.2019 - Vurdert anonym

Det er vår vurdering at det ikke skal behandles direkte eller
indirekte opplysninger som kan identifisere enkeltpersoner i dette prosjektet,
så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet den
13.09.2019 med vedlegg, samt i meldingsdialogen mellom innmelder og NSD.
Prosjektet trenger derfor ikke en vurdering fra NSD. HVA MÅ DU GJØRE DERSOM DU
LIKEVEL SKAL BEHANDLE PERSONOPPLYSNINGER? Dersom prosjektopplegget endres

og det
likevel blir aktuelt å behandle personopplysninger må du melde dette til NSD ved
å oppdatere meldeskjemaet. Vent på svar før du setter i gang med behandlingen av
personopplysninger. VI AVSLUTTER OPPFØLGING AV PROSJEKTET Siden prosjektet ikke
behandler personopplysninger avslutter vi all videre oppfølging. Lykke til med
prosjektet! Kontaktperson hos NSD: Ina Nepstad Tlf. Personverntjenester: 55 58
21 17 (tast 1)

Appendix 3. Scored abridged Patient-generated subjective global assessment (aPG-SGA)



Appendix 4. Radboud oral motor inventory for Parkinson's disease (ROMP)

Parkinson Society British Columbia

Last Updated February 27, 2019

RADBOUD ORAL MOTOR INVENTORY FOR PARKINSON'S DISEASE

Participant Self-Evaluation

The Radboud Oral Motor Inventory for Parkinson's disease (ROMP) is a self-evaluation tool to evaluate perceived problems with speech, swallowing and saliva control in patients with PD or atypical Parkinsonism. This can be used to identify initial concerns or monitor any changes. Share your results with your physician and health care team to help facilitate support in the areas identified as troublesome. You can complete the ROMP every 6 months to a year, or anytime you think you have experienced changes in drooling, communication or swallowing. We recommend keeping previously completed copies for comparison. Please refer to your responses on the ROMP Questionnaire to help increase your awareness of any difficulties with communication and speech.

PART A - SPEECH

1) **My voice nowadays is:**
   a) My voice sounds normal.
   b) My voice sounds a bit softer or more hoarse than it used to be.
   c) My voice is clearly softer or more hoarse.
   d) My voice is very soft or hoarse.
   e) My voice can hardly be heard.

2) **My ability to speak to familiar people:**
   a) Familiar people find me intelligible as normal; I do not have to repeat.
   b) For familiar people, I am sometimes less intelligible when I am tired or do not pay attention.
   c) For familiar people, I am frequently less intelligible; I have to repeat multiple times.
   d) For familiar people, I am very often unintelligible, especially when I am tired.
   e) For familiar people, I am usually unintelligible, also when I repeat.

3) **My ability to speak to strange people:**
   a) Strange people find me intelligible as normal; I do not have to repeat.
   b) For strange people, I am sometimes less intelligible when I am tired or do not pay attention.
   c) For strange people, I am frequently less intelligible; I have to repeat multiple times.
   d) For strange people, I am very often unintelligible, especially when I am tired.
   e) For strange people, I am usually unintelligible, also when I repeat.

4) **The use of my telephone:**
   a) Using the telephone is no problem for me at all.
   b) I use my telephone as I used to do, but I need to pay more attention than I used to do.
   c) I have to repeat regularly when I am on the telephone.
   d) I am reluctant to use the telephone because people do not understand me.
   e) Using the telephone is impossible for me because my speech is inadequate.

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604-662-3240 | 1-800-668-3330 | info@parkinson.bc.ca

5) **When I start to talk:**
   a) I can say what I want to say as easy as I used to.
   b) I sometimes have to think a bit longer than I used to.
   c) I need more time or easily forget what I wanted today.
   d) I need help to formulate my thoughts.
   e) I usually do not know what to say and prefer to stay silent.

