Parkinson's Disease Stigma Questionnaire (PDStigmaQuest): Development and Validation of a Questionnaire for Assessing Stigma in Patients With Parkinson's Disease

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Vasilija Stopić

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List of Abbreviations

DBS	Deep brain stimulation
EFA	Exploratory factor analysis
HIV	Human Immunodeficiency Virus
NMS	Non-motor symptoms
PD	Parkinson’s disease
PDStigmaQuest	Parkinson’s Disease Stigma Questionnaire
PDQ-39	Parkinson’s Disease Questionnaire-39
PIGD	Postural instability and gait difficulty
PROMs	Patient-reported outcome measures
QoL	Quality of life
REM	Rapid eye movement
SES	Mental Health Consumers’ Experience of Stigma Scale
SI	Summary index
SIS	Social Impact Scale
SSCI	Stigma Scale for Chronic Illness

Abstract

Parkinson's disease (PD) patients often have to face stigma due to their diagnosis and the associated motor and non-motor symptoms, e.g., tremor, rigidity, and dribbling of saliva. PD stigma can have a huge impact on the patients' quality of life and therefore has to be understood more comprehensively. However, to date, only disease-generic tools or a short subscale of a PD quality of life questionnaire were available for the quantification and characterization of PD stigma. Thus, the primary aim of this doctoral thesis was to develop, test, and validate a holistic self-reported questionnaire to measure stigma of PD patients specifically. Additionally, in preparation for future studies investigating stigma effects using the newly developed and validated stigma questionnaire, another research objective was pursued: Given that the perceived control of PD patients over their condition was identified to mediate stigma effects on different outcomes such as quality of life, another objective was the cross-cultural adaption of the Parkinson's UK Scale of Perceived Control (PUKSoPC) into German language to enable its use in German-language cohorts.

The development and testing of the preliminary version of the new stigma questionnaire were addressed in a prospective, cross-sectional pilot study. The development of the so-called Parkinson's Disease Stigma Questionnaire (PDStigmaQuest) in German language was based on literature review, clinical experience, input from PD experts from many different disciplines, and patients' feedback. It resulted in a preliminary, self-reported questionnaire consisting of 28 items in five domains, namely uncomfortableness, anticipated stigma, hiding, experienced stigma, internalized stigma. Pilot testing of the preliminary version involving PD patients, healthy controls, caregivers of PD patients, and health professionals provided evidence for the feasibility, comprehensibility, appropriate acceptability, and good internal consistency of the preliminary PDStigmaQuest. Moreover, most items showed satisfactory item characteristics. Importantly, higher stigma scores were found in PD patients compared to healthy controls. Based on pilot study results, the preliminary PDStigmaQuest was modified.

The validation of the modified 25-item PDStigmaQuest was addressed in a prospective, cross-sectional validation study involving PD patients and healthy controls. Dimensionality, acceptability, and psychometric properties of the PDStigmaQuest were tested. The five reverse-scored items were rejected prior to analysis due to answering difficulties, while another item with mainly low inter-item correlations was rejected due to potential lack of fit with other items. An exploratory factor analysis produced the factors of felt stigma, hiding, enacted stigma: rejection, and enacted stigma: patronization, and resulted in the deletion of another item with low loadings on these factors. Besides, the optional work domain was retained so that the final PDStigmaQuest consisted of 18 items in five domains. Study results suggested an appropriate acceptability, high internal consistency, high test-retest reliability, sufficient construct validity, high convergent validity, and adequate known-groups validity of the final PDStigmaQuest. Furthermore, higher stigma scores were found in PD patients compared to healthy controls.

The intercultural adaptation of the English PUKSoPC in German language was conducted by four bilingual neuroscientists. It was based on internationally established guidelines describing a multi-step procedure, which included translation and back-translation of the PUKSoPC. Testing of the final German PUKSoPC on 50 PD patients did not encounter content-related or linguistic difficulties.

In conclusion, this thesis reports the development, pilot testing, and validation of the new self-reported PDStigmaQuest, now available for assessing and characterizing the complex construct of PD stigma. In addition, a German version of the PUKSoPC can now be used to capture perceived control in German-language cohorts as well as to explore its mediating effect concerning stigma. Offering self-reported tools to assess constructs such as stigma and perceived control contributes to highlighting the importance to consider the patients' perspective when evaluating their condition. Findings gathered through the application of the PDStigmaQuest will not only enhance our understanding of PD stigma but could also build the basis for stigma interventions, improving the management of PD in the future.

1. Introduction

1.1 Parkinson's disease

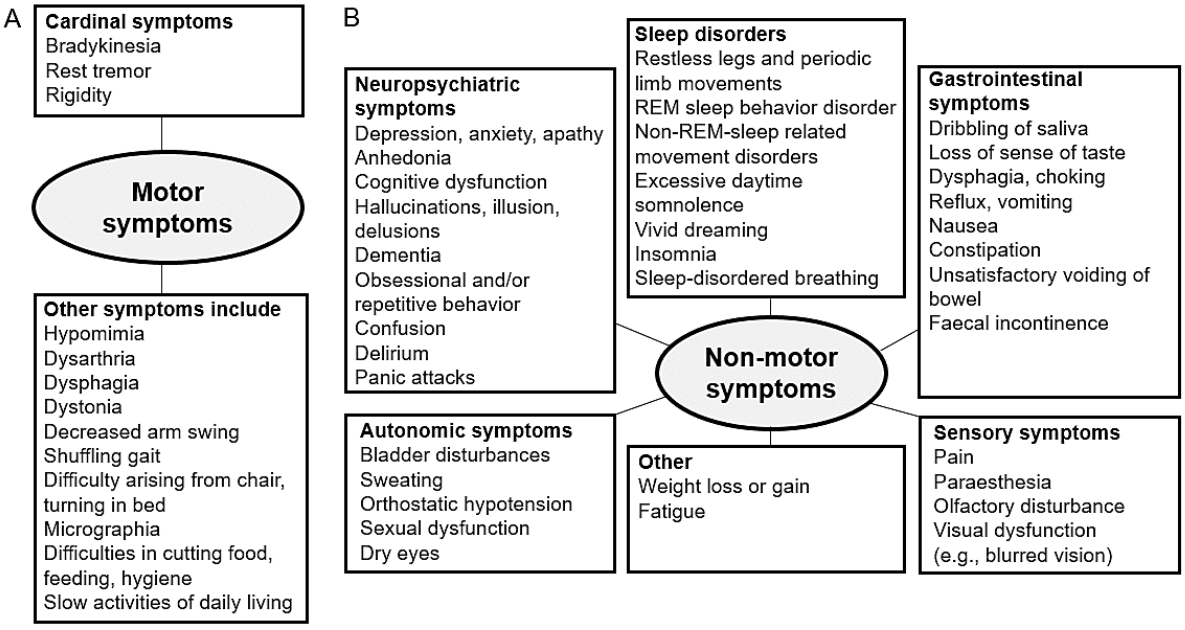
Parkinson's disease (PD) is one of the most common neurodegenerative disorders, with a prevalence increasing strongly at the age of 60 years (De Lau & Breteler, 2006; Jankovic, 2008). While the prevalence is 0.04% in people aged 40 to 49 years, 1.9% of people aged 80 years and above are affected (Pringsheim et al., 2014). Further, PD is the most common cause of Parkinsonism, followed by drug-induced Parkinsonism (Balestrino & Schapira, 2020), and occurs more frequently in men than in women, illustrated by a male-to-female ratio of 1.4:1.0 (Dorsey et al., 2018). Besides gender, relevant risk factors for developing PD are age, environmental exposures (e.g., pesticide exposure, rural living), and family history of PD or tremor, while the exact cause of PD is still unknown (Kalia & Lang, 2015; Noyce et al., 2012).

1.1.1 Symptoms and diagnosis

PD is characterized by cardinal motor manifestations including bradykinesia, rest tremor, and rigidity (Postuma et al., 2015). Other motor symptoms can be seen in Figure 1. Importantly, also non-motor symptoms (NMS) occur in patients with PD, which can be divided into different groups of symptoms (see Figure 1; Chaudhuri, Healy, & Schapira, 2006; Chaudhuri & Schapira, 2009; Schapira et al., 2017). Previous studies indicated that NMS have a higher impact on health-related quality of life (QoL) than motor symptoms (Martinez-Martin et al., 2011; Müller et al., 2013). Overall, the occurrence of motor and NMS in PD is heterogeneous between individual patients (Greenland et al., 2019). In previous literature, a distinction was made between different motor subtypes of PD based on motor examination: the tremor-dominant type, the postural instability and gait difficulty (PIGD)-type, and the mixed type (Jankovic et al., 1990; Marras & Lang, 2013; Thenganatt & Jankovic, 2014). Additionally, literature suggests six different non-motor subtypes in PD (e.g., the cognitive subtype or depression/anxiety subtypes; Sauerbier et al., 2016). Importantly, subtypes can overlap and change with disease progression, showing that PD is a highly heterogeneous disease (Greenland et al., 2019; Sauerbier et al., 2016).

Figure 1

Motor and non-motor symptoms in Parkinson's disease



Note. (A) Motor symptoms in Parkinson's disease. Adapted from Jankovic (2008) and Postuma et al. (2015). (B) Non-motor symptoms in Parkinson's disease. REM = Rapid eye movement. Adapted from Chaudhuri, Healy and Schapira (2006), Chaudhuri and Schapira (2009), and Schapira et al. (2017).

The Movement Disorders Society Clinical Diagnostic Criteria for PD are typically used for diagnosis, which primarily target the motor symptoms (Postuma et al., 2015). According to the criteria, the prerequisite for diagnosis is Parkinsonism, defined by bradykinesia and either rest tremor or rigidity, or both. Furthermore, for clinically established diagnosis, absolute exclusion criteria (e.g., selective slowing of downward vertical saccades) and red flags (e.g., absence of progression of motor symptoms within at least 5 years not explainable by treatment) have to be absent, while at least two supportive criteria (e.g., olfactory loss) have to be present. For improving the accuracy of diagnosis, it has been suggested to make use of the so-called dopamine transporter single-photon emission computed tomography brain scan

(Scherfler et al., 2007). This method can be applied to measure reduction in substantia nigra dopaminergic nerve terminals projecting to the striatum (Kalia & Lang, 2015).

1.1.2 Pathology

In PD, there is a loss of dopaminergic neurons in the substantia nigra, resulting in a dopaminergic depletion in the nigrostriatal pathway, which has an essential role in controlling voluntary motor movement (Chinta & Andersen, 2005; Damier et al., 1999). Previous literature showed that moderate to severe loss of dopaminergic cells in the substantia nigra is associated with bradykinesia and rigidity in PD (Greffard et al., 2006). Another crucial aspect of pathology is the presence of Lewy bodies, which are intracellular inclusions within the cell body with the main component of aggregated α-synuclein, a presynaptic protein (Benskey et al., 2016; Kalia & Lang, 2015; Spillantini et al., 1997). Braak et al. (2003) have proposed six different stages of PD based on a progressing Lewy pathology through different parts of the body: In the first stage, the Lewy pathology affects the peripheral nervous system, the olfactory system, and the medulla, and is subsequently spreading through different parts of the brain. Only in the third stage, the substantia nigra is affected (Braak et al., 2003). This could explain why some NMS (e.g., constipation and olfactory disturbance) in PD are observed prior to typical motor symptoms (Schrag et al., 2015; Stern & Siderowf, 2010; Tolosa et al., 2009). Essentially, PD is a multisystem and multi-transmitter condition not only affecting dopaminergic, but also noradrenergic, serotonergic, and cholinergic pathways (Jellinger, 2012; Klingelhoefer & Reichmann, 2017).

1.1.3 Disease progression

The disease phase characterized by NMS preceding motor symptoms is called premotor or prodromal PD, which can last longer than 20 years (Postuma et al., 2012). The onset of motor symptoms is followed by the diagnosis of PD (early-stage PD; Poewe et al., 2017). With disease progression, symptoms worsen and additional motor and NMS occur (e.g., dyskinesia, urinary symptoms, fluctuations in motor and NMS; Kalia & Lang, 2015). In late-stage PD, poorly treatment responsive symptoms (e.g., dysphagia, freezing of gait, falls,

speech dysfunction, dementia) occur (Kalia & Lang, 2015; Poewe et al., 2017). Mortality rates were found to be slightly higher in PD compared with the general population (Diem-Zangerl et al., 2009; Macleod et al., 2014). The most common causes of death in PD are pneumonia, cerebrovascular, and cardiovascular diseases (Pinter et al., 2015). Just like the occurrence of motor and NMS, the progression in PD is heterogeneous between individual patients (e.g., better prognosis for the tremor-dominant PD type vs. PIGD-type; Jankovic & Kapadia, 2001; Jankovic et al., 1990).

1.1.4 Treatment

So far, no disease modifying drugs influencing the neurodegenerative processes are available for treatment of PD although some are in the drug development pipeline (Kalia & Lang, 2015; McFarthing et al., 2024). Instead, current treatment options target the symptoms of the disease (Armstrong & Okun, 2020).

One main strategy for treating PD is dopaminergic pharmacotherapy, which aims at compensating for the loss of dopamine and dopaminergic function (Bloem et al., 2021; Charvin et al., 2018). Since decades, the most effective drug for treating motor symptoms in PD is levodopa, which can cross the blood-brain barrier and be converted to dopamine in remaining dopamine neurons in the brain (Connolly & Lang, 2014; Hauser, 2009). To reduce peripheral side effects of dopamine (e.g., nausea and vomiting) and prolong efficiency, levodopa is given combined with a decarboxylase inhibitor (e.g., carbidopa or benserazide; Hauser, 2009). However, long-term dopaminergic treatment is associated with the development of motor complications such as motor fluctuations (so-called “on” and “off” periods) and dyskinesia (Balestrino & Schapira, 2020). These are attributed to the intermittent stimulation of dopamine receptors through dopaminergic treatment in contrast to the continuous stimulation in healthy brains (Olanow, Calabresi, & Obeso, 2020; Olanow et al., 2006). Therefore, in advanced PD, continuous subcutaneous or duodenal infusion of levodopa via a portable pump can be considered as a treatment option, significantly reducing motor fluctuations (Balestrino & Schapira, 2020; Devos, 2009; Fung et al., 2024).

Dopamine agonists (e.g., pramipexole, ropinirole, rotigotine, apomorphine), which directly stimulate postsynaptic dopamine receptors in the striatum, can be administered as adjuncts to levodopa therapy or as early monotherapy (Jenner, 2002; Kalia & Lang, 2015). Dopamine agonists are associated with a lower risk for dyskinesia, but may cause some of the same side effects as levodopa (e.g., nausea and daytime somnolence) and are much more often associated with impulse control disorders (e.g., gambling and hypersexuality) and hallucinations (Balestrino & Schapira, 2020; Kalia & Lang, 2015). The dopamine agonist apomorphine is administered subcutaneously (via a pen or a portable pump) or sublingually in advanced PD (Drapier et al., 2016; Olanow, Factor, et al., 2020).

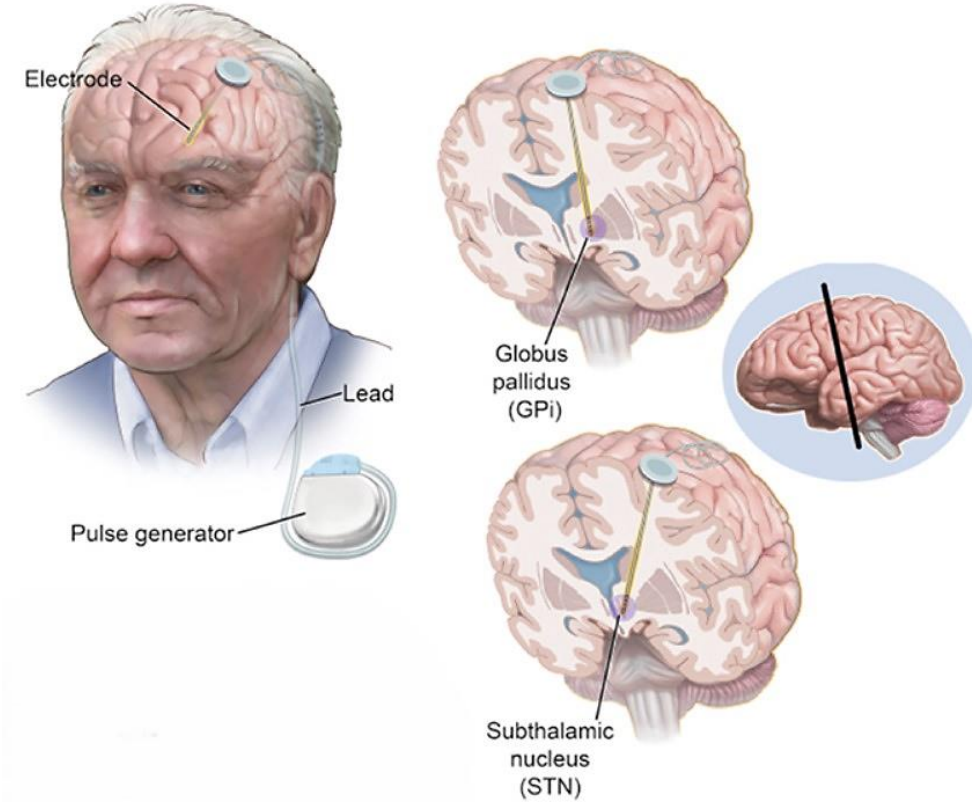
Alternative drugs include monoamine oxidase type B inhibitors and catechol-O-methyl transferase inhibitors, which inhibit enzymes involved in dopamine breakdown and metabolism (Finberg, 2019). Further, the drug amantadine can be very effective reducing dyskinesia (Connolly & Lang, 2014). Importantly, the drug therapy should be adjusted individually to every patient (Lesko & Schmidt, 2012). For example, dopamine agonists should not be applied in patients having a history of addiction, being at an increased risk of developing impulse control disorders (Kalia & Lang, 2015).

For patients in advanced stages of the disease with motor complications such as motor fluctuations and dyskinesia not responsive to medication adjustments, an effective treatment option is deep brain stimulation (DBS; Armstrong & Okun, 2020; Deuschl et al., 2006). DBS involves unilateral or bilateral implantation of electrodes into specific target areas within the brain (Fang & Tolleson, 2017). The most commonly used brain targets are the subthalamic nucleus and the internal segment of the globus pallidus (Hickey & Stacy, 2016; Ramirez-Zamora & Ostrem, 2018). The electrode is connected via subcutaneous wires to an internal pulse generator located in the chest (see Figure 2; Hickey & Stacy, 2016; Volkmann, 2004). In addition to clinical trials demonstrating beneficial effects of DBS in advanced PD compared to best medical treatment, some studies have also shown better outcomes of DBS regarding

QoL and motor function compared to best medical treatment in early-stage PD (Deuschl et al., 2006; Hacker et al., 2020; Schuepbach et al., 2013).

Figure 2

Deep brain stimulation system and most common target brain regions



Note: Simplified illustration of a unilaterally implanted deep brain stimulation system and target brain regions. The electrode is connected via subcutaneous wires to an internal pulse generator in the chest. All components of the system are located in the brain or under the skin. Adapted from Hickey and Stacy (2016), used under Creative Commons Attribution License (CC BY).

Various recommendations exist for the symptomatic management of the different NMS in PD (Seppi et al., 2011). Some NMS such as depression and anxiety can occur related to off periods of motor fluctuations, i.e., periods of reappearance or worsening of motor

symptoms and decreased mobility (Bloem et al., 2021; Storch et al., 2013; Thorp et al., 2018; Witjas et al., 2002). Therefore, dopaminergic drugs can also be considered for the treatment of these specific NMS (Bloem et al., 2021). In contrast, some NMS are worsened by dopaminergic drugs (e.g., orthostatic hypotension), highlighting the need for simultaneous consideration of motor and NMS in terms of symptomatic treatment (Bloem et al., 2021). Besides pharmacotherapy and surgery, there is a growing evidence for the efficacy of non-pharmacological treatment options in PD such as physiotherapy, treatment of cognition and behavior (e.g., cognitive training, cognitive behavioral therapy), occupational therapy, and speech therapy (Bloem et al., 2015; Ramig et al., 2008).

1.2 The construct of stigma

The diagnosis of PD and its symptoms are associated with the burden of PD stigma (Hermanns, 2013; Ma et al., 2016; McDaniels et al., 2023). In the following, an introduction to the construct of stigma is given by defining stigma as well as highlighting its relevance. Subsequently, different stigma models will be presented.

1.2.1 Definition and relevance of stigma

In 1963, the sociologist Goffman defined the term “stigma” as a deeply discrediting attribute, leading to being reduced “from a whole and usual person to a tainted, discounted one” (p. 3). Since then, the attention to stigma in literature significantly increased and several modified definitions have been proposed (e.g., Corrigan & Watson, 2002b; Link & Phelan, 2001; Rüsch et al., 2005). One often used definition of stigma better demonstrating the current understanding is the simultaneous presence of the stigma components, namely “labeling, stereotyping, separation, status loss, and discrimination” (Link & Phelan, 2001, p. 363). Many conditions have been identified being associated with stigma, among others ethnicity, sexual orientation, health-related behaviors (e.g., smoking), and illness (Campbell & Deacon, 2006). Research on chronic illnesses such as PD is often based on health-related stigma, being defined as “a social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse

social judgment" (Weiss et al., 2006, p. 13). Notably, this definition illustrates that stigma can be present without any actual stigma experiences in public when an individual is anticipating social judgement.

