

## Altered communication in Parkinson's disease, its role in stigmatisation of the condition and effect on social relationships

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### ABSTRACT

Communication difficulties in Parkinson's disease (PD) arise not only as the result of the motor symptoms of the disorder, but also as a consequence of cognitive and affective impairments which are recognised as being part of the disease process. These changes are thought to account for much of the stigma associated with the condition, thereby complicating the ability of patients to inter-relate with others, including their closest family. This inevitably affects quality of life for both the patient and those family members involved in his/her care.

The present paper presents an analysis of how the deficits in motor and cognitive function associated with PD in the form of reduced facial expressivity, altered language skills, motor and cognitive slowness and disturbances in the pragmatic aspects of language affect the communication abilities of patients with the disorder and give rise to stigmatisation, which in turn impacts the disability seen in PD.

**Keywords:** Parkinson's disease, stigmatisation, communication, pragmatic language skills

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## **INTRODUCTION**

People with chronic illnesses such as Parkinson's disease (PD) frequently report that they suffer embarrassment and shame as a result of the public perception of their symptoms, which in turn lead to feelings of alienation and rejection by society at large. Stigmatisation of this kind affects not only the person suffering from PD, but those family members involved in caring for the person, as it frequently leads to their withdrawal and isolation into a world of uncertainty and deprivation from normal social contacts, taking their carer with them.

In this paper we aim to identify some of the symptoms in the clinical presentation of PD which lead to the stigmatisation of the condition and potentiate existing difficulties in communication for the patient and his/her carer. This work forms part of the background to a larger research project recently initiated at the Medical University of Białystok in Poland, in which we are investigating aspects of communication difficulties in PD, in particular those affecting the pragmatic aspects of language, with a view to finding ways of improving understanding between patients and their carers in order to facilitate PD sufferers' experience of their condition and ease the burden of caregiving.

Parkinson's disease is the second most common neurodegenerative disorder after Alzheimer's disease [1] affecting 1-2% of people in their sixth decade of life [2]. Until recently, Parkinson's disease was recognized primarily as a movement disorder, defined by the presence of bradykinesia plus at least one of the following motor symptoms: resting tremor, muscular rigidity or postural instability [3]. It is now considered to be a multisystem condition [4] with greater attention increasingly being given to the prominence of the non-motor symptoms of the disorder, which include neuropsychiatric disturbances such as depression and cognitive impairment, sleep disorders, autonomic dysfunctions and sensory disturbances [5]. Despite these difficulties, which are progressive and in the advanced stages of the condition lead to considerable levels of disability, the majority of people suffering from PD continue to live in their own homes in the community, usually with the support of a spouse or close relative. The psychological symptoms, may be just as challenging, if not more so, than the motor presentations of PD for both the patient [6] and his/her carer [7] and are a major contributor to their perceptions of the patient's quality of life [8]. Recent clinical studies have suggested that the non-motor symptoms may also be a clearer marker of the onset of Parkinson's disease than the classic motor symptoms [9]. Despite earlier beliefs to the contrary, PD is associated with a reduction in life expectancy, although this may be mainly in those

with an early disease onset [10] and in patients with cognitive impairment [11].