6) **Having a conversation in a group:**
   a) I can take part in conversations as always.
   b) I can take part in a conversation, but I need to pay more attention.
   c) I can take part in a conversation only when others take into account that I need more time.
   d) I can take part in a conversation only when familiar people assist me.
   e) I feel left out because I cannot take part.

7) **How bothered are you as a result of your difficulty speaking?**
   a) I have no difficulty speaking.
   b) My difficulty speaking bothers me a little.
   c) I am bothered by my difficulty speaking, but it is not my priority concern.
   d) My difficulty speaking bothers me a lot because it is very limiting.
   e) Difficulty speaking is the worst aspect of my disease.

PART B - SWALLOWING

1) **How many times do you choke when eating or drinking?**
   a) I do not choke at all or not more than I used to.
   b) I choke about once a week.
   c) I choke almost daily.
   d) I choke about 3 times a day or during every meal.
   e) I choke more than 3 times a day or multiple times during meals.

2) **Are you limited during drinking?**
   a) I can drink liquids as easily as I used to.
   b) I can easily drink liquids, but I choke a little easier than used to.
   c) I can drink safely only when I concentrate on it.
   d) To drink safely, I need to use a special cup or technique.
   e) I can drink safely only when I take thickened liquids.

3) **Are you limited during eating?**
   a) I can eat as easily as I used to.
   b) I can eat everything, but it takes me longer than before.
   c) I have to avoid tough or hard solid foods (meat, peanuts, etc.).
   d) I can eat only soft or easy chewable food.
   e) I have to use supplemental or non-oral feeding.

4) **Do you have difficulty swallowing pills?**
   a) I take my pills just like I used to.
   b) I have a little more difficulty swallowing my pills than I used to.
   c) I can take my pills only with applesauce or using a specific technique.
   d) Swallowing my pills is a struggle nowadays.
   e) I cannot swallow pills anymore and need another way of taking medication.

5) **Does your swallowing difficulty limit your dining with others?**
   a) Eating with others is no problem for me at all.
   b) I dine and drink with others, but I have to take my swallowing difficulty into account.
   c) I prefer eating in the presence of familiar people in familiar places.
   d) I eat only at home and in the presence of familiar people.
   e) I can eat only at home and with the assistance of a skillful caregiver.

6) **Are you concerned about your difficulty swallowing?**
   a) I do not experience difficulty.
   b) I have some difficulty swallowing, but I am not concerned about it.
   c) I am a little concerned about my difficulty swallowing.
   d) I am becoming more concerned about my difficulty swallowing.
   e) I am very much concerned about my difficulty swallowing.

7) **How bothered are you as a result of your difficulty swallowing?**
   a) I have no difficulty swallowing.
   b) My difficulty swallowing bothers me a little.
   c) I am bothered by my difficulty swallowing, but it is not my priority concern.
   d) My difficulty swallowing bothers me a lot because it is very limiting.
   e) My difficulty swallowing is the worst aspect of my disease.

PART C - SALIVA

1) **Do you experience loss of saliva during the day?**
   a) I do not lose saliva during the day and do not feel accumulation of saliva in my mouth.
   b) I do not lose saliva, but I feel accumulation of saliva in my mouth.
   c) I lose some saliva in the corners of my mouth or on my chin.
   d) I lose saliva on my clothes.
   e) I lose saliva on my clothes, but also on books or on the floor.

2) **How often do you experience increased amounts or loss of saliva?**
   a) Less than once a day.
   b) Occasionally: on average, once or twice a day.
   c) Frequently: 2 to 5 times a day.
   d) Very often: 6 to 10 times a day.
   e) Almost constantly.

3) **Do you experience loss of saliva during the night?**
   a) I do not experience loss of saliva during the night at all.
   b) My pillow sometimes gets wet during the night.
   c) My pillow regularly gets wet during the night.
   d) My pillow always gets wet during the night.
   e) Every night my pillow and other bedclothes get wet.