Stigma can occur in public places such as supermarkets, educational or healthcare settings, but also at home being discriminated against by the own family (Sidanius & Pratto, 2012). Examples of actual stigmatization experiences are being stared at, being excluded from social gatherings, and even losing one's jobs (Lewis et al., 2011; Mason-Whitehead & Mason, 2007; Rao et al., 2008). Discrimination of stigmatized individuals can result in low social status, which can in turn cause further discrimination (Link & Phelan, 2001; Major & O'Brien, 2005). Negative beliefs from others (e.g., that people with mental illnesses are to blame for their problems) can also be internalized so that the stigmatized individual adopts these beliefs (Corrigan & Watson, 2002b). Importantly, stigma can lead to social isolation, poorer mental and physical health, decreased access to medical care, delaying treatment, reduced self-efficacy, and many other detrimental consequences (e.g., Brown et al., 2000; Frost, 2011; Maffoni et al., 2017). These examples illustrate that stigma can have a determinant influence on the affected individual's life and has to be understood comprehensively.

1.2.2 Stigma models

In the last decades, different stigma models were established (e.g., Rüsch et al., 2005; Scambler & Hopkins, 1986). Scambler and Hopkins (1986) introduced a model differentiating between enacted and felt stigma. Enacted stigma refers to experiences of discrimination against individuals with a certain condition due to social unacceptability, while felt stigma represents the fear of enacted stigma and feelings of shame related to the condition (Scambler & Hopkins, 1986). Although this model was developed for stigma in epilepsy, the model was applied to various conditions such as Human Immunodeficiency Virus (HIV) and autism (Boyle, 2018; Gray, 2002; Lekas et al., 2011). During the last decades, not only discrimination experiences but also more subtle social devaluation experiences (e.g., avoidance, being patronized) were included as forms of enacted stigma (Boyle, 2018; Quinn & Earnshaw, 2013).

Investigating felt and enacted stigma, researchers found that felt stigma seems to be more prevalent than enacted stigma and is associated with more unhappiness, anxiety, and self-doubt (Ertugrul & Uluğ, 2004; Ma et al., 2016; Scambler & Hopkins, 1986).

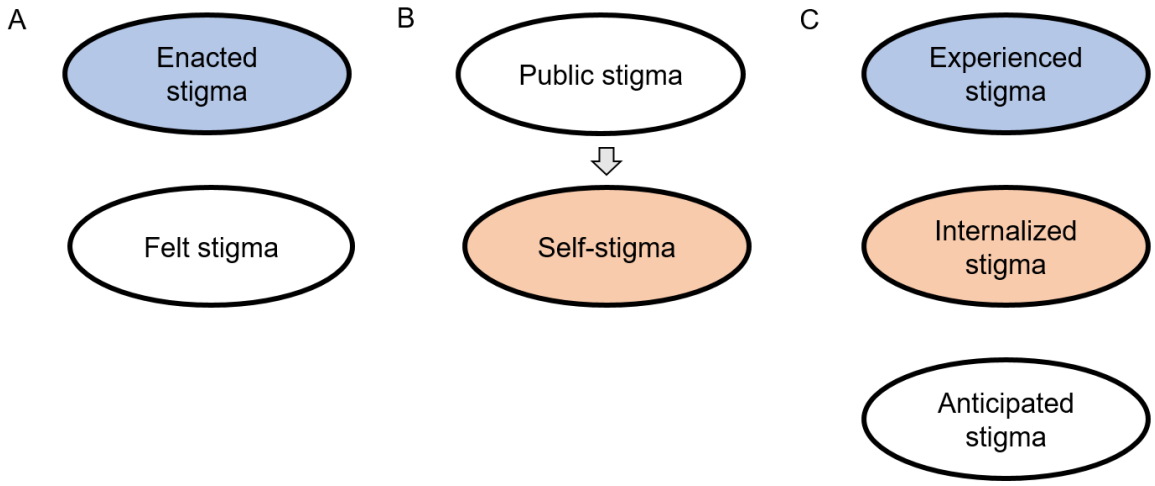
Another popular stigma model is the one by Corrigan and Watson (2002b) developed for the stigma of mental illnesses, including self- and public stigma. The latter refers to the public agreeing with negative beliefs about a stigmatized group as well as the resulting discrimination, while self-stigma refers to the internalization of these negatives beliefs about the self (Corrigan & Watson, 2002b). This model of stigma is based on the assumption that the experience of public stigma leads to the development of self-stigma. However, this model excludes situations in which stigmatization is feared or shame is experienced without having experienced public stigma before or without being aware of potential negative beliefs about his or her condition (e.g., right after the diagnosis of a chronic disease; Boyle, 2018). These situations are addressed by the previously described mechanism of felt stigma. Although felt and self-stigma represent similar but not the same stigma mechanisms, the terms are sometimes used interchangeably (e.g., Hansson et al., 2017).

Researchers developing stigma models also sometimes used the same terms for different constructs and vice versa, illustrating the inconsistent use of terminology in stigma literature (Fox et al., 2018). Especially for this reason, Fox et al. (2018) developed a stigma framework for mental illnesses meant to complement existing stigma frameworks and models. Within the framework, they differentiated between the perspective of the stigmatizer and the perspective of the stigmatized (e.g., a patient with a certain health condition). For the latter perspective, they identified three core stigma mechanisms: experienced stigma, internalized stigma, and anticipated stigma. The stigma mechanism of experienced stigma describes actual experiences of stereotyping, prejudice, or discrimination against an individual (e.g., others making fun of the individual) and is equivalent to the concept of enacted stigma (Fox et al., 2018; Quinn & Earnshaw, 2011; Scambler & Hopkins, 1986; Wahl, 1999). Internalized stigma manifests itself when the stigmatized individual applies the negative beliefs and

feelings that others have about the individual or his condition to oneself (Corrigan & Watson, 2002a; Fox et al., 2018; Quinn & Earnshaw, 2011). For example, people with mental illnesses adopt the beliefs that they are to be blamed for their illness or are dangerous (Corrigan et al., 2000). This stigma mechanism can be considered equivalent to the concept of self-stigma described by Corrigan and Watson (2002a). Finally, anticipated stigma refers to the degree to which an individual expects being the target of stereotypes, prejudice, or discrimination (Fox et al., 2018; Quinn & Chaudoir, 2009). Other researchers have categorized this stigma mechanism as part of felt stigma (Bos et al., 2013; Scambler & Hopkins, 1986). An overview of all presented stigma models is shown in Figure 3.

Figure 3

Stigma mechanisms of three different stigma models



Note. (A) Stigma model by Scambler and Hopkins (1986) initially developed for epilepsy. (B) Stigma model by Corrigan and Watson (2002b) initially developed for mental illness. (C) Stigma model from the perspective of the stigmatized by Fox et al. (2018) initially developed for mental illness. Arrows indicate that a stigma mechanism is assumed to be the result of another stigma mechanism. Stigma mechanisms in the same color (red or blue) can be seen as conceptually equivalent to each other.

1.3 Stigma in Parkinson's disease

Importantly, the nature of stigma and its consequences always depend on the considered stigmatized population (Frost, 2011). This thesis focuses on stigma in PD, which was found to be associated with worse QoL (Islam et al., 2022; Ma et al., 2016). In literature, stigma in PD has been mostly studied by distinguishing between the stigma mechanisms of enacted and felt stigma, sometimes using the terms of self-stigma or internalized stigma to refer to felt stigma, despite of the conceptual difference (e.g., Eccles et al., 2022; Hou et al., 2021; Ma et al., 2016; Rao et al., 2009). Due to its popularity in PD stigma literature, in the following, the model of enacted and felt stigma in PD will be applied to present previous findings on PD stigma. Although not primarily included in the conception of felt stigma, some researchers studying stigma in PD have described self- or internalized stigma as belonging to felt stigma (e.g., Eccles et al., 2022; McDaniels et al., 2023). For reasons of better comprehensibility and consistency, this view will also be taken in this thesis. Negative views held by the public about PD included in the concept of public stigma will not be addressed since in this thesis, stigma from the perspective of the PD patient is central.

1.3.1 Enacted stigma

Considering enacted stigma, many patients reported direct inappropriate reactions from other people to their visible symptoms such as staring, being mislabeled as a drunkard, or others showing unease in the presence of the patient (Chiong-Rivero et al., 2011; Hermanns, 2013; Maffoni et al., 2017). Further, PD patients noticed to be seen as frail by others and not being taken seriously (Hermanns, 2013). One patient described other people's comments about her as being really hurtful (Hermanns, 2013).

Notably, impaired communication caused by hypomimia (also called facial masking), speech dysfunction, bradykinesia, and cognitive dysfunction has been identified as a prominent source of stigmatization (Maffoni et al., 2017; Polityńska et al., 2019). These symptoms do not only affect verbal but also non-verbal communication and can lead to others misunderstanding PD patients and not giving them the right time to express themselves or

take decisions (Maffoni et al., 2017; Miller et al., 2006; Sunvisson & Ekman, 2001). Particularly, facial masking, characterized by a frozen, staring expression, was found to indirectly affect the QoL in PD patients through stigmatization (Ma et al., 2019). Not only people who are not familiar with the symptoms of the disease showed negative reactions to patients' facial masking, but also trained healthcare providers were judging PD patients with higher facial masking as being more depressed, less sociable, and less cognitively capable compared to patients with lower facial masking (Hemmesch, 2014; Tickle-Degnen et al., 2011). However, it was suggested that individuals with less knowledge about the disease tended to make more negative impressions of patients with higher facial masking (Tickle-Degnen & Lyons, 2004).

Extreme reactions to PD include social rejection (e.g., being invited less often) or being forced to leave the workplace (Chiong-Rivero et al., 2011). One patient even reported comments to her tremor like "Oh my god, I hope it's not Parkinson's" (Chiong-Rivero et al., 2011, p. 64), which were reported to cause embarrassment and in turn to influence the patient's decision to conceal having PD.

1.3.2 Felt stigma

In addition to enacted stigma, felt stigma represents a major burden to PD patients, which is experienced to a stronger degree than enacted stigma (e.g., Hou et al., 2021; Ma et al., 2016). It includes feelings of shame and embarrassment in public, which are often described by PD patients and can lead to emotional distress (Angulo et al., 2019; Haahr et al., 2011; Nijhof, 1995; Rao et al., 2009). Angulo et al. (2019) identified four different sources which can cause shame and embarrassment in PD: (1) motor and NMS, (2) self-perception of incapability due to losing autonomy and needing help, (3) the PD patients' belief to break social rules by showing PD symptoms, and (4) perceived deteriorated and undesirable body image.

The shame caused by PD symptoms is experienced in conjunction with different symptoms such as tremor and akinesia: situations were reported, in which the tremor led to

spilling food or drink all over a person or in which akinesia resulted in difficulties pulling out money or credit cards from the wallet (Angulo et al., 2019; Caap-Ahlgren et al., 2002). Importantly, in this context, also NMS were named as a being shameful, with drooling being one of the most reported symptoms. Moreover, sexuality disturbances (e.g., sexual incompetence and dissatisfaction with sexual experiences) and urinary problems among other symptoms can lead to shame in PD patients (Angulo et al., 2019). The shame and embarrassment related to the self-perception of incapability likely arise from losing the capability of performing even basic physical functions such as dressing and undressing (Chiong-Rivero et al., 2011). The social rules which PD patients belief to break with their symptoms are for example that adults should not drool saliva or shuffle their feet when walking (Polityńska et al., 2019). Considering the deteriorated body image, women with PD have described to feel unattractive and experiencing a loss of femininity (Subramanian et al., 2022). In male PD patients, shame could be the reason for longer waiting after symptom onset to seek treatment due to cultural values and pressure to follow masculine stereotypes (Breen et al., 2013; Tsiang & Woo, 2020).

In a study by Fleury et al. (2020), it was found that 85% of PD patients reported shame, while 26% reported embarrassment. Significantly, feelings of both shame and embarrassment can lead to social withdrawal (Ahn et al., 2022; Angulo et al., 2019; Soleimani et al., 2014). These feelings were named among others as the most important reasons for decreased presence in the community (Soleimani et al., 2014). Going further, previous work suggested that shame can result in isolation and splitting private life from public life driven by experiencing the private world as being safer and a place where the patient feels “normal” (Hermanns, 2013; Nijhof, 1995). Notably, some argue that shame can originate from the stigmatized individual without having experienced negative input from others before (Tsiang & Woo, 2020). In contrast, from a social relations perspective, shame in PD is seen as public shame, being a product of other people’s stigmatizing attitudes and actions (Simpson et al., 2013). Therefore,

it is sometimes seen as part of internalized stigma, also called self-stigma (Corrigan & Watson, 2002a; Fox et al., 2018).

As already mentioned, stigma can be internalized when PD patients apply the negative beliefs and feelings others have about PD to themselves (Corrigan & Watson, 2002a; Fox et al., 2018; Quinn & Earnshaw, 2011). For example, the belief that PD patients are unacceptably different from other people due to certain attributes of the disease often becomes internalized by PD patients (Polityńska et al., 2019). The feeling of being a burden to others as well as feeling useless also represent common internalized feelings (Hermanns, 2013; Maffoni et al., 2017). As other stigma components, internalized stigma in PD can result in avoiding social interactions and being less likely to share information about oneself with others (Haahr et al., 2011; Prenger et al., 2020). Additionally, it can lead to tremendous changes in self-image of PD patients and is associated with increased distressing emotions, harmful thoughts, and reduced self-esteem and self-efficacy (Corrigan et al., 2006; Polityńska et al., 2019).

Another important part of felt stigma represents the fear of enacted stigma, also called anticipated stigma (Fox et al., 2018; Scambler & Hopkins, 1986). It may happen that patients avoid telling others about the diagnosis or symptoms due to worrying about negative reactions (Maffoni et al., 2017; McDaniels et al., 2023): For example, with regard to hallucinations, patients worry that family members could consider them as being cognitively impaired after finding out about it (Sunvisson & Ekman, 2001). In addition, some patients stated worries about how others will perceive them when the disease progresses (Hermanns, 2013). Such concerns about negative social judgement were associated with increasing social withdrawal in PD patients (Ahn et al., 2022; Caap-Ahlgren et al., 2002). Besides, anticipated stigma was considered to result in restricted social relationships in PD and can lead to hiding of symptoms (Fothergill-Misbah, 2023; Soleimani et al., 2014).

1.3.3 Hiding symptoms and concealing the diagnosis

Especially in early stages of the disease, hiding symptoms (e.g., by keeping the hands in pockets to hide the tremor) and not telling others about the disease are common in PD

(Hermanns, 2013; Vann-Ward et al., 2017). Some patients also reported to make excuses about noticeable changes such as their slowed gait (Hermanns, 2013). Reasons for these hiding efforts include fear of discrimination experiences and rejection as well as feelings of shame and embarrassment, especially in those who previously had more physical power and physical health (Burgener & Berger, 2008; Soleimani et al., 2014; Subramanian et al., 2024). Some patients encountered positive reactions after prevailing their diagnosis, while others stated negative reactions from family members such as being told not to mention the disease again (Merritt et al., 2018; Vann-Ward et al., 2017). Notably, hiding PD symptoms requires considerable energy and is difficult in late stages of the disease when visible symptoms become worse, bearing a greater risk of enacted stigma in everyday life (Burgener & Berger, 2008; McDaniels et al., 2023).

Negative consequences of hiding the diagnosis can be guilt, avoidance of social exchange, and isolation, which can in turn lead to growing self-hate and less self-compassion (McDaniels et al., 2023). Keeping the disease a secret represents an enormous burden to a PD patient, potentially resulting in more stress and worsening of mental health consequences (Banks & Lawrence, 2006; McDaniels et al., 2023).

1.3.4 Stigma at the workplace

Especially at the workplace, the disease is often kept a secret to avoid a sense of vulnerability and hurtful situations (Carolan, 2023; Merritt et al., 2018; Vann-Ward et al., 2017). Banks and Lawrence (2006) found that only 35% informed their employer about PD. In PD, the mean time period until loss of employment was found to be approximately 5 years with a range of 0 to 17 years (Schrag & Banks, 2006). In a study by Murphy et al. (2013), 67% of retired or unemployed PD patients reported that adjustments at work (e.g., changes in type of work) could have been effective to keep their job for longer. However, stigma was identified as reason for hesitation to ask for adjustments. Especially young PD patients could be less willing to address work-related problems and adjustments at work due to fear of rejection (Koerts et al., 2016).

In general, stigma experiences at the workplace are frequently reported by PD patients and can represent an emotional burden (Mullin et al., 2018; Soleimani et al., 2014). Enacted stigma experiences include pressure to take early retirement, declined requests for adjustments, and discrimination on the job market (Carolan, 2023; Mullin et al., 2018; Polityńska et al., 2019). Felt stigma at work especially includes feelings of embarrassment and anticipated stigma (Polityńska et al., 2019; Soleimani et al., 2014). For example, a health care provider reported feeling awkward and embarrassed about telling her own patients that her symptoms would not affect her work ability (Chiong-Rivero et al., 2011). Some patients also stated fear of being seen less capable of work and worrying about a change in social status, loss of identity, and loss of respect (Carolan, 2023; Merritt et al., 2018).

It was noted that the effect of stigma at work is dependent on the perceived control PD patients experience about their condition, with a higher level of perceived control reducing stigma (Mullin et al., 2018; Verity et al., 2020). However, findings on stigma at the workplace remain limited and are primarily based on qualitative studies.

1.3.5 Contributing and associated factors of stigma

In general, more qualitative than quantitative studies on PD stigma were conducted. The main purpose of the quantitative studies was to identify contributing and associated factors of PD stigma (e.g., Hou et al., 2021; Islam et al., 2022; Salazar et al., 2019). Considering factors of psychological functioning, stigma was associated with reduced self-esteem and self-compassion as well as higher stress levels (Burgener & Berger, 2008; Eccles et al., 2022; Simpson et al., 2014). In this context, the relationship between PD stigma and depression has been well established: PD stigma seems to be a key determinant for depression and vice versa (e.g., Hou et al., 2021; Salazar et al., 2019; Schrag et al., 2001). Importantly, stigma seems to be associated with reduced QoL in PD patients, underlining the relevance of stigma in PD (Islam et al., 2022; Ma et al., 2016; Verity et al., 2020). Even after controlling for gender, disease severity, depression, and motor difficulties, stigma was found to be a determinant factor of PD patients' QoL (Ma et al., 2016). Thereby, felt stigma made a higher contribution

to QoL compared to enacted stigma. Notably, a recent study by Verity et al. (2020) found that perceived control mediated the relationship between stigma and QoL as well as stigma and depression. This concept of perceived control is defined as “the belief that one can determine one's own internal states and behavior, influence one's environment, and/or bring about desired outcomes” (Wallston et al., 1987, p. 5) and could be an important mediator for the effects of PD stigma on well-being (Verity et al., 2020).

Findings on stigma associations with age and disease duration are largely consistent, showing that higher stigma levels are associated with younger age, younger age at onset, and longer disease duration (Eccles et al., 2022; Hou et al., 2021; Lin et al., 2022; Logan et al., 2024; Salazar et al., 2019; Tomic et al., 2017). Further, different studies have suggested that higher stigma levels are associated with impaired activities of daily living (e.g., da Silva et al., 2020; Logan et al., 2024; Ma et al., 2016; Salazar et al., 2019). Considering NMS, an association with stigma was found for different symptoms beyond depression such as apathy, anxiety, and cognition (Burgener & Berger, 2008; Eccles et al., 2022; Oguru et al., 2010; Salazar et al., 2019; Verity et al., 2020; Wu et al., 2014). However, the findings on stigma and specific NMS beyond depression remain scarce. Although results of qualitative studies suggested a major role of motor symptoms in PD stigma (Hermanns, 2013; Maffoni et al., 2017), there are overall inconsistent findings on the relationship of stigma and motor function. While some quantitative studies found an association of stigma with motor function (Hou et al., 2021; Simpson et al., 2014; Tomic et al., 2017), others did not (da Silva et al., 2020; Salazar et al., 2019). A similar inconsistent pattern can be found for the association with the stage of the disease and gender (Corallo et al., 2017; Ma et al., 2016; Salazar et al., 2019; Simpson et al., 2014).

Only a few studies have been conducted to identify predictors of PD stigma (da Silva et al., 2020; Hou et al., 2021; Lin et al., 2022; Salazar et al., 2019). These results were also ambiguous: In one study, depression was identified as the only significant predictor (Lin et al., 2022). In another study, depression and additionally younger age were significant predictors

(Salazar et al., 2019), while impaired activities of daily living were the only significant predictor in a third study, despite of the inclusion of depression and age as potential predictors (da Silva et al., 2020). In contrast, Hou et al. (2021) found that motor function, longer disease duration, younger age, tremor-dominant subtype as well as higher depression scores all represented significant predictors of PD stigma.

The inconsistent results on stigma could be potentially a result of the different cultural contexts the studies were conducted in (Lin et al., 2022). Investigations on the influence of culture and ethnicity on PD stigma are limited but suggest that a there is a differential effect of specific factors dependent of the patients' cultural background (Fothergill-Misbah, 2023; Karacan et al., 2023). Moreover, in previous literature, stigma was measured by means of distinct, partially disease-generic stigma tools differing in included stigma experiences as well as length.