### **Stigmatisation of chronic illness**

The notion of stigmatisation of chronic illness is a concept emerging from the sociological literature, specifically labelling theory [12] and its later refinements [13,14] which held that the meaning attributed to the manifestations of chronic illness depended upon the way in which they were perceived in society. Perhaps the best known example of illness labels being responsible for the stigmatising or negative stereotyping of chronic conditions is seen in the discussion of mental illness [15], but social models have contributed greatly to the understanding of the experiences of people living with dementia [16] and in old age [17], both of which are severely stigmatised. Nonetheless, few studies have attempted to examine the experience of living with PD from this perspective, an exception being articles referring to the actor M.J. Fox who has used his own experience of the illness to try to overcome the stigma associated with the illness [18,19]. In these the focus has been mainly on physical health. Given the significant stigmatisation of dementia and old age it is only to be expected that the mental health issues experienced by people with PD are also a source of such labelling. The extent to which any condition becomes stigmatised depends on various factors, including whether or not the individual is held responsible for the condition, outward manifestations of the illness, its' impact on others and the extent to which it brings about changes in the person's functional competence. Whilst biomedical and psychological approaches have made a significant contribution in seeking to establish the reasons for more or less successful outcomes in PD (e.g. functional ability, quality of life) on the basis of neurobiological and neuropsychological factors associated specifically with the condition, including a social perspective further enhances our understanding of the difficulties of living with PD [20]. This represents a shift away from a purely individual perspective, where the physical impairment associated with PD was seen to rest with the sufferer and the limitations imposed by the illness in creating the disability, to a societal cause, in which mechanisms of social exclusion and oppression, based on the normative values of non-suffering members of society, were identified as being crucial to the nature of the disability [14]. By arguing that society plays an active role in limiting the potential for well-being by disabling the person with PD through the process of stigmatisation, social models provide an additional component for building a better understanding of the distress experienced by people with PD and their families and acknowledging the broader social context in which they must live with the condition.

More recent adaptations of the social model of disability described in [20] have identified two dimensions of social oppression which are disabling to people with impairments. The first of these is structural and relates to the exclusion of people with illnesses limiting movement from certain environments as a result of restricted access to facilities and services. Clearly the functional impairments resulting from the motor symptoms of PD are related to this dimension, but with appropriate modifications to the environment, can be relatively easily overcome. The second source of disablement lies in interpersonal contacts which negatively affect patients' psychological well-being. These include reactions such as staring, impatience, assumptions that the person with PD is simulating or exaggerating their symptoms, hurtful comments, together with a whole host of other responses which signal discomfort at being in the patient's presence. In addition to experiencing these negative stereotypes from others, people with PD may internalise them, further potentiating distressing emotions and generating harmful thoughts about themselves. This then becomes part of the illness experience, causing deleterious changes in self-image and withdrawal from social participation. Structural restrictions, whilst having a lesser direct impact on disability, may cause anger at not being allowed the same opportunities as non-impaired people and suffering discrimination in the workplace, for example, by being pressured to take early retirement. Thus the process of stigmatisation contributes in no small part to the isolation of people with chronic illnesses such as PD.

Although Parkinson's disease may not immediately come to mind as a stigmatised condition, many of its manifestations, meet the criteria for stigmatisation mentioned above. A few studies using an instrument especially designed to measure quality of life in PD, the PDQ-39 [21], which contains a subscale for the measurement of stigma, have reported varying levels of stigma in the self-perception of PD patients, associated with: young-onset (below age 50) [22], akinesias and communication difficulties [23], communication difficulties together with living in rural areas [24] quality of life [25], and severity of the condition, psychological factors and health related quality of life [26]. Motor fluctuations and akinesias appear to cause sufferers greatest embarrassment and humiliation [27]. One study [28] found that levels of perceived stigma did not vary significantly between participants with PD and those with Alzheimer's disease (AD), the latter being among the most highly stigmatised conditions [16]. The PD sample reported slightly less financial insecurity, social rejection and internalised shame, but scored higher than the AD sample for social isolation.

PD may also be stigmatised because a number of the symptoms are associated with other, more negatively regarded conditions. A study carried out by Parkinson's UK in 2013 [29] found that almost half of the people with PD surveyed, reported experiencing discrimination because of having PD. As many as 20% had had their symptoms misinterpreted as drunkenness and 10% had been exposed to verbal abuse in public because of their symptoms. Over 37% reported feeling isolated when in public and 60% admitted that they felt uncomfortable or nervous. Incidents leading to this kind of alienation occurred frequently, 43% of those interviewed reporting that such discrimination or misinterpretation took place at least once a month. Moreover, familiarity with the person did not necessarily defray episodes of this kind. 10% of respondents had encountered unfair treatment at work because of their condition and 30% felt that friends treated them differently, failing to show understanding for their condition.