4) **Does your (loss of) saliva impair your eating and drinking?**
   a) No, my (loss of) saliva does not impair my eating or drinking.
   b) Yes, my (loss of) saliva occasionally impairs my eating or drinking.
   c) Yes, my (loss of) saliva frequently impairs my eating or drinking.
   d) Yes, my (loss of) saliva very often impairs my eating or drinking.
   e) Yes, my (loss of) saliva always impairs my eating or drinking.

5) **Does your (loss of) saliva impair your speech?**
   a) No, my (loss of) saliva does not impair my speech.
   b) Yes, my (loss of) saliva occasionally impairs my speech.
   c) Yes, my (loss of) saliva frequently impairs my speech.
   d) Yes, my (loss of) saliva very often impairs my speech.
   e) Yes, my (loss of) saliva always impairs my speech.

6) **What do you have to do to remove saliva?**
   a) I do not have to remove saliva.
   b) I always carry a handkerchief to remove possible saliva.
   c) I daily use 1 or 2 handkerchiefs to remove some saliva.
   d) I daily need more than 2 handkerchiefs to remove saliva.
   e) I need to remove saliva so frequently that I always keep tissues near me or use a towel to protect my clothes.

7) **Does the loss of saliva limit you in contacts with others?**
   a) My loss of saliva does not limit me in contacts with others.
   b) I have to pay attention, but that does not bother me.
   c) I have to pay more attention because I know that others could see me losing saliva.
   d) I try to avoid contact when I know that I lose saliva.
   e) I notice that others avoid having contact with me because I lose saliva.

8) **Does your loss of saliva limit you in doing activities inside or outside your home (work, hobbies)?**
   a) My (loss of) saliva does not limit me in activities.
   b) I have to pay attention when I am busy, but that does not bother me.
   c) I have to pay more attention, which is rather effortful.
   d) My loss of saliva limits me in being active.

9) **How bothered are you as a result of your (loss of) saliva?**
   a) Due to my loss of saliva, important activities are no longer possible for me.
   b) I hardly notice loss of saliva.
   c) Feeling more saliva or losing it bothers me a little.
   d) I am bothered by my loss of saliva, but it is not my priority concern.
   e) My loss of saliva bothers me a lot because it is very limiting.
   f) Losing saliva is the worst aspect of my disease.

Appendix 5. Written informed consent prior to participation

Spørreskjema om ernæring og Parkinsons sykdom

Forespørsel om deltakelse i forskningsprosjektet

OsloMet - Storbyuniversitetet sammen med Norges Parkinsonforbund og Universitet i Oslo inviterer deg til å delta i spørreundersøkelse. Det er OsloMet – *Storbyuniversitetet* og forskergruppen aldring, helse og velferd som er ansvarlig for prosjektet.

Undersøkelsen skal kartlegge forekomsten av ernæringsproblemer blant personer med Parkinsons sykdom. Svarene som sendes skal vi bruke til å undersøke følgende:

- Hvor mange har symptomer som kan forårsake ernæringsproblem
- Hvor mange har risiko for å utvikle underernæring
- Hvordan er sammenhengen mellom symptomer og risiko for underernæring

Resultatene vil benyttes som grunnlag for å undersøke om kostrådgiving kan bedre ernæringstilstanden til personer med Parkinsons sykdom og til å gi råd til myndighetene om eventuelle behov for ernæringsstøtte.

Hvorfor får du spørsmål om å delta?

Alle som er medlem av Norges Parkinsonforbund får spørsmål om å delta.

Hva skjer med opplysningene som samles inn?

I denne undersøkelsen benytter vi Nettskjema som er et elektronisk spørreskjema. Når vi bruker dette skjemaet, kan vi ikke finne tilbake til den som har svart etter at skjemaet er sendt inn. Det er fordi adressen til den PC-en du benytter for å svare ikke blir lagret. Du svarer derfor helt anonymt og ingen personidentifiserbare data lagres noe sted. All informasjon som kommer inn behandles konfidensielt. Alle som behandler materiale og innhentede data er underlagt taushetsplikt som er regulert i helselovene og forvaltningsloven.