1.3.6 Measuring stigma in Parkinson's disease

Stigma in PD has so far often been measured by using the stigma domain of the Parkinson's Disease Questionnaire-39 (PDQ-39), the most frequently used self-reported questionnaire for QoL in PD (Peto et al., 1995). It showed high reliability and validity and refers to the last four weeks prior to completion of the questionnaire. The stigma domain is one of eight domains and consists of four items, which address concealing PD, avoiding eating or drinking in public, embarrassment caused by PD, and worries about others' reactions. The items are rated on a five-point Likert-scale from *never* (0) to *always* (4). All domain scores are standardized in form of a summary index (SI) score ranging from 0 (no impairment) to 100 (maximum impairment). Due to the domains' high internal consistency, they are often used independently, without measuring other domains (da Silva et al., 2020; Jenkinson et al., 1997). Importantly, the PDQ-39 stigma domain does not include enacted stigma experiences, rather felt stigma experiences and hiding efforts (Peto et al., 1995).

Other tools used to measure PD stigma are disease-generic or have been designed for the application in other conditions. Especially the disease-generic, self-reported Stigma Scale

for Chronic Illness (SSCI) has often been used in PD (Hou et al., 2021; Ma et al., 2016; Rao et al., 2009). The SSCI showed high internal consistency and convergent validity and consists of 24 items being divided into the domains of self-stigma (13 items) and enacted stigma (11 items; Rao et al., 2009). The items are rated on a five-point Likert-scale from *never* (1) to *always* (5), resulting in a maximum total score of 120 (maximum stigma level). The time frame to which the items refer was specified as “lately”. The self-stigma domain includes feelings of embarrassment, worries about others’ attitudes toward the patient, and avoiding telling others about the disease, while the enacted stigma domain includes others’ reactions to the patient and disease. Although the former domain was called self-stigma by the authors, it is often referred to as felt stigma by researchers studying stigma in PD (Eccles et al., 2022; Hou et al., 2021; Ma et al., 2016). This could be driven by the fact that the included items are potentially better describing the concept of felt stigma (Scambler & Hopkins, 1986). Besides, hiding efforts are covered by this domain.

Two scales that have initially been designed for the use in other conditions are the Mental Health Consumers’ Experience of Stigma Scale (SES) and the Social Impact Scale (SIS; Fife & Wright, 2000; Wahl, 1999). Both scales were validated for the use in PD by Burgener and Berger (2008). The SES is a self-reported scale initially designed for mental health consumers and has been applied for measuring PD stigma in a few studies (Burgener & Berger, 2008; Islam et al., 2022; Wahl, 1999). It consists of 9 items rated on a five-point Likert-scale from *never* (1) to *very often* (5), resulting in a maximum total score of 45 (maximum stigma level). No time frame was specified by the developers. The items primarily describe enacted stigma experiences, but also include aspects of anticipated stigma and hiding efforts. Furthermore, the SIS was developed for HIV/AIDS and cancer and refers to the last four weeks (Fife & Wright, 2000). It consists of 24 items divided into the four subscales social rejection (9 items), financial insecurity (3 items), internalized shame (5 items), and social isolation (7 items). The items are rated on a four-point Likert-scale from *strongly disagree* (1) to *strongly agree* (4), resulting in a maximum score of 96 (maximum stigma level). The subscales social

rejection and financial insecurity represent experienced stigma, while internalized shame and social isolation were named as internalized experiences of being stigmatized (Fife & Wright, 2000). Notably, the last two subscales, in addition to internalized stigma, also include components of hiding of the disease and stigma consequences. For both the SIS and SES, convergent validity as well as an acceptable internal consistency reliability was found in a PD sample (Burgener & Berger, 2008).

To the best of my knowledge, other stigma scales were only used sporadically in PD and are not validated for the use in a PD population (Bae & Yeum, 2015; Earnshaw et al., 2013; Harvey, 2001; Islam et al., 2022). Recently, Guerra-Anzaldo et al. (2024) developed a PD-specific stigma scale, which has so far only been applied in the validation study. However, the scale only addresses stigmatizing attitudes towards PD patients and gives no insight into the stigma experience of the patient.

1.4 Research objectives

Since stigma in PD represents a key determinant for PD patients' QoL and can have detrimental consequences (e.g., social isolation), a comprehensive understanding of its nature, triggers and impact on the individual is essential for both treatment and overall PD understanding. However, stigma in PD is still an understudied field and quantitative results are partially inconsistent. As discussed above, stigma in PD has so far mostly been measured by scales which were designed for other conditions or designed to apply for multiple chronic illnesses. Disease-generic scales are helpful when comparing different conditions (Wells et al., 2011), but in the first step, the stigma of a specific condition has to be understood comprehensively. As PD highly differs from other chronic illnesses in terms of symptoms and progression, reactions from other people as well as stigma concerns can differ and should be addressed specifically. For example, since PD is associated with balance problems and tremor, symptoms that are not likely to occur in e.g., Alzheimer's disease (Masters et al., 2015), PD patients are sometimes mislabeled as drunk (Hermanns, 2013).

However, only the applied stigma subscale of the PDQ-39 includes four PD-specific questions, which are not comprehensive enough to assess the complexity of PD stigma (Peto et al., 1995). Therefore, the primary aim of this work was to develop, test, and validate a holistic self-reported questionnaire to assess the stigma of PD patients specifically. The associated research objectives were the following:

(1) To develop a preliminary version of a PD-specific, self-reported stigma questionnaire based on literature review, clinical experience, input from experts in the field of PD, and patients' feedback.
(2) To test the comprehensibility, feasibility, acceptability, item properties, and internal consistency of the preliminary version involving PD patients, healthy controls, caregivers of PD patients, and health professionals and to use the results for amending the preliminary version.
(3) To test the psychometric properties of the amended version of the PDStigmaQuest, including acceptability, construct validity, convergent validity, known-groups validity, test-retest-reliability, and internal consistency and to establish the final version of the PD-specific questionnaire.

This final version of the questionnaire could be used in the next step to investigate associated factors with PD stigma. As the patients' perceived control over their disease was found to mediate relationships between stigma and other factors such as QoL (Verity et al., 2020), it is important to consider perceived control as a mediator when studying PD stigma. In preparation for future studies, another research objective was pursued in this thesis:

(4) To conduct an intercultural, linguistic adaptation of the English Parkinson's UK Scale of Perceived Control (PUKSoPC) in German language to create the basis for a future investigation of perceived control functioning as a mediator between PD stigma and other factors in German-language cohorts.

2. Original Publications

2.1 Parkinson's Disease Stigma Questionnaire (PDStigmaQuest): Development and Pilot Study of a Questionnaire for Stigma in Patients with Idiopathic Parkinson's Disease

Stopic, V., Jost, S. T., Baldermann, J. C., Petry-Schmelzer, J. N., Fink, G. R., Dembek, T. A., Dafsari, H. S., Kessler, J., Barbe, M. T., & Sauerbier, A. (2023). Parkinson's Disease Stigma Questionnaire (PDStigmaQuest): Development and pilot study of a questionnaire for stigma in patients with idiopathic Parkinson's disease. *Journal of Parkinson's Disease*, *13*(5), 829–839. https://doi.org/10.3233/JPD-230071[1]

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Parkinson's Disease Stigma Questionnaire (PDStigmaQuest): Development and Pilot Study of a Questionnaire for Stigma in Patients with Idiopathic Parkinson's Disease

Vasilija Stopic[a], Stefanie T. Jost[a], Juan Carlos Baldermann[a,b], Jan Niklas Petry-Schmelzer[a], Gereon R. Fink[a,c], Till A. Dembek[a], Haidar S. Dafsari[a], Josef Kessler[a], Michael T. Barbe[a,1], Anna Sauerbier[a,d,1]

[1]contributed equally

[a]Department of Neurology, University of Cologne, Faculty of Medicine and University Hospital Cologne, Cologne, Germany
[b]Department of Psychiatry and Psychotherapy, University of Cologne, Faculty of Medicine and University Hospital Cologne, Cologne, Germany
[c]Cognitive Neuroscience, Institute of Neuroscience and Medicine (INM-3), Research Centre Jülich, Jülich, Germany
[d]Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, United Kingdom

Corresponding Authors:

Vasilija Stopic, MSc
Department of Neurology
University Hospital Cologne
Kerpener Str. 62
50937 Cologne, Germany
Tel: +49 221 478-4013
E-mail: vasilija.stopic@uk-koeln.de

Michael T. Barbe, MD, Professor
Department of Neurology
University Hospital Cologne
Kerpener Str. 62
50937 Cologne, Germany
Tel: +49 221 478-7494
E-mail: michael.barbe@uk-koeln.de

Abstract

Background: Stigma is significant in Parkinson's disease (PD). However, no specific tool is available to assess stigma in PD comprehensively.

Objective: This pilot study aimed to develop and test a stigma questionnaire specific to PD patients (PDStigmaQuest).

Methods: Based on a literature review, clinical experience, expert consensus, and patients' feedback, we developed the preliminary, patient-completed PDStigmaQuest in German language. It included 28 items covering five stigma domains: uncomfortableness, anticipated stigma, hiding, experienced stigma, and internalized stigma. In this pilot study, 81 participants (PD patients, healthy controls, caregivers, and health professionals) were included to investigate the acceptability, feasibility, comprehensibility, and psychometric properties of the PDStigmaQuest.

Results: The PDStigmaQuest showed 0.3% missing data points for PD patients and 0.4% for controls, suggesting high data quality. Moderate floor effects**,** but no ceiling effects were found. In the item analysis, most items met the standard criteria of item difficulty, item variance, and item-total correlation. Cronbach's alpha was > 0.7 for four of five domains. PD patients' domain scores were significantly higher than healthy controls' for uncomfortableness, anticipated stigma, and internalized stigma. Feedback to the questionnaire was predominantly positive.

Conclusion: Our results indicate that the PDStigmaQuest is a feasible, comprehensive, and relevant tool to assess stigma in PD and helps to understand the construct of stigma in PD further. Based on our results, the preliminary version of the PDStigmaQuest was modified and is currently validated in a larger population of PD patients for use in clinical and research settings.

Keywords: Stigma, quality of life, pilot study, questionnaire development

Introduction

Idiopathic Parkinson's disease (PD) is characterized by a wide range of both motor and non-motor symptoms (NMS) [1-3]. The disease and many of the associated symptoms, e.g., impaired gait, facial masking, and drooling of saliva, can be associated with the experience of stigmatization in everyday life [4-6]. The term “stigma” was first defined as a rather undesirable attribute distinguishing a person from others, leading to being devalued and discredited by others [7]. Nowadays, stigma is most commonly understood as the “co-occurrence of its components – labeling, stereotyping, separation, status loss, and discrimination” [8].

In the past, several concepts of stigma were proposed [9-12]. Fox et al. (2018) established a stigma framework defining three stigma mechanisms most important to the stigmatized's perspective, namely: anticipated stigma, experienced stigma, and internalized stigma. Anticipated stigma refers to the degree to which a person expects to be stigmatized, regardless of whether he or she is stigmatized or not [9, 13]. Experienced stigma refers to the actual experiences of stereotypes, prejudice, labeling, separation, and discrimination [8, 9, 14]. For example, PD patients report others mislabeling them as drunk or commenting about their “mad” facial expressions [5, 6, 15]. Internalized stigma is defined as “the extent to which people endorse the negative beliefs and feelings associated with the stigmatized identity for the self”, e.g., feelings of being different [9, 16].

Importantly, stigma in PD appears to be a determinant factor for patients’ quality of life and severity of different NMS, including depression, anxiety, or apathy [17-21]. Stigma can cause patients rather to stay at home and experience frustration and isolation [5, 22].

Although stigma is of great importance in PD, there is no specific tool to characterize stigma in PD patients. To our knowledge, only generic stigma measures for chronic illnesses [23-26] or a four-item stigma subscale of the PD Questionnaire (PDQ-39) [27], a frequently used quality of life questionnaire, have been applied in the past to assess stigma in PD patients.

These measures are not comprehensive enough to measure the complex construct of disease-specific stigma in PD.

Therefore, our main objective was to develop a stigma questionnaire to be completed by PD patients directly addressing their stigma, considering core constructs and stigma mechanisms based on the current literature and clinical experience [9]. In this pilot study, we report the acceptability, feasibility, comprehensibility, and psychometric properties of the so-called Parkinson's Disease Stigma Questionnaire (PDStigmaQuest).

Materials and Methods

Development of the PDStigmaQuest

A preliminary version of the questionnaire was developed based on the current literature as well as clinical experience through in-person focus groups and email contacts involving health professionals and researchers with expertise in PD and stigma (from June 2021–September 2021). Neurologists, clinical and research fellows, psychologists, study nurses, occupational therapists, speech therapists, and physiotherapists were involved in the development to establish a holistic picture of stigma in PD. In the next step, the version was discussed with 10 PD patients to ensure comprehensibility and acceptability by patients. Thereafter, based on the patients' feedback, the preliminary version was amended. The full process of development can be seen in Figure 1.

After this process, the German-language PDStigmaQuest as a self-report measure consisted of 28 items in five domains: (1) uncomfortableness (3 items), (2) anticipated stigma (4 items), (3) hiding (4 items), (4) experienced stigma (12 items), and (5) internalized stigma (5 items). Besides the mechanisms defined in the stigma framework by Fox et al. [9], we included domains for uncomfortableness and hiding. These mechanisms were sometimes seen as part of internalized stigma [16]. We decided to address them separately because they do not necessarily result from negative beliefs and feelings of others but can also occur before

experiencing stigma in public. The first item of domain one – uncomfortableness concerning different PD symptoms - included sub-items to evaluate the different symptoms separately.

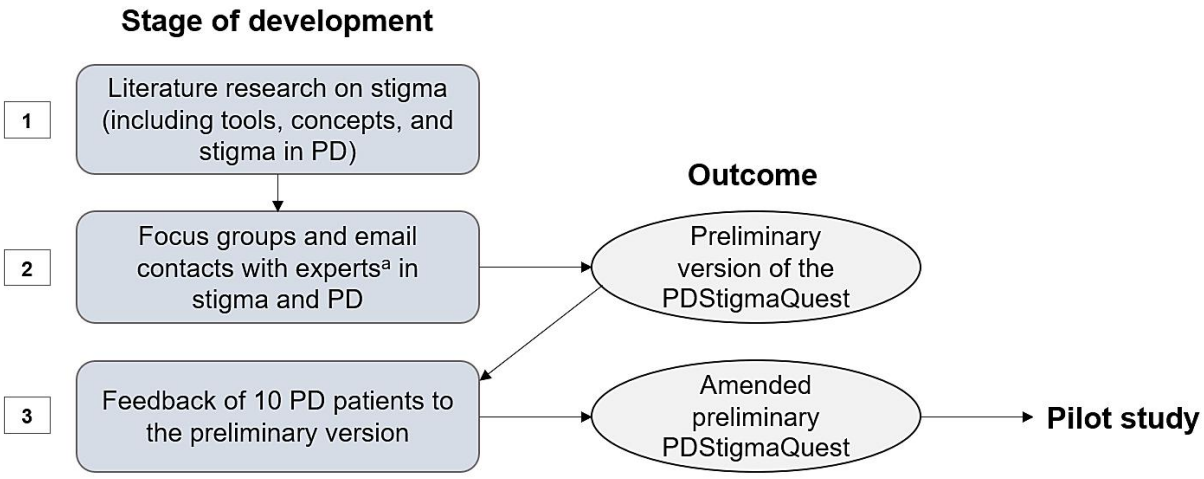

Figure 1: Development process of the PDStigmaQuest tested in the pilot study. PD, Parkinson's disease; PDStigmaQuest, Parkinson's Disease Stigma Questionnaire.

Based on literature research, focus groups and email contacts with experts in stigma and PD as well as input from patients with PD, a preliminary PDStigmaQuest was developed in German language to be tested in the pilot study.

[a]The experts were health professionals and researchers, namely neurologists, clinical and research fellows, psychologists, study nurses, occupational therapists, speech therapists, and physiotherapists.

All items were rated on a five-point Likert scale from 0 (never) to 4 (always). For some items, the response option "not applicable" could be chosen, e.g., if a certain symptom was not experienced or items referring to work when patients with PD were retired. The questionnaire also included reverse-scored items to control for response bias and avoid negative wording [28].

A time frame of the “past four weeks” was chosen as for more extended periods, the answers could be influenced by an impaired memory performance of PD patients [29]. Importantly, many self-reported questionnaires routinely applied in PD refer to the last four weeks or the last month, allowing for comparability [27, 30-32]. At the beginning of the questionnaire, it should be indicated whether the patient or a caregiver or both filled in the questionnaire. At the end of the questionnaire, an optional section for additional comments or ideas was provided to allow participants in the pilot study to comment directly on the questionnaire.

Study design and participants

This was a single-center and cross-sectional pilot study.

Four groups of participants were included: (1) patients with a diagnosis of idiopathic PD according to UK Brain Bank criteria [33], (2) non-spousal healthy controls, (3) caregivers of PD patients, and (4) health professionals with expertise in PD.

Exclusion criteria for all groups were moderate or severe medical conditions other than PD that could have interfered with the ability to complete the study, significant cognitive impairment or insufficient knowledge of the German language based on the judgment of the examining health professional, impaired hearing and/or sight which interfered with the study participation, age under 18 or above 90, and inability to consent. Additional exclusion criteria for patients were PD of non-idiopathic form or other clinically relevant neurological diseases besides PD. Exclusion criteria for other groups were additionally diagnosis of PD, dementia or other neurological or psychiatric disorders, and health professionals without experience in PD or older than 70 years.

All participants were included between March 2022 and June 2022.

Ethical aspects

All participants gave written informed consent. The study was performed under the principles of the Declaration of Helsinki. The local ethics committee approved the study protocols (vote: 21-1385; German Clinical Trials Register: DRKS00025513).

Procedures and materials

After being informed about the purpose of the study and having provided signed informed consent, all participants were asked about sociodemographic data. PD patients were additionally asked about their disease history and therapy. After that, PD patients and healthy controls completed the PDStigmaQuest, followed by a feedback questionnaire. Healthy controls were asked to answer items in the PDStigmaQuest only if they did not include phrases directly referring to the disease as these items did not apply to them, e.g., “I try to hide my Parkinson’s symptoms from others”. The following 10 items should be answered by healthy controls: item 1 (uncomfortableness with symptoms), 7 (fear of being seen as mentally impaired), 12 (decisions taken by others), 18 (being interrupted), 20 (being taken seriously), 22 (others acting as feeling uncomfortable in the presence of the patient/control), 24 (feeling worth as much as others), 25 (feeling like a burden to others), 27 (feeling useless), and 28 (self-respect). In contrast to patients and healthy controls, caregivers and health professionals were only asked to read the PDStigmaQuest carefully and after that, to fill in the feedback questionnaire. It covered mainly closed-ended questions about length, comprehensibility, embarrassment, difficulty of answering, item length, and additional comments. The health professionals’ version of the feedback questionnaire additionally contained questions about the (practical) relevance, comprehensiveness of included symptoms, extensiveness, time interval, and item relevance.

Sample size

Recommended sample sizes for initial scale development including assessment of item performance usually range from 24 to 40 representatives from the population of interest [34,

35], in our case, PD patients. For investigating the comprehensibility of instructions, item wording, or administration, only a sample of 10 per group could be sufficient [34]. Therefore, ≥ 10 representatives of the other groups were included. Due to the diversity of health professionals working with PD patients, ≥ 20 health professionals were included.

Data analysis

Descriptive statistics for demographic characteristics were calculated. Levodopa equivalent daily dose (LEDD) was calculated according to the formula of Tomlinson et al., 2010 [36]. The score of item 1 (uncomfortableness with symptoms) was calculated as follows: For every participant, scores of the applicable symptoms were summed and divided by the number of applicable symptoms. This way, the score of item 1 containing sub-items was comparable to other items' scores. The domain score and total score were calculated similarly: For every participant, scores of the applicable items in a domain or in total were summed, divided by the maximum achievable score on applicable items, respectively, and multiplied by 100. Thus, the maximum score for the domains and the total score was 100.

Data quality was explored by the proportion of missing data points. For patients, acceptability was investigated through floor and ceiling effects measured as the percentage of extreme values (standard value ≤ 15%) [37].

In order to compare PD patients' and healthy controls' scores, new domain scores were calculated only with items answered by PD patients and controls. In the domain hiding, no items applied to healthy controls. Mann-Whitney U tests were conducted to identify differences in the domain scores. Tests were corrected for multiple comparisons according to the Benjamini-Hochberg procedure.

For patients only, an item analysis was conducted to determine item difficulty, item variance, and corrected item-total correlation to evaluate the items' psychometric properties. Item difficulty does not refer to the difficulty of answering the item but is defined as the quotient of the mean score on that item and the maximum achievable score on the same item, multiplied

by 100 [38]. Items with a medium difficulty of 50 can differentiate the best between people with a low and people with a high level of the measured characteristic. As we intended to also differentiate between patients with levels of stigma at the extremes (e.g., differentiate between two patients with low stigma levels), we also intended to include items with item difficulties of 5-20 and 80-95 [38]. The variance of an item should be high and the item-total correlation should be ≥ 0.3 [38, 39]. For item selection, all three values, content-related considerations, and reliability should be considered.