#### **Stigma associated with communication difficulties: facial masking**

A number of different problems associated with PD can give rise to communication difficulties. These include hypomimia, otherwise known as facial masking, which develops as the progressive loss of motor control (which is the hallmark of PD) extends to the facial muscles, affecting the finer movement of the brow, eyes, cheeks, mouth and tongue. The face adopts a frozen, staring expression which creates the impression of an unresponsive, cold, inept or disinterested person, incapable of normal interactions. Masking can affect both voluntary facial movements such as smiling and involuntary ones such as occur when a person expresses surprise or is startled [30]. Stigmatisation occurs when those interacting with the patient form inaccurate impressions based on such misleading interpretations of what are, in fact, symptoms of the disease. This occurs in lay observers [31] and healthcare practitioners alike [32] and it has been demonstrated that even carers often fail in their perceptions of how people with PD are feeling [33]. An example of such misattribution occurred in 2012 during the cycling road race which was part of the London Olympics, when police arrested a man suffering from PD, because they "thought he looked suspicious". The reason given was that he was not smiling [34]. In similar vein, a former baseball player and T.V. sports analyst, heard from his producer while doing a live interview: "Gibby smile. You look like you've seen a ghost" [35]. Such stereotyping means that normally competent people affected by facial masking are required to project an image of themselves which counteracts the often unconsidered and lightly formed impressions of others. This is likely to be at

considerable effort to themselves in view of the fact that they are suffering from a debilitating, degenerative illness. It is no wonder that many people in the public eye decide to make a forthright statement about their condition, as in the case of the T.V sports analyst referred to above, who summarised his position as follows: "I had a choice to make," he said. "Do I get reclusive or do I bring it up front? And I chose to be vocal about it" [35]. However, even this does not always bring the expected results. An appearance on American T.V. in which the actor Michael J. Fox, enacted his decision to make a public statement about his experience of PD, drew unprecedented criticism from a talk radio host, Rush Limbaugh, in which he accused Fox of exaggerating the symptoms of his illness. "He's either off his medication or acting. He is an actor after all," Limbaugh is quoted as saying. Although he apologised for this, he later resumed his attack by telling listeners that in his book "Lucky Man" Fox admitted to not taking his medication before appearing in front of a Senate subcommittee to highlight the effects of the disease [36]. The reasons why Fox may have chosen to do this were not considered, the action being simply dismissed as being invalid. Such incidents demonstrate how people with PD continue to be subjected to negative actions and stigmatising attitudes as a result of the ways in which their acts of communication are perceived. One of the patients in our study described this inability to communicate his intentions as "feeling like a corpse locked inside an unresponsive body" [37].

Facial masking has also been reported to influence personality judgements of people with PD by healthcare professionals. An early study by Pentland and colleagues showed that rehabilitation therapists were more likely to form a negative view patients with PD than others, rating them as being more anxious, hostile, suspicious, sad, bored, tense, introverted, passive and less stable and likeable than a control group with heart disease [38]. In particular, judgements concerning personality, such as extraversion and neuroticism, were inaccurate in relation to PD, although more experienced professionals were better able to make appropriate interpretations with regard to the latter [32,39,40]. This shows that the loss of facial expressivity can cause additional problems for people with PD and may manifest in the form of incongruent or even negative social interactions with other people. However, the fact that increased awareness of PD, built through experience, may mitigate some of these problems and provides a useful indication for further research, suggesting that raising awareness of the lesser known features of PD, such as facial masking, may help to reduce inappropriate and stigmatising perceptions of those suffering from the condition. In so doing it might also help to reduce

some of the negative emotional consequences for the patient [20].