Frivillig deltakelse

Det er frivillig å delta i prosjektet. Når du går inn i nettskjemaet kan du når som helst avslutte besvarelsen. Ingenting av det du legger inn vil bli lagret før du trykker **SEND.**

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?

Prosjektet skal etter planen avsluttes 01.08.2021 Opplysningene om det vil oppbevares anonymisert inntil 01.08.2026.

Hva gir oss rett til å behandle personopplysninger om deg?

Undersøkelsen er vurdert og godkjent av Regional etisk komite (REK) sør-øst (refnr:2019/865).

På oppdrag fra OsloMet – Storbyuniversitetet har NSD-Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?

Dersom du har spørsmål til studien, ta kontakt med prosjektleder Asta Bye på mail: abye@oslomet.no.

Om du i finner ut at du har behov for å komme i kontakt med helsepersonell etter å ha svart på spørreskjemaet kan du henvende deg direkte til Norges Parkinsonforbund (tlf. 22 00 83 00 eller mail: post@parkinson.no) som vil hjelpe deg med å komme i kontakt med relevante fagpersoner.

Undersøkelsen tar ca 8-10 min å gjennomføre

Appendix 6. The questionnaire as presented in Nettskjema

Når du svarer på dette spørreskjemaet, samtykker du til å delta.

Norges Parkinsonforbund

Sideskift

Side 2

Bakgrunnsspørsmål (7 spørsmål)

Hvilket kjønn har du? *

- ○ Kvinne
- ○ Mann

Hvilken aldersgruppe tilhører du? *

- ○ Under 40 år
- ○ 40-49 år
- ○ 50-59 år
- ○ 60-69 år
- ○ 70-79 år
- ○ 80-89 år
- ○ 90+ år

Hva er din høyeste fullførte utdanning? *

- ○ 10-årig grunnskole

- Videregående utdanning
- 3-5 år høyere utdanning
- 6 år eller høyere utdanning
- Annet

Hva er din nåværende stilling? *

- Arbeid
- Pensjonist
- Ufør
- Annet

Hvilken sykdom har du? *

- Parkinsonisme
- Parkinsons sykdom
- Atypisk parkinsonisme/parkinson pluss
- Progressiv supranukleær parese (PSP)
- Multippel system atrofi (MSA)
- Cortico basal degenerasjon (CBD)

Hvor lenge har du hatt sykdommen? *

- Under 1 år
- 1-3 år
- 3-5 år
- 5-7 år
- 7-10 år
- Mer enn 10 år

Hvilken behandling har du? *

- ◯ Kun tabletter
- ◯ Hjernestimulator
- ◯ Duodopa
- ◯ Apomorfin penn
- ◯ Apomorfin pumpe

Sideskift

Side 3

Spørsmål om svelgevansker (7 spørsmål)

Hvor ofte opplever du å sette ting i halsen(vrangen) når du spiser eller drikker? *

- ◯ Jeg setter (nesten) aldri i halsen
- ◯ Jeg setter i halsen en eller to ganger i uken
- ◯ Jeg setter i halsen en gang om dagen
- ◯ Jeg setter i halsen tre ganger om dagen, eller en gang hvert måltid
- ◯ Jeg setter i halsen mer enn tre ganger om dagen, eller flere ganger per måltid

Er det vanskelig for deg å svelge drikke? *

- ◯ Jeg kan drikke som før
- ◯ Jeg kan drikke som før, men svelger lettere i vrangen
- ◯ Jeg kan bare drikke uten å svelge i vrangen hvis jeg konsentrerer meg
- ◯ Når jeg drikker må jeg bruke en kopp eller teknikk
- ◯ Jeg kan bare drikke tykflytende væsker trygt

Er det utfordrende for deg å svelge mat? *

- ◯ Nei, jeg kan spise som før
- ◯ Ja, jeg kan spise alt, men bruker lengre tid enn før