For patients, a preliminary internal consistency analysis of the stigma domains was conducted (Cronbach's alpha, standard value ≥ 0.7) [38, 40]. Including the option "not applicable" in some items resulted in systematic data loss for internal consistency analysis. Therefore, only for the internal consistency analysis, items answered as not applicable were coded as zeros [41]. For this study, the method was considered acceptable because an item not applicable to the patient also means that the patient does not experience the stigma described by the item.

The feedback questionnaires of all participants were analyzed descriptively to consider criticism and suggestions for improving the preliminary version of the PDStigmaQuest.

All analyses were conducted using Statistical Package for Social Science (SPSS version 28.0). *P* values < 0.05 were considered statistically significant.

Results

Demographic characteristics

In total, 27 PD patients (33.3% female) with a mean age of 63.9 (± 5.7) years, a mean disease duration of 11.4 (± 5.0) years, and a mean LEDD of 828.1 mg/d (± 358.3) were included. Their average years of education were 13.9 (± 3.4). Patients were married (63.0%), divorced (22.2%) or widowed (14.8%), and mostly retired (77.8%) or (self-)employed (18.5%). Nine patients (33.3%) were undergoing deep brain stimulation.

Twenty-two healthy controls (45.5% female; mean age of 62.0 (± 11.2) years) were included. Age and gender did not differ significantly compared to patients ($p > 0.05$). Mean years of education were 16.8 (± 2.5) and controls were mainly married (63.6%) or divorced (18.2%) and (self-)employed (63.6%) or retired (31.8%).

Besides, 10 caregivers of PD patients (70.0% female) with a mean age of 55.8 (± 13.1) years were included, as well as 22 health professionals with expertise in PD (77.3% female; 11 neurologists, three psychologists, two study nurses, two speech therapists, two physiotherapists, two occupational therapists) with a mean age of 35.4 (± 9.0) years.

PDStigmaQuest scores, acceptability, and data quality

Descriptive statistics of PDStigmaQuest scores and acceptability parameters for PD patients are shown in Table 1. All questionnaires were completed by the patient without the help of caregivers. In PD patients, moderate floor effects were found, while ceiling effects were absent. Overall, there were 5/1512 (0.3%) missing data points for PD patients and 3/792 (0.4%) for controls.

Table 1 Distribution and acceptability of PDStigmaQuest domain scores in percentage (%) for patients with Parkinson's disease.

	M	*SD*	Min	Max	Floor effect	Ceiling effect	Applicable Items
Uncomfortableness	32.0	19.2	0	68.7	3.7	0	100.0
Anticipated Stigma	27.2	20.8	0	75.0	18.5	0	87.0
Hiding	17.6	20.1	0	65.6	37.0	0	100.0
Experienced Stigma	22.1	14.5	0	54.6	3.7	0	94.1
Internalized Stigma	21.7	16.1	0	50.0	22.2	0	100.0
Total Score	24.6	14.8	0.4	54.7	0	0	96.2

Abbreviations: PDStigmaQuest, Parkinson's Disease Stigma Questionnaire.

Note: For every patient, scores of the applicable items of a domain were summed, divided by the respective maximum achievable score in a domain, and multiplied by 100.

PDStigmaQuest scores: comparison of PD patients and healthy controls

For domain scores calculated only with items answered by PD patients and healthy controls, descriptive statistics are presented separately in Figure 2. Domain scores were significantly higher in PD patients for the domains uncomfortableness (p = 0.035), anticipated stigma (p = 0.032), and internalized stigma (p = 0.032). In the domain hiding, no items applied to healthy controls; therefore, no comparison was made.

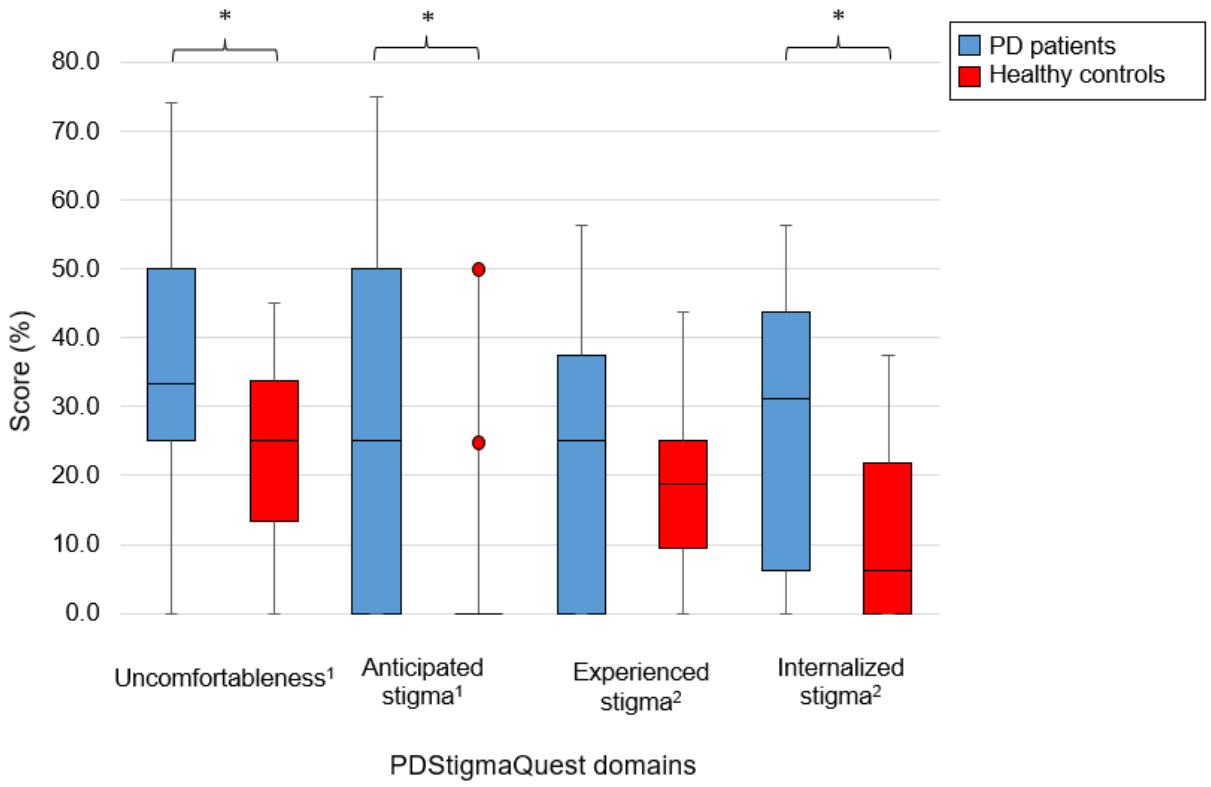

Figure 2: Descriptive statistics of items answered by patients with Parkinson's disease and healthy controls in the different PDStigmaQuest domains. PD, Parkinson's disease; PDStigmaQuest, Parkinson's Disease Stigma Questionnaire.

Domain scores are presented as percentage of the maximum domain score. Mann-Whitney U tests were calculated between patients with Parkinson's disease and controls. Red dots represent outliners by healthy controls. In the domain hiding, no comparison was made as no items applied to healthy controls. No boxplot can be seen for the domain anticipated stigma in healthy controls as all values in the box were 0. [1]1 item; [2]4 items; *p < 0.05.

Item analysis

For PD patients, item difficulty, item variance, and corrected item-total correlation are shown in Table 2. Items with item difficulties of 5-20 (indicating lower stigma levels) were item 2 (uncomfortableness with appearance), 9 (concealing PD), 10 (hiding treatment), 11a (speaking openly with family and close friends about PD), 14 (others making fun of the patient), 15a (rejection by friends), 17 (others avoiding looking at the patient), 20 (being taken seriously), 22 (others acting uncomfortable), and 26 (feeling responsible for PD). Only item 15b (rejection by family members) had an item difficulty < 5. Items with a variance near 0 (< 0.5) were item 14 (others making fun of the patient), 15b (rejection by family members), and 17 (others avoiding looking at the patient). Items with item-total correlations < 0.3 were item 17 (others avoiding looking at the patient), 19 (being observed), 23 (respect by others), and 24 (feeling worth as much as others).

Table 2 Item analysis for patients with Parkinson's disease.

	Item	*n*	Item difficulty	Item variance	Item-total correlation
	Domain 1: Uncomfortableness				
	Uncomfortableness with…				
1	PD symptoms	27	**35.33**	**0.51**	**0.54**
2	PD treatment[a]	27	14.81	**0.64**	**0.89**
3	PD appearance	26	**45.19**	**1.60**	**0.56**
	Domain 2: Anticipated Stigma				
4	Reactions to PD	27	**24.07**	**1.11**	**0.80**
5	Devaluation at work[a]	13	**25.00**	**1.00**	**0.43**
6	Reactions to disease progression	27	**37.04**	**1.18**	**0.56**
7	Being seen as mentally impaired	27	**21.30**	**0.90**	**0.93**
	Domain 3: Hiding				
8	Hiding of PD symptoms	27	**25.00**	**1.62**	**0.53**
9	Concealing PD	27	12.04	**0.88**	**0.82**
10	Hiding of PD treatment[a]	27	12.04	**0.80**	**0.85**
11a	Speaking openly with family and close friends about PD[b]	27	14.81	**1.10**	**0.75**
11b	Speaking openly with others (except for family and close friends) about PD[b]	27	**27.78**	**1.49**	**0.75**
	Domain 4: Experienced Stigma				
12	Decisions taken on behalf of patient by others	27	**27.78**	**1.03**	**0.50**
13	Unfair treatment at work[a]	10	**27.50**	**2.32**	**0.82**
14	Others making fun of the patient	27	10.19	0.48	**0.32**
15a	Rejection by friends	27	17.59	**1.06**	**0.44**
15b	Rejection by family members	27	3.70	0.21	**0.51**
16	Behavior of others after learning about PD treatment[ab]	24	**21.88**	**1.25**	**0.50**
17	Others avoiding looking at the patient	26	10.58	0.33	0.05
18	Being interrupted	27	**34.26**	**1.63**	**0.71**
19	Being observed	26	**33.65**	**0.96**	0.26
20	Being taken seriously[b]	26	16.35	**1.04**	**0.70**
21	Being invited less often	26	**22.12**	**0.91**	**0.74**
22	Others acting as feeling uncomfortable in the presence of the patient	27	14.81	**0.71**	**0.85**
23	Respect by others[b]	27	**23.15**	**1.61**	0.07
	Domain 5: Internalized Stigma				
24	Feeling worth as much as others[b]	27	**22.22**	**1.33**	0.03
25	Feeling like a burden to others	27	**34.26**	**1.63**	**0.52**
26	Feeling of being responsible for PD	27	6.48	**0.51**	**0.76**
27	Feeling useless	27	**20.37**	**1.16**	**0.76**
28	Self-respect[b]	27	**25.00**	**1.46**	**0.34**

Abbreviations: PD, Parkinson's Disease.

Note: In bold are item difficulties > 20, item variances ≥ 0.5, and item-total correlations ≥ 0.3, representing preferable item characteristics.

[a]item with response option "not applicable". [b]reverse-scored item.

Internal consistency

Cronbach's alpha was 0.72 for domain uncomfortableness, 0.71 for anticipated stigma, 0.77 for hiding, 0.77 for experienced stigma, and 0.52 for internalized stigma.

Feedback to the preliminary version of the PDStigmaQuest

Frequencies of responses to the closed-ended feedback questions about the questionnaire are shown in Table 3. Positive responses were at least 60% for each question. In PD patients, healthy controls, and caregivers, responses indicating negative feedback regarding the questionnaire were > 20% for questions referring to the questionnaire's length and difficulty of answering specific questions. In health professionals, negative responses were > 20% for questions referring to questionnaire's length, ease of understanding the items, adding or deleting symptoms in item 1, time interval, and lower level of relevance for specific items. Qualitative data (i.e., participants' suggestions for improving the questionnaire) were considered in the modification process of the PDStigmaQuest.

Table 3 Responses (%) to the closed-ended feedback questions to the preliminary PDStigmaQuest.

		PD patients	Healthy controls	Caregivers	Health professionals
1. Did you find the questionnaire too long?	**No**	85.2	95.5	60.0	68.2
	Yes	11.1	4.5	40.0	31.8
	NR	3.7	0	0	0
2. Were the questions easy to understand?	No	11.1	4.5	20.0	27.3
	Yes	88.9	95.5	80.0	72.7
	NR	0	0	0	0
3. Did you have difficulties with some questions formulated in the present and others in the past?[a]	**No**	96.3	100.0	–	–
	Yes	3.7	0	–	–
	NR	0	0	–	–
4. Did you find any question(s) embarrassing?	**No**	92.6	90.9	90.0	90.9
	Yes	7.4	9.1	10.0	9.1
	NR	0	0	0	0
5. Did you find any question(s) difficult to answer?	**No**	74.1	86.4	70.0	77.3
	Yes	25.9	13.6	20.0	13.6
	NR	0	0	10.0	9.1
6. Did you find any question(s) too long?	**No**	96.3	100.0	90.0	86.4
	Yes	3.7	0	10.0	9.1
	NR	0	0	0	4.5
7. Do you find the questionnaire relevant?[b]	No	–	–	–	4.5
	Yes	–	–	–	95.5
	NR	–	–	–	0
8. Does the questionnaire help you to better understand your PD patients' current condition?[b]	No	–	–	–	9.1
	Yes	–	–	–	86.4
	NR	–	–	–	4.5
9. Do you find that symptoms in question 1 should be deleted and/or others added?[b]	**No**	–	–	–	63.6
	Yes	–	–	–	31.8
	NR	–	–	–	4.5
10. Do you find the questionnaire comprehensive enough?[b]	No	–	–	–	4.5
	Yes	–	–	–	95.5
	NR	–	–	–	0
11. Do you find the chosen time interval of four weeks reasonable for evaluating the different statements?[b]	No	–	–	–	31.8
	Yes	–	–	–	63.6
	NR	–	–	–	4.5
12. Did you find any question(s) less relevant for the patients' stigma?[b]	**No**	–	–	–	68.2
	Yes	–	–	–	27.3
	NR	–	–	–	4.5

Abbreviations: NR, No Response; PD, Parkinson's disease; PDStigmaQuest, Parkinson's Disease Stigma Questionnaire.

Note: Amended from [42]. Responses indicating positive feedback about the questionnaire are in bold.

[a]questions only for participants filling in the questionnaire. [b]additional questions for health professionals.

Discussion

The present study aimed to develop and test the comprehensibility, feasibility, and psychometric properties of a self-completed questionnaire addressing stigma in PD patients. Our results demonstrate that the PDStigmaQuest is a feasible and comprehensive tool easily applied to measure stigma in a general PD population.

Acceptability and data quality

The PDStigmaQuest showed only 0.3% missing data points for PD patients and 0.4% for controls, suggesting high data quality. Moderate floor effects were found, which could be explained by the fact that some patients stated not caring about others' opinions. In future studies, it would be essential to capture personality traits like neuroticism, as it was found that this trait is associated with stigma in PD [43]. People with a low level of neuroticism worry less and could therefore experience lower levels of stigma [44]. Notably, the floor effects were only found for three of five domains (i.e., anticipated stigma, hiding, and internalized stigma) and not for the total score. Furthermore, ceiling effects were absent, indicating an appropriate acceptability of the PDStigmaQuest.

PDStigmaQuest scores: comparison of PD patients and healthy controls

PD patients' domain scores were significantly higher for the domains uncomfortableness, anticipated stigma, and internalized stigma. For the domain experienced stigma, PD patients' domain scores were higher than those of healthy controls, however, not reaching statistical significance. Explorative post-hoc analyses for the specific items of this domain showed that only the item 12 score (decisions taken by others) was significantly higher in PD patients ($p = 0.028$). These results were somehow expected as items 18 (being interrupted) and 20 (being taken seriously) cover aspects that also older people in general might experience. Furthermore, item 22 (others acting as feeling uncomfortable) might be more common among PD patients in earlier stages of the disease and, therefore, not highly represented in our cohort

with advanced stage of PD (mean disease duration of 11.4 years). This aspect warrants further investigation.

Differences in the domain hiding could not be explored as this domain addresses hiding aspects of the disease and therefore represents experiences that healthy controls do not experience.

Item analysis

Item analysis revealed that the majority of items met standard criteria. Only three items showed relatively low scores for more than one of the three criteria item difficulty, item variance, and item-total correlation: item 14 (others making fun of the patient), 15b (rejection by family members), and 17 (others avoiding looking at the patient). Items' difficulty and variance indicated that these experienced stigma aspects were very rare. Particular attention was paid to these items in the modification process.

Internal consistency

Internal consistency results showed good internal consistency for four of five domains. Only the domain internalized stigma showed a Cronbach's alpha < 0.7. This result can be explained by negative correlations between items 24 (feeling worth as much as others) and 26 (feeling responsible for PD). Both items showed high floor effects. Item 26 showed an item difficulty of 6.48. Nevertheless, we decided to keep this item as we assume that it will apply to PD populations in other countries [45].

Feedback to the preliminary version of the PDStigmaQuest

Feedback to the preliminary PDStigmaQuest was predominantly positive. Comments especially led to modifying symptoms in item 1 (uncomfortableness with PD symptoms) and rewording of items. Special attention was paid to repetitive feedback. As critical comments on the time interval were highly contradictory, we decided to keep the chosen time interval of four weeks.

Modification of the PDStigmaQuest

Based on the results of the statistical analysis and participants' comments on the questionnaire, the PDStigmaQuest was modified as follows: (1) at the beginning of the questionnaire, it should only be indicated whether the questionnaire was filled in alone or with help, (2) instead of offering the "not applicable" option for items referring to work, we added an optional section for these items, (3) response option "not applicable" was only offered for item 1 regarding uncomfortableness with symptoms and therefore reworded to "symptom not applicable", (4) some symptoms in item 1 were deleted, reworded, or summarized, (5) three items were deleted: item 10 (hiding of treatment), item 16 (behavior of others after learning about PD treatment), and item 17 (others avoiding looking at the patient), (6) items 11a and 11b (speaking openly about the disease) as well as 15a and 15b (rejection by others) were summarized to one item respectively, (7) eight items were reworded, (8) the order of the items was changed in the way that reverse-scored items were well distributed across the questionnaire.

Limitations

This pilot study has some limitations. Firstly, a relatively high proportion (33.3%) of patients undergoing deep brain stimulation could influence the transferability of our results to the general PD population. However, disease duration, LEDD, PD domain, and total scores did not differ between patients with and without deep brain stimulation. Further, the PDStigmaQuest is intended as a questionnaire for PD patients with and without invasive therapies. Therefore, we consider including PD patients with deep brain stimulation is necessary and justified. Secondly, only 18.5% of patients were (self-)employed and could answer the items referring to work. Therefore, the study's results regarding these items were cautiously interpreted when modifying the questionnaire. Thirdly, comparing PD patients and controls about the domains of uncomfortableness and anticipated stigma included only one item for each domain answered by both groups. However, other items in the domains,

including e.g., “because of my PD symptoms”, differed by their very nature between PD patients and controls since controls cannot have these experiences at all.

Conclusions

In conclusion, the results of this pilot study indicate that the German version of the PDStigmaQuest is a feasible, comprehensive, and relevant tool to assess stigma in PD patients. Based on the results, the preliminary version of the PDStigmaQuest was modified and is currently formally validated for further use in clinical and research settings in German and English language. To our knowledge, this is the first specific stigma tool in PD and will allow to comprehensively measure the prevalence and severity of stigma in PD patients and reveal its association with other clinical parameters like motor and NMS and quality of life.

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Conflict of interest

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Data availability

The data used to support the findings of this study are available from the corresponding author upon reasonable request.

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2.2 Validation Study of the Parkinson's Disease Stigma Questionnaire (PDStigmaQuest)

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Validation Study of the Parkinson's Disease Stigma Questionnaire (PDStigmaQuest)

Vasilija Stopic[a], Stefanie T. Jost[a], Julius Haupt[a], Gregor A. Brandt[a], Christina van der Linden[a], Jan Niklas Petry-Schmelzer[a], Till A. Dembek[a], Gereon R. Fink[a,b], Lucia Batzu[c,d], Alexandra Rizos[c], K. Ray Chaudhuri[c,d,e], Haidar S. Dafsari[a], Doreen Gruber[f,g], Georg Ebersbach[f], Josef Kessler[a], Michael T. Barbe[a,1], Anna Sauerbier[a,d,1]

[1]contributed equally

[a]Department of Neurology, University of Cologne, Faculty of Medicine and University Hospital Cologne, Cologne, Germany
[b]Cognitive Neuroscience, Institute of Neuroscience and Medicine (INM-3), Research Centre Jülich, Jülich, Germany
[c]Parkinson's Foundation International Centre of Excellence, King's College Hospital, London, United Kingdom
[d]Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, United Kingdom
[e]NIHR Mental Health Biomedical Research Centre and Dementia Biomedical Research Unit, South London and Maudsley NHS Foundation Trust and King's College London, London, United Kingdom
[f]Movement Disorders Hospital, Kliniken Beelitz GmbH, Beelitz-Heilstätten, Germany
[g]Department of Neurology, Otto-von-Guericke University Magdeburg, Magdeburg, Germany

Corresponding Authors:

Vasilija Stopic, MSc
Department of Neurology
University Hospital Cologne
Kerpener Str. 62
50937 Cologne, Germany
Tel: +49 221 478-4013
E-mail: vasilija.stopic@uk-koeln.de

Anna Sauerbier, MD, PhD
Department of Neurology
University Hospital Cologne
Kerpener Str. 62
50937 Cologne, Germany
Tel: +49 221 478-86180
E-mail: anna.sauerbier@uk-koeln.de

Abstract

Background: Stigma is a relevant aspect of Parkinson's disease (PD). Specific stigma tools are needed to address the complex construct of stigma in PD comprehensively.