### **Stigma associated with communication difficulties: speech difficulties**

Speech difficulties in PD such as slurring, stuttering, mumbling, speaking more quietly, breathily or hoarsely are common. Words may be expressed more rapidly and the tone become monotonous, reflecting changes in prosody. Specifically, the ability to modulate speech in order to emphasize certain words as a means of expressing emotions is affected [41]. In one study, patients appeared to have difficulty in conveying various emotional states, especially anger, their speech being rated as sounding neutral [42]. The patient may have difficulties with word finding, dysfluencies are common and impede the regular flow of language making it sound halting and hesitant. The increased number of pauses means that utterances become abnormally long in comparison to those of healthy speakers [43]. Limitations in prosody and the motor control of speech acts translate, in a very real sense, into how others perceive the intentions that the person with PD may wish to convey. In addition, patients with PD are also impaired in some of the pragmatic or social aspects of language, having problems with initiating conversations [44] and in their use of linguistic strategies to demonstrate politeness [45], often appearing rude, apathetic or dismissive as a result. These difficulties no doubt, determine reactions to the patient which reflect the misattribution of the distortions in the communication to the attitude or character of the patient, rather than to the symptoms of the disease. In turn, there may be a negative backwash effect in the way in which they impact on the mood and social participation of the patient. Blind analyses of speech samples from patients with PD and control subjects, in which the listeners were not aware which of the speakers were affected by PD, confirm that negative stereotyping may occur on the basis of vocalizations. Speech patterns alone led listeners to evaluate the PD patients as being less interested and involved, not relating well to the interviewer, enjoying the interview less and being less friendly. No differences were perceived with regard to the intelligence of the speakers [46,47].

Communication in PD is disrupted far more extensively than merely in terms of speech production. Receptive factors such as ways in which language is processed are also impaired, for example, in the understanding of differences in prosodic tone [48,49,50] and the meaning of metaphors, which may be the reason for many carers' observations that the person with PD appears to have lost his/her sense of humour [51].

How these changes affect the communicative ability of those suffering from PD

has so far, received relatively little attention in the literature. It is an important area of study, as the social or pragmatic aspects of communication are likely to have important implications for the relationship between the patient and those supporting him/her in everyday life. Changes in language processing abilities may be present even in the absence of dementia or when speech remains intelligible, but may contribute to stigmatisation of the person with PD because of the false image of the patient they project. An important aspect of the present research lies in attempting to identify the cognitive and affective basis of these more pragmatic communication difficulties and relating them to the understanding of patients' communicative problems in everyday life. A better understanding of this area of functioning of people with PD is seen as being a route to finding interventions to improve social relationships with family carers, healthcare workers and the wider community.

### **Internal stigmatisation**

The discussion so far concerning impaired communication has focused on stigmatisation as the result of visible symptoms of PD being attributed to features of behaviour or personality that are considered socially unacceptable. Alternatively, they may be misattributed as resembling conditions that are equally socially branded because of strong negative stereotyping, such as old age, dementia or mental illness.

But not all types of stigmatisation are external in the sense that they are enacted by other people. Awareness of the negative labels associated with PD in the perception that certain attributes of their illness make them unacceptably different from others often becomes internalized by people with Parkinson's disease. Their experience of the illness may lead to embarrassment, shame, repulsion and rejection which often form the steps in the cascade of events that comprise the illness experience. They in turn, lead to changes that are even more fundamental to the sick person's image of themselves and to altered perceptions of self. The process of internalising stigma concerns the meaning that is attributed to having an illness such as PD. Negative stereotypes towards illness and impairment generally build up before the onset of illness, from a non-impaired perspective. As the illness unfolds, people may continue to relate to their established views of PD. This is reflected in their apprehension concerning diagnosis and fears about being a burden and may fuel their drive to maintain independence [20].

It is no surprise that stigmatisation is a barrier to diagnosis and treatment as it frequently accompanies the condition from its earliest presentation. One of the patients in our study put it this way:

I'd guessed what he (the doctor) was going to say. I could have told him myself it was PD. But when he actually said it, I was numb. I couldn't take in any of the other things he told me. All I had in my head was the word "Parkinsons". Ringing in my ears ... "Parkinsons, Parkinsons". I went home and I didn't know who to tell. I didn't want anyone to know. And for a long time I tried to hide it. But there comes a time, you know, when it's difficult ... the effort is just too much and you finally give in ... you just have to accept it [37].