- ○ Ja, jeg må unnlate hard og seig mat (kjøtt, nøtter osv...)
- ○ Ja, maten må være myk eller finmalt
- ○ Jeg må bruke sondeernæring

Har du problemer med å svelge piller? *

- ○ Nei, jeg svelger piller like lett eller vanskelig som før (ingen endring)
- ○ Ja, jeg har litt problemer med å svelge piller enn før
- ○ Ja, jeg kan bare ta piller med syltetøy eller teknikker som gjør det lettere
- ○ Ja, å svelge piller er et stort problem
- ○ Ja, jeg kan ikke svelge piller lenger og inntak av medisin må gjøres på annen måte

Begrenser din svelging deg i å spise med andre? *

- ○ Å spise med andre er ikke noe problem for meg
- ○ Jeg spiser med andre, men må ta hensyn til mine svelgevansker
- ○ Jeg foretrekker å spise med kjente mennesker på kjente steder
- ○ Jeg spiser bare hjemme og sammen med kjente mennesker
- ○ Jeg kan bare spise hjemme og med sakkyndig hjelp

I hvilken grad bekymrer du deg over problemene med å svelge? *

- ○ Jeg har ikke problemer med å svelge
- ○ Jeg har litt problemer med å svelge, men det bekymrer meg ikke
- ○ Jeg er litt bekymret over mine problemer med å svelge
- ○ Jeg er blitt mer bekymret over mine problemer med å svelge
- ○ Jeg er veldig bekymret over mine problemer med å svelge

Hvor plaget er du av dine problemer med svelging? *

- ○ Jeg har ikke problemer med å svelge

- ◯ Mine problemer med å svelge plager meg litt
- ◯ Jeg er plaget av mine problemer med å svelge, men det er ikke min største bekymring
- ◯ Mine problemer med å svelge plager meg mye, for det begrenser mye

Sideskift

Side 4

Spørsmål om ernæringstilstand (4 delspørsmål)

1. Høyde og vekt

Høyde (oppgi med tall i cm)

Jeg er ca. __ cm *

Vekt (oppgi med tall i kg)

Jeg veier ca. __,_kg *

For 6 mnd siden veide jeg ca. __,_ kg *

For ett år siden veide jeg ca. __,_kg *

De siste 2 ukene har vekten min: *

- ◯ minsket
- ◯ vært uforandret
- ◯ økt

2. Mat og drikke

Sammenliknet med mitt normale, har matinntaket mitt siste måneden vært: *

- ○ som vanlig
- ○ mer enn vanlig
- ○ mindre enn vanlig

Jeg spiser og drikker nå: *

- ○ vanlig mat, men mindre mengder enn vanlig
- ○ litt fast føde
- ○ kun flytende
- ○ kun næringsdrikker
- ○ veldig lite av alt
- ○ kun sondeernæring eller intravenøs ernæring

3. Symptomer som har hindret deg fra å spise som før

De siste ukene har jeg hatt følgende problem som har hindret meg fra å spise tilstrekkelig (angi ett eller flere alternativer) *

- ☐ ingen problem
- ☐ kvalme
- ☐ diaré
- ☐ vondt i munnen
- ☐ smerter
- ☐ maten smaker annerledes eller ingenting
- ☐ ingen appetitt, ikke lyst til å spise
- ☐ brekninger
- ☐ forstoppelse
- ☐ munntørrhet

- [ ] plaget av lukter

Andre symptomer enn de nevnt ovenfor?

4. Fysisk funksjon

Den siste måneden vil jeg beskrive aktiviteten min som: *

- ○ normal, ingen begrensninger
- ○ ikke normal, men er oppe og er i noe aktivitet
- ○ ikke vært i form, men vært oppe mer enn halve dagen
- ○ vært i litt aktivitet, tilbringer det meste av dagen i sengen eller i stol
- ○ sengeliggende

Tusen takk for at du deltar!