Objective: To test the dimensionality and psychometric properties of the newly developed Parkinson's Disease Stigma Questionnaire (PDStigmaQuest).

Methods: In this multi-center, cross-sectional study including PD patients and healthy controls, the dimensionality of the PDStigmaQuest was examined through exploratory factor analysis. Acceptability and psychometric properties were investigated. PDStigmaQuest scores of patients and healthy controls were compared.

Results: In total, 201 PD patients and 101 healthy controls were included in the final analysis. Results suggested high data quality of the PDStigmaQuest (0.0001% missing data for patients). The exploratory factor analysis produced four factors: felt stigma, hiding, enacted stigma: rejection, and enacted stigma: patronization, explaining 47.9% of variance. An optional work domain for employed patients was included. Moderate floor effects and skewness, but no ceiling effects were found. Cronbach's alpha of 0.85 indicated high internal consistency. Calculated item-total correlations met standard criteria. Test-retest reliability was high (r_s = 0.83). PDStigmaQuest scores correlated significantly with other stigma measures (r_s = 0.56-0.69) and were significantly higher in patients than in healthy controls and higher in patients with depressive symptoms than in those without.

Conclusions: The patient-reported 18-item PDStigmaQuest showed strong psychometric properties of validity and reliability. Our results suggest that the PDStigmaQuest can be used to assess and evaluate stigma comprehensively in PD, which will improve our understanding of the construct of PD stigma.

Keywords: Stigma, quality of life, validation study, questionnaire

Introduction

Stigma is a determinant factor for Parkinson's Disease (PD) patients' quality of life (QoL).[1-3] For the term "stigma", numerous definitions have been proposed in the last decades.[4-7] In the field of chronic illnesses, stigma is often studied as health-related stigma, a "social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment".[8] Scambler and Hopkins initially introduced the distinction between felt stigma, including fear of being stigmatized and feelings of shame associated with the disease, and enacted stigma, referring to actual experiences of discrimination.[9, 10] Fox et al. established a more complex stigma framework, including anticipated stigma (expectations of stigmatization), experienced stigma (actual stigmatization), and internalized stigma (adopting others' negative beliefs).[11]

Stigma plays a significant role in PD: For example, patients report experiences of being mislabeled as drunk, being stared at, feeling like being a burden to others, and feeling ashamed.[12-15] Especially in the early disease stages, patients try to hide PD-related symptoms from others.[13, 16] Importantly, stigma can cause social isolation, obstruct seeking medical care, and is associated with non-motor symptoms (NMS) like depression and anxiety.[17-22]

However, our current knowledge of stigma in PD is sparse and mainly based on qualitative studies. There is currently no specific tool available for addressing the highly complex construct of stigma in PD comprehensively. To our knowledge, to date, mainly generic stigma measures for chronic illnesses or the PD Questionnaire 39 (PDQ-39) stigma subscale consisting of four items have been applied in PD.[23-27] Therefore, our objective was to develop and validate a stigma questionnaire specific to PD patients to help to address and evaluate PD stigma. The development process and data of the pilot study presenting the preliminary version of the patient-reported Parkinson's Disease Stigma Questionnaire (PDStigmaQuest) have been reported previously.[28] Here, we report validation data from the new PDStigmaQuest.

Methods

Study design and participants

This multi-center (Cologne University Hospital, Germany; Movement Disorders Hospital in Beelitz, Germany) and cross-sectional validation study included patients with a diagnosis of PD according to the MDS criteria[29] and non-spousal and non-caregiver healthy controls. In- and outpatients were approached for participation in the study. For recruitment of both patients and controls, posters and flyers were used. Exclusion criteria were: age < 18 or > 90 years, moderate to severe medical conditions other than PD that could have interfered with the ability to complete the study, impaired hearing or sight interfering with study participation, significant cognitive impairment or insufficient knowledge of the German language based on the judgment of the examining health professional, and inability to consent. Additional exclusion criteria for patients were: PD of non-idiopathic form or other clinically relevant neurological diseases besides PD. Additional exclusion criteria for healthy controls were: PD diagnosis or other neurological or psychiatric disorders.

All participants were included between August 2022 and January 2024.

Ethical aspects

All participants provided written informed consent. The study was performed under the principles of the Declaration of Helsinki. The local ethics committee approved the study protocols (Cologne vote: 21-1385; Beelitz vote: 2023-85-BO). The study was registered at the German Clinical Trials Register: DRKS00025513.

Procedures and materials

Patients were tested under regular medication (MedON). Firstly, participants were asked about sociodemographic data, PD patients additionally about their disease history and current treatment. After that, different tools were assessed in German:

The German-language PDStigmaQuest is a patient-reported questionnaire developed based on literature, clinical experience, focus groups, and PD patients' and caregivers' feedback.[28] The version resulting from the pilot study consisted of 25 items based on the stigma concept by Fox et al. adapted for PD including two optional items for employed PD patients.[11, 28] To test for uncomfortableness related to PD symptoms, the first item included sub-items to evaluate specific motor symptoms and NMS separately. Five items were reverse-scored items to control for response bias and avoid negative wording.[30] Each item was rated on a five-point Likert scale from "never" (0) to "always" (4) regarding the past four weeks. Only item 1 (uncomfortableness related to PD symptoms) included the option "symptom not applicable" for sub-items. The PDStigmaQuest total score was calculated as the sum of all item scores. Since some items directly referred to the disease (e.g., "I try to hide my Parkinson's symptoms from others"), these could not be answered by healthy controls without PD. The controls were asked to fill in the following generally formulated items: item 1 (uncomfortableness with symptoms), 4 (feeling worth as much as others), 5 (feeling like a burden to others), 7 (feeling useless), 8 (self-respect), 11 (being seen as mentally impaired), 15 (decisions taken by others), 19 (being interrupted), 21 (being taken seriously), and 23 (others acting as feeling uncomfortable in the presence of the patient/control).

For retest evaluation, all patients were asked to complete only the PDStigmaQuest a second time 7-14 days after initial completion.

Beyond the PDStigmaQuest, the following self-rated scales and questionnaires were administered:

- The Stigma Scale for Chronic Illness (SSCI) contains 24 items measuring the stigma of chronic illnesses such as PD, Alzheimer's dementia, or epilepsy.[26] It consists of two subscales: self-stigma and enacted stigma. These are rated on a 5-point scale from "never" (1) to "always" (5), resulting in a maximum total score of 120. Higher values indicate higher stigma levels.

- The PDQ-39 is the most frequently used questionnaire for QoL in PD.[27, 31] It contains 39 items in eight different domains. The items are rated on a 5-point scale from "never" (0) to "always" (4). As the domains contain different numbers of items, the domain scores are standardized on a summary index (SI) score from 0 (no impairment) to 100 (maximum impairment). In this study, only the stigma subdomain was used. Due to the domains' high internal consistency (stigma: Cronbach's α = 0.80), they are often used independently of other domains.[32, 33]
- The Beck Depression Inventory II (BDI-II) is an instrument measuring depression severity.[34] It consists of 21 items assessed on a 4-point scale (0-3), resulting in a maximum total score of 63. Higher scores indicate higher depression levels.
- The Hospital Anxiety Depression Rating Scale (HADS) is a scale for anxiety and depressive states.[35] It consists of 14 items divided into two subscales for anxiety and depression, each including 7 items. These are rated on a 4-point scale (0-3), resulting in a maximum score of 21 points for each subscale.

The following clinician-rated tools were administered:

- The Montreal Cognitive Assessment (MoCA) is a short screening test for mild cognitive impairment with various tasks testing the following cognitive domains: Short-term memory, visual-spatial abilities, executive functions, language, attention, concentration, working memory, and orientation.[36] A maximum total score of 30 (maximum performance) can be achieved.
- The Movement Disorders Society Unified Parkinson's Disease Rating Scale III (MDS-UPDRS III) is a clinician-based rating scale for motor function in PD.[37] It includes 18 items rated on a scale from "normal" (0) to "severe" (4) for different motor aspects (e.g., rigidity, tremor), most of them rated separately for the left and right side of the body, resulting in a maximum total score of 132 (maximum impairment). The MDS-UPDRS III additionally contains a Hoehn and Yahr (HY) classification for motor staging of PD,

ranging from stage 0 (no signs of disease) to 5 (wheelchair bound or bedridden unless aided).

The SSCI, PDQ-39 stigma domain, and MDS-UPDRS III were only applied in patients.

Sample size

For conducting exploratory factor analyses (EFA), a minimum of 200 participants is proposed for questionnaires with up to 40 items.[38] A ratio of patients to controls of 2:1 was used based on other validation studies.[39, 40]

Data analysis

Descriptive statistics for demographic and clinical characteristics were calculated. The Shapiro-Wilk test was applied to test for normal distribution of data. Levodopa equivalent daily dose (LEDD) was calculated according to the formula of Tomlinson et al.[41] The score of PDStigmaQuest item 1 (uncomfortableness with symptoms) was calculated by summing up the scores of all applicable symptoms and dividing the sum by the number of applicable symptoms. Data quality was explored by the proportion of missing data points.

Only for patients, the following analyses were conducted:

(1) *Dimensionality:* For this analysis, the optional stigma domain for employed patients was left out as many patients were retired (n = 137). Further, based on participant feedback, patients had problems answering the reverse-scored items. We found that 15.4% of patients initially answered at least one reverse-scored item in the direction of the other non-reversed items, which was subsequently crossed out and changed. In 11.9% of patients, at least one answer to the reversed items did not match the other answers. Since we aimed to develop an easy-to-use and reliable tool, we decided to remove these five items prior to analysis, avoiding potentially biased item characteristics. Inter-item correlations between all other stigma items were calculated, and items mostly showing correlations < 0.3 or > 0.9 with other items were removed

due to potential lack of fit with other items or collinearity.[42] A principal axis EFA with oblique rotation (promax, kappa = 4) was applied as many PDStigmaQuest items were right-skewed, and principal axis EFA does not make distributional assumptions. Oblique rotation was chosen as we assumed that the questionnaire's stigma factors would correlate and oblique rotation permits correlation between factors.[43] The Kaiser-Meyer-Olkin (KMO) measure was applied for testing sampling adequacy. Values > 0.7 are considered middling, values > 0.8 meritorious, and values > 0.9 marvelous.[44] KMO values for individual variables should be > 0.5. Bartlett's test of sphericity was used for testing the adequacy of the correlation matrix.

(2) *Acceptability* was tested through floor and ceiling effects (percentage of extreme values ≤ 15%) and skewness.[45] For the latter, limits were -1 and +1.[46]

(3) *Internal consistency:* Cronbach's alpha was calculated for PDStigmaQuest as a whole as some domains only consisted of 2 items (standard value ≥ 0.7).[30, 40, 47] The work domain not applying to many patients resulted in systematic data loss for internal consistency analysis. Therefore, only for calculating Cronbach's alpha, items referring to work left out by unemployed/retired patients were coded as zero.[48] This approach was considered acceptable because the work domain not applying to a patient also means that the patient cannot be confronted with stigma at work. Further, for every item, corrected item-total correlation (standard value ≥ 0.3) and inter-item correlations (standard value > 0.20 and < 0.75) in every domain were calculated.[30, 49]

(4) *Test-retest reliability* was investigated through Spearman correlation between the initial assessment and the retest (7-14 days later) PDStigmaQuest total score.

(5) *Convergent validity* was tested through correlations with other stigma measures (SSCI, the stigma domain of the PDQ-39; $r_s > 0.50$).[50]

(6) *Known-groups validity:* Based on the well-established relationship between stigma and depression, known-groups validity was tested by comparing PDStigmaQuest scores in

patients with and without depressive symptoms using a Mann-Whitney *U* test.[21] We hypothesized that stigma scores should be higher in PD patients with than without depressive symptoms. To identify patients with depressive symptoms, the cut-off BDI-II ≥ 14 was used as originally suggested by Beck et al. for detecting mild depression.[34, 51]

The following analyses were conducted with data from patients and controls:

(1) *Group confirmation:* To ensure that relevant PD symptoms were not similarly present in healthy controls, Mann-Whitney U tests were conducted between PD patients and healthy controls for the following scales: MoCA total, BDI-II total, HADS-A, and HADS-D. Tests were corrected for multiple comparisons according to the Benjamini-Hochberg procedure.

(2) *Comparison of PDStigmaQuest scores:* To compare PD patients' and healthy controls' stigma scores, a Mann-Whitney U test was conducted with new stigma scores summing up only items answered by both groups. We hypothesized that stigma scores should be higher in PD patients than in healthy controls.

All analyses were conducted using Statistical Package for Social Sciences (SPSS; version 28.0). *P*-values < 0.05 were considered statistically significant.

Results

Demographic characteristics

In total, 201 PD patients and 101 healthy controls matched by age and sex were included in the final analysis. Demographics and clinical characteristics are presented in Table 1.

Table 1 Demographics and clinical characteristics of patients with Parkinson's disease and healthy controls.

	Patients	**Healthy controls**	***p*-value**
Sex (female)	34.3%	45.5%	0.058
Age (years)[a]	64.4 ± 9.7: 32-86	62.5 ± 10.1: 42-87	0.110
Education (years)[a]	15.3 ± 3.1: 7.5-23	16.2 ± 3.3: 9-27	**0.036**
Family status			0.908
Married	74.1%	70.3%	
Single	9.0%	10.9%	
Divorced	10.9%	11.9%	
Widowed	6.0%	6.9%	
Occupation			**<0.001**
(Self-)employed	30.3%	58.4%	
Retired	67.2%	37.6%	
Other	2.5%	4.0%	
Disease duration (years)[a]	7.9 ± 5.0: 0.4-26.8	N/A	N/A
LEDD (mg)[b]	667.6 ± 464.9	N/A	N/A
MDS-UPDRS III (score)[b]	26.0 ± 12.3	N/A	N/A
HY (stage)[c]	2.0 (2.0-3.0)	N/A	N/A
Treated with DBS	22.9%	N/A	N/A

Abbreviations: DBS, Deep brain stimulation; HY, Hoehn and Yahr; LEDD, Levodopa equivalent daily dose; MDS-UPDRS III, Movement Disorders Society Unified Parkinson's Disease Rating Scale III; N/A, not applicable.

Note: Significant differences are highlighted in bold.

[a]Mean ± *SD*: range [b]Mean ± *SD* [c]Median (Interquartilerange).

Data quality and dimensionality

In patients, there was one missing data point in the PDStigmaQuest (0.0001% missing). In healthy controls, no data were missing.

Correlations of item 6 (feeling responsible for PD) were $\geq$ 0.3 with only two other items, thus item 6 was removed. KMO was 0.84 for the remaining items, showing that our sampling was adequate. Further, KMO values for individual variables were all > 0.5. Bartlett's test of sphericity was statistically significant ($p < 0.001$), indicating that our correlation matrix was appropriate for conducting a factor analysis. Kaiser-Guttman criterion extracting factors with eigenvalues > 1 suggested a four-factor solution explaining 46.0% of the variance. In the

pattern matrix, loadings of item 16 on the factors were all < 0.30, so this item was dropped.[42] Subsequently, the EFA was completed again showing a four-factor solution explaining 47.9% of the variance (Table 2): 8 items loaded onto a factor interpreted as “felt stigma”, 3 items loaded onto a factor measuring “hiding”, 3 items loaded onto a factor measuring “enacted stigma: rejection”, and 2 items loaded onto a factor measuring “enacted stigma: patronization”. The factor felt stigma was correlated with the other factors hiding (r = 0.50), enacted stigma: rejection (r = 0.39), and enacted stigma: patronization (r = 0.36). Factors enacted stigma: rejection and enacted stigma: patronization were also moderately correlated (r = 0.42).

Table 2 Pattern matrix of the final exploratory factor analysis.

	Item	Factor			
		1	2	3	4
	Felt stigma				
1	In the presence of others, I feel uncomfortable … [list of symptoms]	**0.629**			
3	I am unhappy about how my Parkinson’s symptoms affect my appearance.	**0.563**			
5	I see myself as a burden to others.	**0.647**			
7	I feel useless.	**0.613**			
9	I worry about how others may react to my Parkinson’s disease.	**0.539**	0.364		
10	I worry about how others will perceive me when my Parkinson’s disease progresses.	**0.648**			
11	I am afraid that others could consider me mentally impaired.	**0.467**			
20	Because of my Parkinson’s symptoms, others have looked at me.	**0.403**			
	Hiding				
2	I feel uncomfortable when others address me regarding the treatment of my Parkinson’s disease (e.g., pills, patches, pump, or deep brain stimulation).		**0.413**		
12	I try to hide my Parkinson’s symptoms from others.		**0.758**		
13	I have kept my Parkinson’s disease secret from someone.		**0.900**		
	Enacted stigma: rejection				
17	Friends or family members have turned away from me because of my Parkinson’s disease.			**0.632**	
22	I have got invited by others less often than prior to my Parkinson’s disease.			**0.701**	
23	Others have behaved as if my presence made them feel uncomfortable.			**0.676**	
	Enacted stigma: patronization				
15	I have experienced others making decisions for me before I can make them for myself.				**0.770**
19	I have experienced others not letting me talk.	0.320			**0.422**

Abbreviations: PD, Parkinson’s Disease.

Note: Loadings < 0.3 omitted.[42] Items assigned to the respective factor in bold.

PDStigmaQuest scores and acceptability

Descriptive statistics of PD patients' PDStigmaQuest scores and acceptability parameters are shown in Table 3. The maximum total score for (self-)employed patients summing up the final 18 items is 72, while unemployed/retired patients can achieve a total score of 64 (without the two items referring to work). In PD patients, floor effects were found for the domains hiding, enacted stigma: rejection, enacted stigma: patronization, and optional domain of work, but not for the domain felt stigma and total score. No ceiling effects were found. A moderate skewness was found for domains hiding and enacted stigma: rejection.

Table 3 Distribution and acceptability of PDStigmaQuest domain scores for patients with Parkinson's disease.

	Mean	***SD***	**Minimum**	**Maximum**	**Maximum achievable**	**Floor effect (%)**	**Ceiling effect (%)**	**Skew-ness**
Felt stigma	9.2	5.4	0	27.9	32	3.0	0	0.6
Hiding	2.4	2.7	0	12.0	12	35.8	0.5	1.2
Enacted stigma: rejection	0.8	1.5	0	7.0	12	67.2	0	2.2
Enacted stigma: patronization	1.8	1.7	0	6.0	8	31.3	0	0.7
Optional: work domain (n = 64)	1.7	1.5	0	5.0	8	31.3	0	0.4
Total Score	14.7	8.9	0	43.91	72	2.0	0	0.6

Abbreviations: PDStigmaQuest, Parkinson's Disease Stigma Questionnaire.

Internal consistency

Cronbach's alpha was 0.85 for the whole scale. Inter-item correlations and corrected item-total correlations are presented in Table 4.

Table 4 Internal consistency analysis for patients with Parkinson's disease.

	Item	*n*	Inter-item correlation	Item-total correlation
	Domain 1: Felt stigma			
1	Uncomfortableness related to PD symptoms	200	**0.34-0.52**	**0.63**
2	Uncomfortableness related to PD appearance	200	**0.29-0.52**	**0.51**
3	Feeling like a burden to others	200	**0.27-0.51**	**0.51**
4	Feeling useless	200	**0.27-0.51**	**0.53**
5	Worries about reactions to PD	200	**0.28-0.70**	**0.62**
6	Worries about reactions to disease progression	200	**0.27-0.70**	**0.64**
7	Fear of being seen as mentally impaired	200	**0.29-0.48**	**0.56**
8	Being observed	200	**0.27-0.36**	**0.45**
	Domain 2: Hiding			
9	Feeling uncomfortable being asked about PD treatment	201	**0.40-0.43**	**0.46**
10	Hiding of PD symptoms	201	**0.43-0.66**	**0.67**
11	Concealing PD	201	**0.40-0.66**	**0.65**
	Domain 3: Enacted stigma: rejection			
12	Rejection by friends and family members	201	**0.42-0.45**	**0.51**
13	Being invited less often	201	**0.45-0.49**	**0.56**
14	Others acting as feeling uncomfortable in the presence of the patient	201	**0.42-0.49**	**0.54**
	Domain 4: Enacted stigma: patronization			
15	Decisions taken on behalf of patient by others	201	**0.44**	**–**
16	Being interrupted	201	**0.44**	–
	Optional domain: Work			
17	Fear of devaluation at work	64	0.18	–
18	Unfair treatment at work	64	0.18	–

Abbreviations: PD, Parkinson's Disease.

Note: In bold are inter-item correlations > 0.2 and item-total correlations ≥ 0.3, representing preferable item characteristics.[30, 49] New numeration of items refers to the final questionnaire.

Test-retest reliability

Spearman correlation between initial and retest PDStigmaQuest total score was 0.83 ($n = 147$, $p < 0.001$).