In a recent survey by Parkinson's UK [52] almost 40% of people with Parkinson's disease reported that they felt the need to hide their symptoms or lie about having the condition. The research suggests those who try to hide their condition believe the symptoms are not socially acceptable and that people may feel awkward or embarrassed around them.

A clinical picture in which motor symptoms are dominant makes establishing a diagnosis relatively straightforward; where non-motor symptoms predominate, the task is more difficult and uncertainty about the diagnosis is prolonged. These initial difficulties can be distressing, as patients feel that their concerns are not being adequately acknowledged, yet are fearful that something is seriously amiss. Such difficulties are not uncommon in Parkinson's disease which often has an insidious or subtle onset. The early symptoms, especially those of a psychological nature, which precede the onset of motor symptoms [3], may not be easily recognized by the patient or indeed most physicians, frequently requiring specialised knowledge. The resultant uncertainty about what may be wrong, accompanied by feelings of lack of control over their situation, may cause feelings of resentment and alienation:

My doctor just kept saying there was nothing wrong, but I knew there was. I couldn't convince him. He treated me like a neurotic, a batty old woman who kept wasting his time. In the end I went privately and well ... it was a shock... [37].

Initial reactions to hearing the diagnosis may include shock, disbelief, anger and a sense of betrayal. Since patients are frequently able to trace the onset of symptoms back several years before the diagnosis, they sometimes describe feelings of initial relief, which they see as confirming their long-held suspicions that "something was wrong". Patients sometimes describe this in terms of putting an end to the uncertainty of knowing that their health was deteriorating, but not being able to account for their problems. Others use various metaphors such as feeling that "a door had been slammed in my face and I had suddenly been left alone" or that the diagnosis felt "like the end of the world" to describe the life-altering experience that

learning the diagnosis and coming to terms with its physical and emotional impact had for them [37].

### **Meaning internalised: shame**

Nijhof [53] drew attention to the fact that having PD was frequently interpreted by sufferers themselves as a problem of shame. From this social relations perspective, feelings of shame are seen as resulting from the stigmatizing attitudes and actions of other people, which occur because PD, in its presentation, is seen as breaking social rules [20]. These “rules” are simply that adults do not dribble, they should not shuffle their feet when walking, and they should demonstrate conventional responses in social contacts, such as smiling – all of which are difficult for people with PD. The fact that as a result of their condition, their behaviour diverges from established norms is a cause of the shame they experience in public settings. Feelings of shame account for the fact that PD sufferers tend to withdraw from many aspects of social life preferring their home environment, which is seen as a safe refuge, highlighting the social relational nature of shame [20].

Patients’ accounts of their illness experience often feature words such as “shame” and “embarrassed”:

I didn’t really want you to come ... to see me the way I am. I feel ashamed about what this illness has done to me. It’s like ... I’m a different person ... I can’t really go out anymore ... I’m so embarrassed about eating with friends because I spill things and make a mess. I don’t really talk anymore when I’m with people, because the words won’t come ... as you can see [37].

Another patient expressed embarrassment about his condition:

I am embarrassed about my tremor. I often try to keep my hand out of sight ... in my pocket ... I feel embarrassed when I see peoples’ eyes moving towards it” [37].

Stigmatisation however, is not only the experience of patients, as it frequently has repercussions for carers and other family members. The children of younger patients in particular, may experience shame as they become aware that their family is different, because a parent is unable to participate in activities in the same way as that of their friends: “He doesn’t like me coming to school, because his friends say I look different” [37].

Even when other people are sympathetic, their actions may be rejected because the patient or his/her family do not want to feel they are the subject of pity: “People are kind and they want to help, but he (patient’s son) doesn’t want to feel different. He doesn’t want pity” [37]. Sometimes patients feel that their children are frightened by the symptoms of the disease and do not want to discuss

it, as they sometimes see their parents “almost paralysed” by the condition and do not know how to react.