Convergent validity

The final PDStigmaQuest correlated moderately with the PDQ-39 stigma domain ($r_s = 0.56$, $p < 0.001$) and strongly with the SSCI total score ($r_s = 0.69$, $p < 0.001$).

Known groups validity

Final PDStigmaQuest scores were higher in patients with depressive symptoms (mean = 20.8, *SD* = 9.6) than in patients without depressive symptoms (mean = 13.1, *SD* = 8.1, $p < 0.001$).

Comparison of patients and controls

Descriptive characteristics of MoCA total, BDI-II total, HADS-A, and HADS-D score for PD patients and controls are presented in Table 5. All examined clinical characteristics were significantly higher in PD patients than in controls.

New stigma scores summing up only items in the final PDStigmaQuest answered by PD patients and controls were higher in PD patients (mean = 5.5, *SD* = 3.9) than in healthy controls (mean = 3.3, *SD* = 2.5, $p < 0.001$).

Table 5 Comparison of patients with Parkinson's disease and healthy controls regarding relevant clinical characteristics.

	Patients			**Healthy controls**			***p*-value**
	n	**Mean**	***SD***	***n***	**Mean**	***SD***	
MoCA total	197	26.1	2.6	98	27.7	1.9	**<0.001**
BDI-II total	197	8.8	6.2	100	5.0	5.0	**<0.001**
HADS-A	194	4.5	3.2	101	3.6	2.9	**0.016**
HADS-D	194	4.1	3.2	101	2.3	2.3	**<0.001**

Abbreviations: BDI-II, Beck Depression Inventory II; HADS, Hospital Anxiety and Depression Scale; MoCA, Montreal Cognitive Assessment.

Note: Mann-Whitney *U* tests between patients with Parkinson's disease and healthy controls to analyze differences in relevant clinical characteristics. Bold font highlights significant results, $p < 0.05$; All *p*-values are corrected for multiple comparisons using Benjamini-Hochberg procedure.

Discussion

In this study, we report validation data from the PDStigmaQuest, the first questionnaire specifically and comprehensively addressing stigma in PD. Our results illustrate that the new PDStigmaQuest, consisting of 18 items, is a valid and reliable self-reported questionnaire to comprehensively assess and evaluate stigma in a real-life PD population. Face validity can be assumed as experts, PD patients, and caregivers developed and reviewed the scale.[28]

Data quality and dimensionality

The assessment of the PDStigmaQuest revealed high data quality with only 0.0001% missing data in patients and no missing data in controls. Results from EFA indicated sufficient construct validity. EFA identified 4 factors: felt stigma, hiding, enacted stigma: rejection, and enacted stigma: patronization. We additionally included an optional work domain for employed patients. The identified factors only partially overlap with our initially assumed domains based on one of the latest stigma conceptualizations: uncomfortableness, internalized stigma, anticipated stigma, hiding, and experienced stigma.[11] Instead, the factors identified in the EFA align with the earlier stigma model by Scambler and Hopkins, consisting of felt and enacted stigma, extended by the domain of hiding.[9] Our proposed domains of uncomfortableness, internalized stigma, and anticipated stigma were grouped as only one factor: felt stigma. Our initially assumed domain experienced stigma was divided into two aspects: rejection and patronizing by others. These also represent two components of the enacted stigma concept by Scambler and Hopkins.[9] Our additional hiding domain specific to PD patients due to their partly concealable condition was preserved, with one additional item previously assigned to uncomfortableness (feeling uncomfortable being asked about PD treatment), which could have resulted from the high correlation between the factors felt stigma and hiding (r = 0.50). Fox et al. based their stigma concept on stigma insights concerning mental illness, which may explain the differences observed to the findings of our study in PD.[11] In contrast, Scambler

and Hopkins investigated stigma for persons with another neurological disease, epilepsy, in which stigma is conceptually closer to PD stigma.[9]

Acceptability

Moderate floor effects were found for domains of hiding, enacted stigma: rejection, enacted stigma: patronization, and work. In the context of other health conditions, it is often reported that felt stigma, including fear of being stigmatized, is significantly more prevalent than experiences of enacted stigma, e.g., rejection and patronization.[52, 53] Especially enacted stigma: rejection items refer to extreme forms of stigma, including breaking off contact to the PD patient.[54] Therefore, this domain was expected to show floor effects. We nevertheless included these items since they are essential to portraying stigma in PD. Furthermore, it was shown that hiding efforts are more prevalent in the early stages of the disease, potentially leading to moderate floor effects of the domain hiding in our PD cohort representing the general PD population.[13] Floor effects of the domain work could be explained by the fact that some PD patients stated to be self-employed and, therefore, the stigma items might not be fully applicable. Future studies should differentiate between employed and self-employed patients when investigating work-related stigma. To date, little is known about PD patients' work-related stigma, which has to be investigated more intensively in the future, representing an important stigma aspect in PD.[55, 56] Notably, there were no floor effects for the total score and ceiling effects were absent. In summary, the results indicated an appropriate acceptability of the final PDStigmaQuest.

Internal consistency and test-retest reliability

For the final PDStigmaQuest, Cronbach's alpha was 0.85, indicating high internal consistency. Inter-item correlations in the different stigma domains were all satisfactory except for work items. In this domain, one item represents felt stigma and the other enacted stigma experiences according to Scambler and Hopkins.[9] The differential prevalence of the two stigma aspects could have led to low inter-item correlations with higher values on the felt

stigma than on the enacted stigma item. However, given the importance of employment for PD patients, we consider including both stigma types within an optional domain for employed patients necessary. All calculated item-total correlations for domains met standard criteria. Test-retest correlation of the final PDStigmaQuest was 0.83, indicating high test-retest reliability.

Convergent and known-groups validity

The final PDStigmaQuest showed satisfactory correlations with other stigma measures, suggesting high convergent validity. Furthermore, data provided evidence for adequate known-groups validity due to the difference in PDStigmaQuest scores between patients with and without depressive symptoms. This finding is consistent with previous stigma literature, showing higher stigma levels in patients with higher depression levels.[19, 21, 22, 57, 58]

Comparison of PD patients and healthy controls

Comparing PD patients and healthy controls regarding relevant PD symptoms, we observed higher scores in patients than in healthy controls, providing evidence for a representative control group. New stigma scores summing up only items in the final PDStigmaQuest answered by PD patients and controls were significantly higher in PD patients, suggesting that the stigma experiences in the PDStigmaQuest are not equally made by elderly people without PD and rather represent PD-specific experiences.

Limitations

This validation study also has some limitations. Firstly, the two items referring to work-related stigma (n = 64) could not be explored with regard to dimensionality as for EFA, a minimum of 200 cases is required.[38] However, we decided to retain these items due to their high importance for employed PD patients. Furthermore, since these items represent a dimension of stigma that can only be experienced by a subgroup of patients, treating this domain separately and not as a part of other stigma aspects affecting the general PD population was considered appropriate. Secondly, only seven items of the final PDStigmaQuest were

applicable also to healthy controls and therefore, could be compared to PD patients. All other items were not completed by healthy controls as they included PD-related wording like “because of my Parkinson’s disease” and already implied that healthy controls cannot have these experiences at all. Thirdly, there was a difference between PD patients and healthy controls in years of education as well as employment status. Although to our knowledge, education has not been associated with stigma in PD, it has been identified as an influencing factor in other conditions such as epilepsy so that it would be reasonable controlling years of education in further studies.[59] The difference in employment status is somehow expected as PD patients retire 4–7 years earlier than the general population.[60] Lastly, the field’s current understanding of stigma in PD remains limited, highlighting the need for cross-validation of our findings in different PD cohorts, with a special need for investigating stigma in different countries and socio-cultural backgrounds as well as providing longitudinal data.

Conclusions

In conclusion, our results indicate that the patient-reported PDStigmaQuest has strong psychometric properties of validity and reliability and is helpful in assessing and evaluating PD-specific stigma. In future, the PDStigmaQuest can be applied to understand the different aspects of PD stigma and their potential influencing factors, e.g., demographics, and its relationship to clinical characteristics in more detail. This might contribute to improve the management of stigma in clinical practice and, as a consequence, patients’ QoL.

Future studies validating the PDStigmaQuest in different languages and independent multi-cultural PD cohorts are warranted.

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Conflict of Interest

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Data Availability

The data used to support the findings of this study are available from the corresponding author upon reasonable request.

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2.3 Intercultural adaptation of the PUKSoPC in German language

Stopic, V., Rizos, A., Simpson, J., Eccles, F. J. R., Dembek, T. A., Barbe, M. T., & Sauerbier, A. (2024). Interkulturelle Adaptation der PUKSoPC in deutscher Sprache: Eine Skala zur gefühlten Kontrolle von Parkinson-Patientinnen und -Patienten. *Der Nervenarzt, 95*(2), 141–145. https://doi.org/10.1007/s00115-023-01569-2

Interkulturelle Adaptation der PUKSoPC in deutscher Sprache

Eine Skala zur gefühlten Kontrolle von Parkinson-Patientinnen und -Patienten

V. Stopic[1], A. Rizos[2], J. Simpson[3], F. J. R. Eccles[3], T. A. Dembek[1], M. T. Barbe[1], A. Sauerbier[1,4]

[1]Klinik und Poliklinik für Neurologie, Universitätsklinik Köln, Köln, Deutschland
[2]Department of Neurology, King's College Hospital NHS Foundation Trust, London, United Kingdom
[3]Division of Health Research, Faculty of Health and Medicine, Lancaster University, Lancaster, United Kingdom
[4]Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, United Kingdom

Zusammenfassung

Hintergrund. Die gefühlte Kontrolle von Menschen mit Parkinson-Erkrankung spielt eine große Rolle für ihre Lebensqualität. Simpson et al. entwickelten eine für die Parkinson-Erkrankung spezifische Skala der gefühlten Kontrolle namens Parkinson's UK Scale of Perceived Control (PUKSoPC). Wir stellen in dieser Arbeit eine interkulturell adaptierte deutsche Übersetzung der englischen Originalversion vor.

Methoden. Nach Zustimmung der Originalautoren wurde ein international etabliertes Prozedere für die interkulturelle Adaptation eingesetzt. Die englischsprachige Originalversion wurde unabhängig von zwei bilingualen Neurowissenschaftlern übersetzt und anschließend von beiden eine Konsensusversion gebildet. Diese wurde an 10 Parkinson-Patientinnen und -Patienten getestet und von zwei weiteren Neurowissenschaftlern unabhängig in die englische Sprache rückübersetzt. Nach Bildung einer Konsensusversion wurde diese englische Version von allen vier Übersetzern mit der Originalversion verglichen. Differenzen zwischen den Versionen resultierten in Modifikationen der deutschen Übersetzung, sodass die Rückübersetzung möglichst genau dem Original entsprach. Die finale Version wurde von zwei der Originalautoren genehmigt und an 50 Parkinson-Patientinnen und -Patienten klinisch getestet.

Ergebnisse. Im Rahmen des Übersetzungsprozesses einigten sich die vier Übersetzer auf eine kulturell adaptierte deutsche Fassung der PUKSoPC. Bei der Testung der finalen Version an 50 Parkinson-Patientinnen und -Patienten zeigten sich keine sprachlichen oder inhaltlichen Probleme.

Diskussion. Die vorgestellte, sprachlich validierte deutsche Version der PUKSoPC steht nun zur Erhebung der gefühlten Kontrolle von Parkinson-Patientinnen und -Patienten in Forschung und klinischem Alltag zur Verfügung.

Schlüsselwörter: Parkinson-Erkrankung, Gefühlte Kontrolle, Skala, Übersetzung, Validierung

Intercultural adaptation of the PUKSoPC in German language

Abstract

Background. The level of perceived control in people with Parkinson's disease plays a significant role in affecting their quality of life. Simpson et al. developed a scale of perceived control specific to Parkinson's disease called the Parkinson's UK Scale of Perceived Control (PUKSoPC). In this work, we present a cross-culturally adapted German translation of the original English version.

Materials and methods. After receiving approval by the original authors, an internationally established procedure was used for cross-cultural adaptation. Firstly, the original English version was translated into German independently by two bilingual neuroscientists, who then agreed on a consensus version. This was tested on 10 people with Parkinson's disease and independently back translated into English by two different neuroscientists. After forming a consensus version, this English version was compared with the original version by all four translators. Differences between the versions resulted in modifications to the German translation so that the back-translation matched the original as closely as possible. The final version was approved by two of the original authors and clinically tested on 50 people with Parkinson's disease.

Results. During the translation process, the four translators agreed on a culturally adapted German version of the PUKSoPC. Testing of the final version on 50 people with Parkinson's disease did not reveal any linguistic or content-related problems.

Conclusion. The linguistically validated German version of the PUKSoPC presented in this paper is now freely available for measuring the levels of perceived control in people with Parkinson's disease to advance both research and clinical practice.

Keywords: Parkinson’s disease, Perceived control, Scale, Translation, Validation

Gefühlte Kontrolle hat einen großen Einfluss auf das psychische Wohlbefinden von Menschen mit Parkinson-Erkrankung. Mit der Parkinson's UK (United Kingdom) Skala der gefühlten Kontrolle (Parkinson's UK Scale of Perceived Control – PUKSoPC) wurde die erste Skala entwickelt, welche die gefühlte Kontrolle von Parkinson-Patientinnen und -Patienten krankheitsspezifisch erfasst. Da die Skala bislang nur in englischer Sprache vorlag, haben wir diese gemäß international anerkannten Vorgaben übersetzt und interkulturell adaptiert. In dieser Arbeit wird der Übersetzungsprozess sowie die validierte deutsche Version vorgestellt.

Das Konzept der gefühlten Kontrolle spielt eine wichtige Rolle bei chronischen Erkrankungen wie der Parkinson-Erkrankung [12]. Sie wird definiert als „die Überzeugung, dass man seine eigenen internen Zustände und Verhalten bestimmen, seine Umgebung beeinflussen und/oder gewünschte Ergebnisse erzielen kann“ [12]. Die gefühlte Kontrolle stellt einen bedeutsamen Faktor bei der Adaptation an eine chronische Erkrankung dar [5, 10]. Ein hoher Grad an gefühlter Kontrolle bei Parkinson-Patientinnen und -Patienten ist assoziiert mit hoher Lebensqualität, der genauen Einhaltung der Medikamenteneinnahme sowie geringer Ausprägung einer Depression [13]. Trotz der hohen Spezifität der gefühlten Kontrolle bei der Parkinson-Erkrankung wurden in der Vergangenheit lediglich krankheitsübergreifende Instrumente zur Messung verwendet [2, 8]. Aus diesem Grund entwickelten Simpson et al. (2018) eine für die Parkinson-Erkrankung spezifische Skala der gefühlten Kontrolle namens Parkinson's UK Scale of Perceived Control – PUKSoPC, welche bisher nur in der Originalversion auf Englisch vorlag [9]. Die selbstberichte Skala besteht aus 15 Aussagen in den folgenden 5 Teilskalen mit jeweils 3 Aussagen: „Positiv denken“, „Sich informieren“, „Dinge tun“, „Planen“ und „Engagiert sein“. Die Zustimmung zu den einzelnen Aussagen soll auf einer Skala von 1 (gar nicht) bis 5 (ganz genau) bewertet werden.

Wir stellen in dieser Arbeit eine gemäß international anerkannter Vorgaben erstellte, interkulturell adaptierte deutsche Übersetzung vor.

Methoden

Vor Beginn der Übersetzung wurde das Einverständnis der Autoren der Originalversion des PUKSoPCs zum Vorhaben eingeholt (JS, FE). Zur Adaptation in deutscher Sprache wurde ein international anerkanntes Prozedere durchlaufen [1, 4]: Als Erstes wurde die englischsprachige Originalversion unabhängig von zwei bilingualen Neurowissenschaftlern mit Expertise im Bereich der Parkinson-Erkrankung (AR, AS) möglichst wörtlich in die deutsche Sprache übersetzt. Anschließend wurden beide Versionen von den Übersetzern verglichen und eine Konsensusversion erstellt. Um mögliche erste Verständnisprobleme zu beseitigen, wurde diese Version bei 10 Patientinnen und Patienten mit idiopathischer Parkinson-Erkrankung (Diagnose gemäß UK Brain-Bank-Kriterien) am Universitätsklinikum Köln klinisch getestet (VS). Die Kommentare der Patientinnen und Patienten wurden in die deutsche Fassung eingearbeitet. Letztere wurde anschließend von zwei weiteren bilingualen Neurowissenschaftlern mit Expertise im Bereich der Parkinson-Erkrankung (TD, MB) unabhängig voneinander in die englische Originalsprache zurückübersetzt. Nach Abgleich der Versionen wurde von den Übersetzern eine englische Konsensusversion erstellt. Diese wurde anschließend von allen beteiligten Übersetzern (AR, AS, TD, MB) mit der Originalversion verglichen. In diesem Rahmen wurden geringe Differenzen zwischen beiden englischen Versionen aufgedeckt. Bei abweichend übersetzten Wörtern in der englischen Rückübersetzung wurden die Wörter in der deutschen Version noch einmal betrachtet und durch Synonyme ersetzt, die den Sinn der Wörter in der Originalversion besser widerspiegelten. Die finale deutsche Übersetzung sowie die englische Rückübersetzung wurden zudem an zwei der Autoren der Originalarbeit (JS, FE) geschickt und von diesen genehmigt. Zuletzt wurde die finale Version an 50 Patientinnen und Patienten mit idiopathischer Parkinson-Erkrankung (Diagnose gemäß UK Brain-Bank-Kriterien) am Universitätsklinikum Köln klinisch getestet (VS, AS), um mögliche sprachliche und inhaltliche Probleme zu erkennen.

Ergebnisse

Die erste Testung der deutschen Version an 10 Patientinnen und Patienten mit idiopathischer Parkinson-Erkrankung (VS) ergab keine sprachlichen oder inhaltlichen Probleme. Lediglich Aussage 10 „Ich habe Mittel und Wege, die mir helfen, daran zu denken, was ich tun wollte“ wurde von einer Patientin aufgrund der Länge als etwas unleserlich erachtet. Leider ist es im Deutschen grammatikalisch nicht möglich, eine kürzere Version des Satzes zu finden, ohne den Sinn abzuändern. Daher wurde der Satz beibehalten. Bei der Findung einer Konsensusversion durch alle vier Übersetzer stellte sich heraus, dass einige Wörter in der englischen Sprache anders verwendet werden als in der deutschen Sprache. Die Übersetzung des Titels der Skala war zunächst nicht ganz eindeutig, da der Begriff „perceived control“ in diesem Kontext im Englischen eine affektive Komponente enthält, die in der Übersetzung „wahrgenommene Kontrolle“ nicht ganz deutlich wird. Aus diesem Grund wurde als Übersetzung „gefühlte Kontrolle“ gewählt. Die Antwortoptionen „quite a lot“ und „very much“ wurden mit „ziemlich genau“ und „ganz genau“ übersetzt. Angepasst an den deutschen Sprachraum wurde „Parkinson’s“ mit „Parkinson-Erkrankung“ übersetzt. Die wörtliche Übersetzung des Ausdrucks „remember to do things“ in Aussage 10 „sich erinnern, Dinge zu tun“ wird in der deutschen Sprache so nicht verwendet, sodass die Übersetzung „sich erinnern, was man tun wollte“ gewählt wurde. Als nationale Organisation, bei welcher man sich als Patientin oder Patient engagieren kann, wurde in der Originalversion in Aussage 15 als Beispiel „Parkinson’s UK“ gewählt, welche durch die in Deutschland bekannte „Deutsche Parkinson Vereinigung“ ersetzt wurde.

Die Zusendung der finalen deutschen Übersetzung sowie englischen Rückübersetzung an zwei der Autoren der Originalarbeit (JS, FE) resultierte in einigen wenigen Anmerkungen zur englischen Rückübersetzung, welche jedoch dadurch entkräftet wurden, dass die deutsche Version als sprachlich passend erachtet wurde.

Bei der Testung der finalen Version der deutschen Übersetzung des PUKSoPCs an 50 Patientinnen und Patienten mit idiopathischer Parkinson-Erkrankung (VS, AS) zeigten sich keinerlei sprachliche oder inhaltliche Probleme. Die finale, interkulturell adaptierte deutsche Übersetzung ist in **Abb. 1** gezeigt.

Parkinson's UK Skala der gefühlten Kontrolle (Parkinson's UK Scale of Perceived Control - PUKSoPC)

Bitte denken Sie darüber nach, wie sehr jede der folgenden Aussagen auf Sie zutrifft, und kreuzen Sie die passende Antwort an.

		Gar nicht	Nur ein wenig	Etwas	Ziemlich genau	Ganz genau
1	Ich versuche, mich auf das Positive im Leben zu konzentrieren.					
2	Ich kann mit meiner Stressbelastung umgehen.					
3	Ich kann damit umgehen, wenn ich mich niedergeschlagen fühle.					
4	Ich weiß, was mir hilft, meine körperlichen Symptome so weit wie möglich zu bewältigen.					
5	Ich weiß, wo ich mehr Informationen zu der Parkinson-Erkrankung finden kann, wenn ich sie brauche.					
6	Ich kenne die verschiedenen Behandlungsmöglichkeiten der Parkinson-Erkrankung.					
7	Ich versuche, mich an sozialen Aktivitäten mit Freunden und Familie zu beteiligen, wann immer ich kann.					
8	Ich versuche, an Aktivitäten teilzunehmen, die gut für meine körperliche Gesundheit sind.					
9	Ich versuche, an Aktivitäten teilzunehmen, die gut für mein geistiges Wohlbefinden sind.					
10	Ich habe Mittel und Wege, die mir helfen, mich daran zu erinnern, was ich tun wollte.					
11	Ich stelle sicher, dass meine Pläne flexibel sind, damit ich sie wenn nötig ändern kann.					
12	Ich setze mir Ziele für Sachen, die ich tun möchte.					
13	Ich teile mein Fachwissen über die Parkinson-Erkrankung mit Anderen, wann immer ich kann.					
14	Ich helfe meiner Familie und Freunden, mehr über die Parkinson-Erkrankung zu erfahren.					
15	Ich engagiere mich bei einer nationalen Parkinson Organisation (z. B. der Deutschen Parkinson Vereinigung).					

Anleitung zur Bewertung

Jede Antwort wird wie folgt bewertet:

Gar nicht	1
Nur ein wenig	2
Etwas	3
Ziemlich genau	4
Ganz genau	5

Zur Berechnung der Punktzahl jeder Teilskala werden die Punkte der folgenden Aussagen addiert:

Positiv denken	1 2 3
Sich informieren	4 5 6
Dinge tun	7 8 9
Planen	10 11 12
Engagiert sein	13 14 15

Die Gesamtpunktzahl ist die Summe aller Punkte (oder die Summe der Teilskalen).

Abb. 1: Interkulturell adaptierte deutsche Übersetzung der Parkinson's UK Skala der gefühlten Kontrolle (Parkinson's UK Scale of Perceived Control - PUKSoPC).

Diskussion

In dieser Arbeit wurde eine interkulturell adaptierte deutsche Übersetzung der PUKSoPC, einer Skala zur gefühlten Kontrolle von Patientinnen und Patienten mit idiopathischer Parkinson-Erkrankung, vorgestellt. Diese wurde auf Basis international anerkannter Vorgaben für interkulturelle Übersetzungen von Fragebögen und Skalen erstellt [1, 4]. Die Testung der finalen Version zeigte keinerlei sprachliche oder inhaltliche Probleme. Daher kann angenommen werden, dass sie ebenfalls wie die validierte Originalversion eine gute Augenschein-Validität, Test-Retest Reliabilität sowie solide Faktorenstruktur aufweist.

Mit der Entwicklung der PUKSoPC wurde erstmals eine Skala vorgestellt, welcher die gefühlte Kontrolle von Patientinnen und Patienten mit idiopathischer Parkinson-Erkrankung erfasst. Unter Nutzung der Skala bei dieser Patientengruppe konnte bereits gefunden werden, dass gefühlte Kontrolle als Mediator fungiert zwischen Stigma und Lebensqualität sowie Stigma und Depression [11]. Das Konstrukt des Stigmas spielt bei der Parkinson-Erkrankung ebenfalls eine wichtige Rolle: Es bezeichnet das gefühlte oder tatsächliche Auftreten von Labeling, Stereotypen, Ausgrenzung, Statusverlust oder Diskriminierung aufgrund der Parkinson-Erkrankung [3, 6, 7]. Somit kann ein hohes Maß an gefühlter Kontrolle den negativen Effekt, den ein hohes Maß an Stigma auf die Lebensqualität und Depression hat, abschwächen. Ebenfalls wurde gezeigt, dass gefühlte Kontrolle u. a. mit psychologischer Unterstützung, Wissen über Medikamente sowie Alter und Geschlecht assoziiert ist [13]. Auf Grundlage dieser Erkenntnisse könnten solche Einflussvariablen modifiziert werden, was zu einer Steigerung der gefühlten Kontrolle und damit wiederum zu einer Verbesserung der Lebensqualität der Patientinnen und Patienten mit idiopathischer Parkinson-Erkrankung führen kann.

Da bislang nur die englische Originalversion zur Nutzung in der Forschung zur Verfügung stand, beruhen diese Erkenntnisse lediglich auf Studien, welche im englischsprachigen Raum durchgeführt wurden. Da es naheliegend ist, dass das Konzept der gefühlten Kontrolle

allgemein von großer Bedeutung bei der Parkinson-Erkrankung ist, sollte es auch möglich sein, die gefühlte Kontrolle in deutschsprachigen Regionen routinemäßig in klinischer Praxis und klinischen Studien erheben zu können. Aus diesem Grund stellen wir hiermit eine kulturell adaptierte, deutsche Übersetzung der PUKSoPC vor, welche kostenlos zur Verfügung steht. Eventuell offenbaren sich in deutschsprachigen Regionen aufgrund interkultureller Unterschiede andere Einflussfaktoren und Zusammenhänge als zuvor gefunden werden konnten. Die Erforschung möglicher Unterschiede in der Ausprägung der gefühlten Kontrolle wird ebenfalls durch unsere Übersetzung ermöglicht. Die Nutzung eigenständig übersetzter Versionen ist daher nicht mehr notwendig oder angebracht.

Die deutsche Übersetzung kann kostenlos auf Anfrage an den korrespondierenden Autor als PDF-Version bezogen werden.

Fazit für die Praxis

- Die Parkinson’s UK Scale of Perceived Control (PUKSoPC) ist die erste krankheitsspezifische Skala zur Messung der gefühlten Kontrolle bei Patientinnen und Patienten mit Parkinson-Erkrankung.
- Wir stellen in dieser Arbeit eine kulturell adaptierte deutsche Übersetzung der im Original in englischer Sprache verfassten Skala vor, welche kostenlos für den Einsatz in klinischer Praxis und Forschung verfügbar ist.
- Durch Nutzung international anerkannter Vorhaben bei der interkulturellen Adaptation kann von vergleichbaren psychometrischen Eigenschaften der Übersetzung ausgegangen werden.

Korrespondenzadresse

Dr. Anna Sauerbier
Klinik und Poliklinik für Neurologie
Universitätsklinik Köln
Kerpener Str. 62, 50937 Köln, Deutschland
anna.sauerbier@uk-koeln.de

Einhaltung ethischer Richtlinien

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Für diesen Beitrag wurden von den Autor/-innen keine Studien an Menschen oder Tieren durchgeführt.

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3. Discussion

The present work aimed at developing, testing, and validating a holistic self-reported questionnaire to assess the stigma of PD patients specifically. Additionally, in preparation for future studies investigating stigma effects using the new stigma questionnaire in German-language cohorts, the PUKSoPC, a scale for the stigma-related construct of perceived control, should be cross-culturally adapted into German language to enable the investigation of a potential mediating effect of perceived control. These research objectives were addressed in two prospective, cross-sectional studies and an intercultural adaptation process of the PUKSoPC based on internationally established guidelines.

3.1 Summary of the results

The development process of the PD-specific stigma questionnaire called PDStigmaQuest involving health professionals and PD patients resulted in a preliminary, self-reported German language questionnaire consisting of 28 items in the five domains named uncomfortableness, anticipated stigma, hiding, experienced stigma, internalized stigma. Evaluating the preliminary version in a pilot study involving PD patients, healthy controls, caregivers of PD patients, and health professionals showed feasibility, comprehensibility, appropriate acceptability, and good internal consistency of the PDStigmaQuest. Moreover, the majority of items satisfied established criteria for item difficulty, item variance, and item-total correlation in the item analysis. In addition, higher stigma scores were found in PD patients compared to healthy controls. Especially results from item analysis and feedback to the questionnaire led to modifications of the preliminary PDStigmaQuest such as deletion or rewording of items and adding an optional section for items referring to work instead of offering a “not applicable” response option.

In the next step, the modified 25-item PDStigmaQuest was tested with regard to dimensionality, acceptability, and psychometric properties in a validation study involving PD patients and healthy controls. Due to patients’ problems with answering reverse-scored items,

the five reverse-scored items were rejected prior to analysis (for further explanation, see data analysis section of 2.2 Validation Study). Analysis of inter-item correlations resulted in rejecting one item with mainly low inter-item correlations, indicating lack of fit with other items. The rejected item measured feeling responsible for PD. An exploratory factor analysis (EFA) produced the factors of felt stigma, hiding, enacted stigma: rejection, and enacted stigma: patronization. Another item measuring to which degree others were making fun of the patient had to be rejected due to low loadings on the factors. In addition to these four identified stigma domains, the optional work domain was retained. After analysis, the final PDStigmaQuest consisted of 18 items in five domains (for the final German version, see Appendix). Overall, results of the validation study indicated an appropriate acceptability, high internal consistency, high test-retest reliability, sufficient construct validity, high convergent validity, and adequate known-groups validity of the final PDStigmaQuest. Furthermore, higher stigma scores were found in PD patients compared to healthy controls.

The intercultural adaptation of the English PUKSoPC by four bilingual neuroscientists following a multi-step procedure resulted in an adapted German version of the PUKSoPC. In the course of translation, the neuroscientists identified that some words are used differently in English than in German so that German words were changed in the way that the meaning of English words was retained. No linguistic or content-related problems emerged during the testing of the final German version on 50 PD patients.

3.2 Development and validation process of the PDStigmaQuest

3.2.1 Initial development

The development of the initial version of the PDStigmaQuest based on a multistep, multidisciplinary procedure, including literature review, input from health professionals and researchers working with PD patients, and patients' feedback resembles the development processes of relevant existing tools applied in PD (Chaudhuri et al., 2002; Martinez-Martin et al., 2019; Weintraub et al., 2012). In line with our inclusion of different groups of health professionals working with PD patients (neurologists, physiotherapists, psychologists, etc.),

other studies have also attributed great importance to the involvement of different groups of experts working with the target patient group to establish a comprehensive picture of the measured construct (e.g., Pennington et al., 2013; Rashid et al., 2022). Although some studies did not involve patients in the development (Chaudhuri et al., 2002; Leentjens et al., 2014), experts in the domain of patient-reported outcome measures (PROMs) emphasized the importance of including patients in the development of a measurement tool (Cella et al., 2007). As stigma in PD is highly subjective and understudied and only PD patients themselves can describe their internal shame, anticipated and internalized stigma experiences, it was particularly important to include the patients' perspective. In contrast, symptom-oriented scale developments without patients' input could have been justified by relying on the expertise of highly experienced clinicians with profound knowledge about the target patient groups and the associated symptoms (Chaudhuri et al., 2002; Leentjens et al., 2014).

The stigma model chosen in the development process to represent the basis for the included stigma domains for the preliminary PDStigmaQuest version (Fox et al., 2018) was not the model of felt and enacted stigma, which has been commonly applied with regard to PD stigma (Scambler & Hopkins, 1986). As the overall understanding of stigma has improved in the past (Bos et al., 2013), the more recent and more detailed stigma model by Fox et al. (2018) developed to extend older stigma models was considered appropriate to cluster the generated stigma items. In a recent publication of Carolan (2023), the mechanisms included in the model by Fox et al. (2018) for describing the perspective of the stigmatized have already been applied on PD stigma. Further, this model has built the basis for recent questionnaire developments with regard to other constructs like mental health issues (Healey, 2022; Vorstenbosch et al., 2022).

3.2.2 Pilot testing

In line with the development processes of other tools designed for PD or other health conditions, the pilot testing of the preliminary version of the PDStigmaQuest represented an important phase of tool development (e.g., Chaudhuri, Martinez-Martin, et al., 2006; Husni et

al., 2007; Martinez-Martin et al., 2019; Schmitt et al., 2018). The inclusion of caregivers in the pilot testing of a questionnaire or scale for a specific patient group is not a standard procedure, but is in accordance with the trend to involve PD patients' caregivers in research when evaluating the PD patients' situation (Chen et al., 2022; Chiong-Rivero et al., 2011; Khlebtovsky et al., 2012). Their feedback to the questionnaire was regarded as particularly important as they spend a large proportion of time with PD patients, are often informed about their feelings, and also notice stigmatizing reactions from other people (Chiong-Rivero et al., 2011).

In the pilot study, we found floor effects in three of five stigma domains. Floor effects of stigma measures appear to be a prominent finding across various health conditions and were also detected in a stigma scale applied in PD (Molina et al., 2013; Ohlsson-Nevo et al., 2020; Peters et al., 2017; Reinius et al., 2017; Schönenberg & Prell, 2022). As Peters et al. (2017) have already highlighted, the lack of sensitivity to distinguish between very low stigma levels does not necessarily have to be a problem for a stigma tool as such low levels would typically not require intervention. Moreover, some of these stigma scales also included extreme stigma experiences like losing friends due to the disease (Molina et al., 2013; Peters et al., 2017; Reinius et al., 2017), which many patients do not experience but represent significant stigma components and therefore, had to be included.

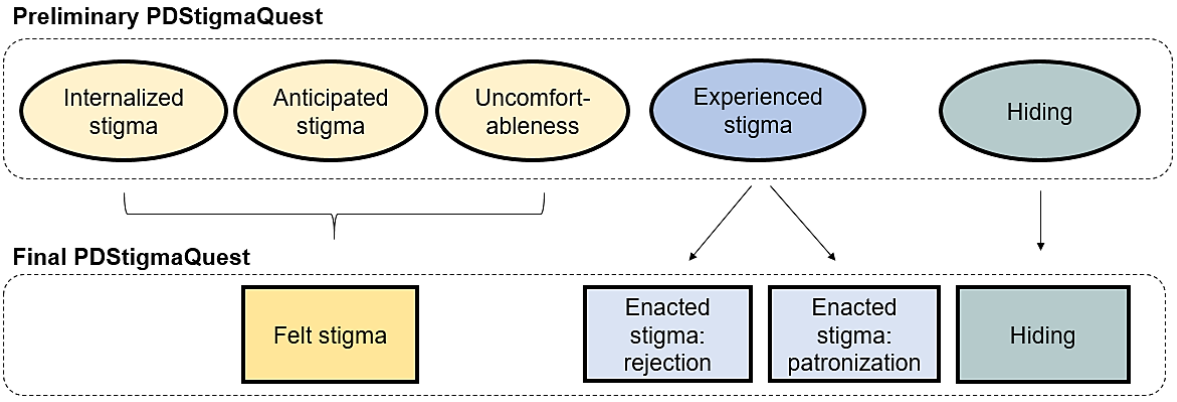
3.2.3 Validation

As a final step, the validation study was conducted, which represents a necessary step to show that a tool is psychometrically sound and suitable for use (DeVon et al., 2007). The validation study of the PDStigmaQuest included testing of dimensionality, acceptability, as well as various forms of reliability and validity. As in the pilot study, floor effects were found, in this case, for four of five domains (for the discussion of floor effects in stigma measures, see 3.2.2 Pilot testing). The optional work items could not be included in the dimensionality analysis, given that many patients were retired. Consequently, these items were retained in the final questionnaire as an optional work domain. The factors identified in the EFA including

all other items only partially overlapped with the stigma domains chosen for the preliminary PDStigmaQuest, namely uncomfortableness, anticipated stigma, hiding, experienced stigma, and internalized stigma (Fox et al., 2018). Instead, four factors were identified, which were interpreted as felt stigma, hiding, enacted stigma: rejection, and enacted stigma: patronization. These stigma domains correspond to the model of felt and enacted stigma, expanded by the hiding domain (Scambler & Hopkins, 1986). However, our proposed domains do not contradict the identified factors. Rather, the domains of uncomfortableness, anticipated stigma, and internalized stigma were consolidated to form the factor of felt stigma, experienced stigma was divided into two subtypes, and the hiding domain was preserved and extended by one item initially classified as uncomfortableness (see Figure 4).

Figure 4

Comparison of the stigma domains of the preliminary and final version of the Parkinson's Disease Stigma Questionnaire



Note. Comparison of the stigma domains proposed in the preliminary Parkinson's Disease Stigma Questionnaire and the final stigma domains identified by an exploratory factor analysis. The preliminary domains of internalized stigma, anticipated stigma, and uncomfortableness were grouped to felt stigma, experienced stigma was divided into two subtypes, and a hiding domain was preserved. PDStigmaQuest = Parkinson's Disease Stigma Questionnaire.

Nevertheless, the results of the EFA suggest that the concept of PD stigma can be best described by the model of Scambler and Hopkins (1986) rather than recent, more detailed stigma models. Importantly, this result is consistent with previous PD stigma literature, in which the model of felt and enacted stigma was most commonly applied (e.g., Eccles et al., 2022; Hou et al., 2021; Ma et al., 2016). In line with previous findings on the prevalence of felt and enacted stigma, PDStigmaQuest scores also support the finding that felt stigma is more prevalent than enacted stigma (Ma et al., 2016).

Furthermore, the domains derived from the dimensionality analysis are similar to the domains of the SSCI, a disease-generic stigma scale often applied in PD, covering the domains of felt and enacted stigma (Rao et al., 2009). In addition to these, the PDStigmaQuest includes hiding aspects and enacted stigma was divided into the subtypes of rejection and patronization. Notably, Rao et al. (2009) deliberately excluded items in the EFA which formed a third factor only applicable to concealable conditions, with the aim of only including generic stigma experiences. Consequently, the SSCI could not include all relevant aspects of PD stigma as the developers had to ensure that every item also applies to the other medical conditions/diagnoses. Therefore, the PDStigmaQuest may prove more appropriate in contrast to the SSCI when the aim is to capture as many stigma components relevant to PD patients as possible. Although the stigma domain of the PDQ-39 was also designed to capture PD stigma specifically, the PDStigmaQuest includes a wider range of stigma experiences, since the PDQ-39 stigma domain consists of four items and only includes felt stigma and hiding experiences, so that an evaluation of enacted stigma is not possible (Peto et al., 1995).

Comparing the stigma domains of the SIS and SES, the two other scales validated for the use in PD, with the domains of the final PDStigmaQuest, it can be postulated that the PDStigmaQuest subdomains enable a more adequate assessment of PD stigma (Fife & Wright, 2000; Wahl, 1999). Although the items in the SES were not divided into different subdomains, it is noticeable that the items in majority represent enacted stigma experiences with only one item encompassing aspects of anticipated stigma and hiding efforts, so that the

PDStigmaQuest enables a more comprehensive assessment of PD stigma also addressing felt stigma and different hiding experiences (Wahl, 1999). Additionally, it is evident that the scale was initially developed for mental health consumers as enacted stigma experiences are tailored to this target group and for example, do not include patronization experiences highly relevant for PD stigma. The structure of the SIS seems to be more similar to the PDStigmaQuest since it also includes a social rejection subdomain and aspects of internalized shame, being part of the felt stigma domain of the PDStigmaQuest (Fife & Wright, 2000). However, the other two subdomains of financial insecurity and social isolation rather represent consequences of stigma rather than the stigma concept itself, which can be seen as a potential weakness of the SIS in measuring stigma.

Importantly, compared to the stigma tools previously validated for PD, the PDStigmaQuest is the only tool with a separate, optional domain measuring stigma experiences at work (Fife & Wright, 2000; Peto et al., 1995; Rao et al., 2009; Wahl, 1999). The SIS as well as the SES also include items addressing stigma at work but as the SES does not include different subdomains and in the SIS, the work items are distributed across several domains, it is rather difficult to capture the differential effect of stigma at work. By means of the separate work domain in the PDStigmaQuest, it is possible to build a separate score for this highly relevant aspect of PD stigma (Carolan, 2023) and to analyze its effects as well as contributing factors.

Overall, the results of the validation study illustrate that the PDStigmaQuest is a reliable and valid self-reported questionnaire to comprehensively measure and evaluate PD stigma. Concerning validity and reliability, the PDStigmaQuest showed comparable psychometric properties to the stigma tools previously validated for PD (Burgener & Berger, 2008; Fife & Wright, 2000; Peto et al., 1995; Rao et al., 2009; Wahl, 1999). All tools including the PDStigmaQuest displayed convergent and construct validity as well as at least acceptable internal consistency when being applied in a PD cohort, demonstrating that all tools are suitable for the use in PD. However, to the best of my knowledge, the test-retest reliability of

the SIS and SES was not tested in a PD cohort so that it is unclear whether measurements of these scales are stable over time (Hendrickson et al., 1993). In conclusion, the PDStigmaQuest should be preferred over other stigma tools when the aim of use is to measure and evaluate PD stigma specifically and comprehensively.

3.3 Intercultural adaptation of the English PUKSoPC in German language

The intercultural, linguistic adaptation of the English PUKSoPC in German language was based on internationally recognized standards (Beaton et al., 2000; Guillemin et al., 1993), which have previously been used by other neuroscientists for the translation of relevant measurement tools applied in neurological diseases (Buhmann et al., 2016; Jost et al., 2018; Storch et al., 2010). Due to the application of these standards, it is likely that the psychometric properties of the translation are comparable to those of the original version. For the original scale, high construct validity, good concurrent, convergent, and divergent validity could be shown, as well as strong internal consistency and test-retest reliability (Simpson et al., 2018). Therefore, the use of our translation should also enable a valid and reliable measurement of perceived control.

The availability of a German version of the PUKSoPC bears great potential. Since the original scale was developed in 2018 and was only included in a few studies, the German version can be used to further validate the scale in another population (Eccles et al., 2022; Zarotti et al., 2024). Importantly, our translation of the PUKSoPC in German language contributes to the investigation of PD-specific perceived control in different cultures and ethnicities. This is especially relevant for this construct, since intercultural differences in perceived control have already been observed in the general population: In a meta-analysis, Cheng et al. (2013) revealed that the association between external locus of control (i.e., attribution of outcomes to external factors like coincidences; Rotter, 1966) and symptoms of anxiety was less pronounced in collectivist societies in comparison with individualist societies. This finding has been explained by reduced importance of agentic goals in collectivist cultures (Cheng et al., 2013). Moreover, cross-cultural differences in related constructs of perceived

control have been previously identified in PD patients. For example, as already mentioned, there seem to be cross-cultural differences in PD stigma (Karacan et al., 2023).