Cultural factors are known to play a role in biasing judgements in relation to facial expressivity among practitioners, there being a lesser tendency to impute negative internal states as markers of sociability in Asian (Taiwanese) culture, while American practitioners were less likely to demonstrate a negative bias toward making judgements of cognitive competence on this basis [40]. In rural communities of Tanzania, PD is seen as a dishonourable condition and as a result, both patients and their entire families are stigmatised to the extent that they are not able to take part in the social and working life of their community [28,54].

### **The psychosocial impact of stigma**

The psychosocial impact of stigmatisation is crucial to understanding the process of disablement in PD. Few studies appear to have addressed this issue, but associations have been established between perceived stigma and depression in people with PD [20,55]. More generally, there is evidence that stigma is associated with various forms of psychological distress, including shame and embarrassment, social isolation, reduced self-esteem, anxiety and emotional stress in chronic illness [56,57].

The extent to which negative stereotypes are internalised may depend on how much the person knows about PD. A study of public attitudes towards PD [58] showed that those interviewed were more or less equally divided on the question of whether stigma was associated with the condition. These views were unrelated to respondent’s age, gender, education or income level, although those living in rural areas attached more stigma to the condition. Negative attitudes towards the illness were associated with the potential consequences, such as being a burden, the likelihood of mental deterioration and becoming dependent on others, while social issues such as the attitudes of other people, sexuality and loneliness were considered less important. Negative attitudes to PD were more common in younger age groups and among those who either did not know anyone with PD or knew little about the condition. They were also related to the belief that PD is more unpleasant than other illnesses and that it carries significant levels of stigmatisation.

Through being internalised, feelings of shame and embarrassment become part of the person’s self-identity. A few qualitative studies have explored the concept of self-identity in PD and participants have described the challenges of living with PD and how it affects their sense of self and their social roles. People with chronic illness may feel discredited, which can be influenced by

stigmatizing and disabling societal views of illness [20].

Labelling interactions also result in social rejection of the person with PD, as others respond with fear, uncertainty or embarrassment regarding his/her continued performance in the workplace and other spheres of social functioning. Fearful anticipation of these reactions means that patients often seek to hide the signs of their illness for as long possible, but this only serves to accentuate their feelings of insecurity, internalized shame and social isolation, which along with social rejection are conceptualised as the four dimensions or consequences of the labelling or stigmatizing process [28]. Apart from their loss of health, they thus also risk losing social support and earning capacity and must adapt to alterations in family relationships which only increases their vulnerability to the illness [59].

## CONCLUSION

Communication difficulties are a major contributory factor to the stigma of PD. Stigmatisation reflects the lack of understanding and discomfort that people without a knowledge of, or familiarity with PD demonstrate in their social contact with sufferers of the condition. Some of the patients in our study mentioned that they would prefer to spend time with other people with PD, as they felt they would have a better understanding of their difficulties and be more tolerant, relating to them on mutually acceptable terms. This is an endorsement of the value of self-help and specific illness orientated support groups for people with PD.

People with PD and their families frequently avoid social contact due to apprehension and fear of stigmatisation in the form of negative judgements from others. This leads to withdrawal and social isolation, causing further problems for both sufferer and carer. In generating embarrassment and shame for the sufferer, stigmatisation has a negative impact on how people with PD see themselves and alters their perception of the social roles they are able to fulfil. These altered perceptions of self limit opportunities for social engagement, adding to the disability created by the illness and causing distress and disharmony in the lives of both patients and their carers. There is a clear indication here of the need to develop appropriate educational interventions addressed not only to people with PD, but even more pertinently, to the general public in order to mitigate the adverse effects of these processes.

Finally, stigmatisation is recognized as being one of the foremost challenges to quality of life of people suffering from Parkinson's disease and their carers. The social marginalisation that is consequent upon stigma has been associated with depression in PD. Psychological difficulties in

themselves are frequently stigmatising and so the process of alienation is consolidated. This has important practical implications as it may deter people from seeking treatment for depression because of the additional stigma [20].

## Conflicts of interest

The authors declare that they have no conflicts of interest.

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