3.4 Possible future applications of the PDStigmaQuest

Besides the German version of the PUKSoPC, the validated PDStigmaQuest presents numerous opportunities for future applications. First, it is necessary to analyze the association of PD-specific stigma with QoL and other demographic and clinical parameters such as motor and NMS. Although the association with some contributing factors like depression and QoL has already been established (Hou et al., 2021; Ma et al., 2016; Salazar et al., 2019), it would be helpful to investigate whether these effects can be confirmed for PD-specific stigma. Especially for factors, for which inconsistent results have been found with regard to their association with stigma in PD (e.g., gender and motor function; Hou et al., 2021; Salazar et al., 2019; Simpson et al., 2014), the application of the PDStigmaQuest could provide evidence to establish a clearer picture. In addition, the association with various NMS should be further explored due to the limited number of studies addressing this important stigma aspect. When studying stigma related to symptoms, it would also be essential to distinguish between different kinds of motor and NMS: Since PD is a highly heterogeneous disease (Greenland et al., 2019), it is possible that some specific symptoms are accompanied by stigma, whereas others are not. Moreover, the PDStigmaQuest should be utilized to identify predictors of PD-specific stigma: Studies on this topic remain scarce and previous results using the PDQ-39 stigma domain or the SSCI as outcome variables provided inconsistent result patterns (da Silva et al., 2020; Hou et al., 2021; Lin et al., 2022; Peto et al., 1995; Rao et al., 2009; Salazar et al., 2019). Importantly, considering previous findings, associations of PD-specific stigma with demographic and clinical parameters should be investigated by including perceived control as a potential mediator to improve the quality of interpretations (Verity et al., 2020). In German-language research, this can now be realized by applying the culturally-adapted German version of the PUKSoPC to measure perceived control specifically in PD.

Second, the PDStigmaQuest can be used to investigate the highly understudied effect of ethnicity and culture on PD stigma. In the past, this topic has only been addressed in a few studies (Di Luca et al., 2023; Karacan et al., 2023; Zhao et al., 2008). Results of these studies indicate that Asian PD patients experience higher levels of stigma compared to White patients, which requires future exploration. In other conditions (e.g., mental illnesses), it is well established that stigma varies across cultures and ethnicities (Eylem et al., 2020). The PDStigmaQuest can now be applied to examine this highly important topic in multi-ethnic populations to further expand our understanding of stigma in PD patients, with the overall aim to improve individual health care delivery. In this context, it would also be necessary to translate and cross-culturally adapt the PDStigmaQuest into different languages, enabling its use over different parts of the world. For this objective, the adaptation process applied to translate the PUKSoPC into German language could serve as a model, given that the application of these internationally recognized standards suggests that the translated versions of the PDStigmaQuest are likely to exhibit psychometric properties comparable to those of the original version (Beaton et al., 2000; Guillemin et al., 1993).

Third, the PDStigmaQuest could be valuable in assessing the natural course of PD stigma longitudinally, since longitudinal data on PD stigma remains highly scarce (Lin et al., 2022). Going a step further, insights into factors contributing to the development and change in PD stigma could be used in the future to establish specific interventions for improving PD stigma. To evaluate the effectiveness of interventions, it would be crucial to identify the minimal clinically important difference for the PDStigmaQuest, defining the smallest change considered important or meaningful by the patients (Copay et al., 2007).

Finally, since literature suggests a huge impact of stigma on patients' QoL (Ma et al., 2016), the PDStigmaQuest could be applied routinely in health care settings to monitor a patient's stigma level over the course of the disease. Future studies should establish stigma severity levels for the PDStigmaQuest, which could help health care professionals to determine at which time point a change in therapy or an intervention for improving stigma

should be considered. Thereby, the different stigma domains captured by the PDStigmaQuest could serve as a reference point for individualized management: For example, some studies suggested that hiding efforts are most prevalent in early phases of PD (Vann-Ward et al., 2017), while in later disease stages other stigma components could be more expressed. In this context, the PDStigmaQuest could also be applied to monitor the effects of invasive treatment options like DBS on PD stigma. To date, the effect of DBS on stigma was only explored by using the PDQ-39 stigma domain (Deuschl et al., 2006; Peto et al., 1995). This implies that only the change in felt stigma and some hiding efforts has been measured so far. In contrast, the PDStigmaQuest could compare the effects of DBS on felt stigma with the effects on enacted stigma due to the inclusion of both stigma aspects. To the best of my knowledge, the effect of other invasive treatment options in PD on stigma was not investigated so far, which could be done in future by using the PDStigmaQuest.

To notice, the presented potential applications of the PDStigmaQuest serve merely as examples: The questionnaire can be used to address further unmet needs with regard to the understudied construct of PD stigma, bearing great potential due to being a PD-specific tool.

3.5 Benefits of disease-specific tools and patient-reported outcome measures

In particular, disease-specific tools offer various benefits. One of the major benefits is that the utilization of a disease-specific tool enables to identify small, clinically important changes, which is highly relevant in the context of testing treatments and interventions designed to improve PD stigma (Patrick & Deyo, 1989). Furthermore, the evaluation of improvement by the clinician could be more closely associated with changes detected by disease-specific tools than generic tools as this evaluation is also highly specific (Patrick & Deyo, 1989).

In addition to adjusted item content, disease-specific tools offer the advantage that item wording as well as the instructions are adjusted to the specific patient group (Kirkley & Griffin, 2003; Patrick & Deyo, 1989). Adjusted wording and instructions are especially important in the case of PD because the disease is associated with cognitive impairment (Chaudhuri, Healy,

& Schapira, 2006). Additionally, since only about 5% of all PD patients show symptoms before the age of 60 years (Reeve et al., 2014), it is essential that the wording and instructions of an applied tool are also understandable to elderly adults, which can be ensured by constructing a disease-specific tool like the PDStigmaQuest or the PUKSoPC. Another benefit of specific tools especially relevant for PROMs is that the design of a disease-specific tool can be tailored to the target patient group. In the construction of the PDStigmaQuest, it could be ensured that its design is not too complicated, enabling patients to quickly understand how to complete the questionnaire.

Both the PDStigmaQuest and PUKSoPC represent PROMs, which also offer many benefits. In the last decades, the use of PROMs in the clinical context has become increasingly important, since there was a shift to put emphasis on the patients' perspective in both health care and research (Crawford et al., 2002; Goldbeck-Wood & Belfield, 2017; Meadows, 2011). In this context, it was noted that aims of healthcare like reducing disability or improving QoL can only be evaluated by the patients themselves (Black, 2013). Especially the perception of stigma and control are highly subjective so that a measurement from the patients' perspective seems most appropriate. Moreover, with regard to testing the effects of treatments, some effects are only known by the patient and the measurement from the patients' perspective avoids that valuable information gets lost when the clinician evaluates patients' responses to interview questions (U.S. Department of Health and Human Services FDA Center for Drug Evaluation and Research et al., 2006). Finally, in contrast to clinician-reported outcome measures, PROMs are not affected by inter-observer or -rater variability, highlighting that their use is particularly advantageous in multicenter-studies with many clinicians involved (U.S. Department of Health and Human Services FDA Center for Drug Evaluation and Research et al., 2006).

3.6 Limitations

The studies included as part of this thesis also compromise some limitations. First, the development and pilot study of the PDStigmaQuest were conducted at only one center,

namely the University Hospital of Cologne. Therefore, one could argue that the stigma experiences captured by the PDStigmaQuest are highly subjective to the patients at this center. However, the development was not only based on patients' input but also on previous stigma literature and clinical experience from PD experts, from which many have worked at different centers before. In addition, we included stigma experiences previously reported in qualitative and quantitative studies from different parts of the world (e.g., da Silva et al., 2020; Hermanns, 2013; Lin et al., 2022). Furthermore, in the modification process based on the results of the study, it was considered that some items should not be dropped as they could apply to patients in other parts of the world.

One limitation of the pilot study was the high proportion of patients with DBS (33.3%) included in the study, potentially influencing the results' transferability to the general population of PD patients. However, results indicated no significant differences in stigma experiences between patients with and without DBS, since the PDStigmaQuest total score as well as the domain scores did not differ significantly between these two groups. Further, relevant disease and treatment-related characteristics of levodopa equivalent daily dose, disease duration, and age at onset did not differ between these groups. Particularly, the PDStigmaQuest is intended to be applied to all PD patients independent of the patients' treatment (including DBS).

Additionally, the transferability of results of the validation study to the most severe disease stages is limited since only 4.5% of patients with Hoehn and Yahr stages 4 and 5 were included. These stages are characterized by severe disability of PD patients, restricting the ability to participate in studies not explicitly designed for advanced PD. Another related limitation considering the transferability of results was that, in both the pilot and validation study, PD patients with severe cognitive impairment were excluded, thereby constraining the applicability of the findings to this particular patient group. However, exclusion of these patients was considered necessary to ensure that the content and instructions of the PDStigmaQuest were properly understood.

Notably, only a low proportion of (self-)employed patients was included in the pilot (18.5%) and validation study of the PDStigmaQuest (33.0%), limiting the data available for testing the work items. Considering this limitation, the results concerning work items in the pilot study were interpreted with caution. Importantly, the proportion of (self-)employed patients in the validation study seems to be representative for the PD population, since 41.3% of male PD patients and 31.9% of female PD patients in a population-based cohort were (self-)employed (Gustafsson et al., 2015). Nevertheless, the number of (self-)employed patients was not sufficient to include these two work items in the dimensionality analysis, since for a EFA, at least 200 cases are required (Comrey, 1988). However, stigma experiences related to work can only be reported by a subgroup of PD patients. Therefore, offering an optional domain for these items rather than including them in other domains affecting the general PD population appeared to be the most appropriate approach.

Another limitation is that many items could not be answered by healthy controls due to PD-related formulations such as “because of my Parkinson’s symptoms”. Only 10 of 28 items of the preliminary PDStigmaQuest in the pilot study and 7 of 18 items of the final PDStigmaQuest in the validation study could be answered by healthy controls. However, for items referring directly to the disease, the difference between patients and controls had not to be tested since they could only apply to people having PD (e.g., “I try to hide my Parkinson’s symptoms from others.”).

Importantly, until now, the psychometric properties of the PDStigmaQuest were only tested on a German sample. Since recent literature suggests that stigma differs across ethnicities and cultures (Fothergill-Misbah, 2023; Karacan et al., 2023), it is highly necessary to conduct intercultural adaptations of the PDStigmaQuest in other languages to enable cross-validation of our findings in PD cohorts from other countries.

Finally, although the use of internationally recognized standards for adapting the PUKSoPC permits the assumption that the translation offers comparable psychometric properties to the original version, this can only be confirmed by testing these properties in a

German validation study. This is particularly important regarding the PUKSoPC as one item asking about involvement with a national organization could more apply to patients in the UK than to patients in Germany. The considerably higher number of publications on patient and public involvement in research as well as health services originated in the UK compared to other European countries is a potential indicator for a greater emphasis on patient involvement in the UK compared to other countries like Germany (Biddle et al., 2021).

3.7 Conclusions and outlook

The primary aim of the present thesis was to develop, test, and validate a holistic self-reported questionnaire for the measurement of PD-specific stigma. A preliminary version of the stigma questionnaire named PDStigmaQuest was developed and tested in a prospective, cross-sectional pilot study, providing first evidence that the PDStigmaQuest is a comprehensive and feasible questionnaire. Pilot study results including item characteristics and feedback were used to modify the preliminary version of the questionnaire. Subsequently, the psychometric properties of this version were tested in a prospective, cross-sectional validation study. Results suggested that the final self-reported PDStigmaQuest consisting of 18 items in five domains is a valid and reliable tool for measuring PD-specific stigma holistically. Since PD patients' perceived control over their condition could act as a mediator for the relationship of PD stigma and other factors, an associated objective was to conduct an intercultural, linguistic adaptation of the PUKSoPC in German language to prepare for future studies investigating effects of PD-specific stigma. This has been achieved by applying internationally established guidelines for the adaptation, resulting in a German version of the PUKSoPC which did not encounter any linguistic or content-related problems during testing.

Consequently, both the German PDStigmaQuest and PUKSoPC are now available for measuring PD-specific stigma and perceived control, respectively, from the patients' perspective in German-language PD cohorts. This contributes to the efforts to put more emphasis on the patients' perspective when evaluating their condition. Furthermore, the development and validation of the PDStigmaQuest fills a gap in PD research by enabling to

measure PD stigma specifically and comprehensively, focusing on the specific concerns and experiences of PD patients. Findings on PD stigma gathered through the application of the PDStigmaQuest, especially findings on contributing factors (see chapter 3.4 for possible future applications), could be used for improving the management of PD stigma in the future.

Future studies should focus on the development of a short form of the PDStigmaQuest, highly relevant for contexts, in which significant time constraints make it difficult to use the comprehensive version of the PDStigmaQuest. In addition, a short form would be easier to complete for PD patients in advanced disease stages, characterized by severe disability and cognitive impairment. Besides, PD stigma research would particularly benefit from the development and validation of a questionnaire focusing on the stigma experienced by PD patients' caregivers, since stigma is not limited to the patient and remains highly understudied in patients' caregivers.

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5. Erklärung zum Eigenanteil an der Dissertation

Alle Publikationen erfolgten in Kollaboration mit Ko-Autoren. Das Studienkonzept und –design der beiden Studien “Parkinson’s Disease Stigma Questionnaire (PDStigmaQuest): Development and Pilot Study of a Questionnaire for Stigma in Patients with Idiopathic Parkinson’s Disease” und “Validation Study of the Parkinson’s Disease Stigma Questionnaire (PDStigmaQuest)”, veröffentlicht im „Journal of Parkinson’s Disease“, wurden durch mich in Zusammenarbeit mit Dr. Dr. Anna Sauerbier, Prof. Dr. Michael T. Barbe und PD Dr. Haidar S. Dafsari erstellt, mit Dr. Stefanie T. Jost und Prof Dr. Josef Kessler in beratender Funktion. Die Datenerhebung der genannten Studien erfolgte durch mich, mit Unterstützung von Dr. Dr. Anna Sauerbier und Prof. Dr. Michael T. Barbe. Die Datenerhebung der Studie “Validation Study of the Parkinson’s Disease Stigma Questionnaire (PDStigmaQuest)” wurde zusätzlich unterstützt durch Julius Haupt, PD Dr. Doreen Gruber, Prof. Dr. Georg Ebersbach und zwei studentische Hilfskräfte. Die Datenanalyse erfolgte durch mich, mit Dr. Dr. Anna Sauerbier und Dr. Stefanie T. Jost in beratender Funktion. Das Verfassen der beiden Manuskripte erfolgte durch mich, mit Dr. Dr. Anna Sauerbier und Prof. Dr. Michael T. Barbe in beratender Funktion. Das Erstellen der Tabellen und Abbildungen der Manuskripte erfolgte eigenständig durch mich.

Bei der Publikation “Intercultural adaptation of the PUKSoPC in German language” wurden Konzeption und Design durch mich in Zusammenarbeit mit Dr. Dr. Anna Sauerbier erarbeitet. Die Originalversion des Fragebogens PUKSoPC wurde von Prof. Dr. Jane Simpson, Dr. Gerasimos Chatzidamianos, Dr. Ian Fletcher, Luis Perpetuo und Dr. Fiona J. R. Eccles erstellt. Der Übersetzungs- und Adaptationsprozess erfolgte durch Dr. Dr. Anna Sauerbier, Alexandra Rizos, Prof. Dr. Michael T. Barbe und Dr. Till A. Dembek. Die Organisation und Koordination dieses Prozesses, das Testen der deutschen Übersetzung an Parkinson-Patient:innen sowie das Verfassen des Manuskripts erfolgten durch mich, mit Dr. Dr. Anna Sauerbier in beratender Funktion.

Appendix

Final version of the German Parkinson's Disease Stigma Questionnaire

Parkinson's Disease Stigma Questionnaire (PDStigmaQuest)

Wer füllt diesen Fragebogen aus? ☐ Sie als Patient/-in alleine ☐ mit Hilfe von: _____

Bitte lesen Sie sich die Aussagen sorgfältig durch und kreuzen Sie jeweils die Antwort an, die in den **letzten 4 Wochen, einschließlich heute,** am ehesten auf Sie zutraf (**eine** Antwort pro Aussage). Bitte lassen Sie keine Aussage aus und antworten Sie wahrheitsgetreu und spontan.

	Symptom nicht zutreffend	Nie	Selten	Manch-mal	Oft	Immer
1. Mir ist es in Anwesenheit Anderer unangenehm, …						
a. … wie mein Gesichtsausdruck aussieht.		☐	☐	☐	☐	☐
b. … wie meine Stimme oder Sprache klingt.		☐	☐	☐	☐	☐
c. … wenn ich langsam bin.		☐	☐	☐	☐	☐
d. … wie meine Haltung aussieht.		☐	☐	☐	☐	☐
e. … wie ich gehe.		☐	☐	☐	☐	☐
f. … wenn ich zittere.	☐	☐	☐	☐	☐	☐
g. … wenn ich überbeweglich bin (starke, ruckartige Bewegungen).	☐	☐	☐	☐	☐	☐
h. … wenn ich plötzlich stehen bleibe und nicht weitergehen kann.	☐	☐	☐	☐	☐	☐
i. … wenn ich Probleme habe, mich an etwas zu erinnern oder mich zu konzentrieren.	☐	☐	☐	☐	☐	☐
j. … wenn ich müde oder erschöpft bin.	☐	☐	☐	☐	☐	☐
k. … wenn ich stark schwitze.	☐	☐	☐	☐	☐	☐
l. … wenn ich tagsüber Speichelfluss habe.	☐	☐	☐	☐	☐	☐
m. … wenn ich meine Blase nicht kontrollieren kann.	☐	☐	☐	☐	☐	☐
n. … wenn ich nervös, besorgt oder ängstlich bin.	☐	☐	☐	☐	☐	☐
o. … wenn ich traurig oder deprimiert bin.	☐	☐	☐	☐	☐	☐
p. … wenn auffällt, dass ich etwas übermäßig oder wiederholt getan habe (z. B. Glücksspielsucht, Hypersexualität, Kaufsucht, Esssucht).	☐	☐	☐	☐	☐	☐

Beurteilen Sie bitte die **letzten 4 Wochen, einschließlich heute.**

	Nie	Selten	Manch-mal	Oft	Immer
2. Ich bin unglücklich darüber, wie meine Parkinson-Symptome mein Auftreten beeinflussen.	☐	☐	☐	☐	☐
3. Ich sehe mich als Last für Andere.	☐	☐	☐	☐	☐
4. Ich habe das Gefühl, nutzlos zu sein.	☐	☐	☐	☐	☐
5. Ich mache mir Sorgen darüber, wie Andere auf meine Parkinson-Erkrankung reagieren könnten.	☐	☐	☐	☐	☐
6. Ich mache mir Sorgen darüber, wie Andere mich wahrnehmen werden, wenn meine Parkinson-Erkrankung voranschreitet.	☐	☐	☐	☐	☐
7. Ich habe Angst, dass Andere mich für geistig eingeschränkt halten könnten.	☐	☐	☐	☐	☐
8. Wegen meiner Parkinson-Symptome wurde ich von Anderen beobachtet.	☐	☐	☐	☐	☐
9. Mir ist es unangenehm, wenn Andere mich auf die Behandlung meiner Parkinson-Erkrankung ansprechen (z. B. Tabletten, Pflaster, Pumpe oder Tiefe Hirnstimulation).	☐	☐	☐	☐	☐
10. Ich versuche, meine Parkinson-Symptome vor Anderen zu verstecken.	☐	☐	☐	☐	☐
11. Ich habe meine Parkinson-Erkrankung vor jemandem verheimlicht.	☐	☐	☐	☐	☐
12. Freunde oder Familienmitglieder haben sich wegen meiner Parkinson-Erkrankung von mir abgewendet.	☐	☐	☐	☐	☐
13. Ich wurde von Anderen seltener eingeladen als vor meiner Parkinson-Erkrankung.	☐	☐	☐	☐	☐
14. Andere verhielten sich, als wäre ihnen meine Anwesenheit unangenehm.	☐	☐	☐	☐	☐
15. Ich habe die Erfahrung gemacht, dass Andere Entscheidungen für mich übernehmen, bevor ich diese selbst treffen kann.	☐	☐	☐	☐	☐
16. Ich habe die Erfahrung gemacht, dass Andere mich nicht (aus-)reden lassen.	☐	☐	☐	☐	☐

Waren Sie in den **letzten 4 Wochen, einschließlich heute,** berufstätig? **Ja** ☐ **Nein** ☐

Falls ja, beantworten Sie bitte auch die folgenden Fragen:

	Nie	Selten	Manch-mal	Oft	Immer
17. Ich habe Angst, auf der Arbeit als weniger leistungsfähig als vor meiner Parkinson-Erkrankung eingeschätzt zu werden.	☐	☐	☐	☐	☐
18. Ich wurde wegen meiner Parkinson-Erkrankung auf der Arbeit ungerecht behandelt.	☐	☐	☐	☐	☐