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### The Relationship between the Experience of Hypomimia and Social Wellbeing in People with Parkinson's Disease and their Care Partners

#### Sarah D. Gunnery<sup>a</sup>, Barbara Habermann<sup>b</sup>, Marie Saint-Hilaire<sup>c</sup>, Cathi A. Thomas<sup>c</sup>, and Linda Tickle-Degnen<sup>a</sup>

<sup>a</sup>Department of Occupational Therapy, Tufts University, Medford, MA, USA

<sup>b</sup>School of Nursing, University of Delaware, Newark, DE, USA

<sup>c</sup>Department of Neurology, Boston University Medical Center, Boston, MA, USA

#### Abstract

**Background**—Though hypomimia, also called *facial masking*, is experienced by many people with Parkinson's disease (PD), little is known about how the experience of this motor impairment relates to their own and their care partners' (CP) social life and relationship quality.

**Objective**—To test if the experience of facial masking relates to social wellbeing in people with PD and their CPs.

**Method**—Forty individuals with PD and their CPs rated PD's difficulty showing facial expression (facial masking), and completed questionnaires about their own social wellbeing and depression.

**Results**—PD-reported and CP-reported facial masking of PD were positively correlated with experience of social rejection in both partners, though this relationship was diminished when controlling for depression. CPs' rating of their partner's facial masking was negatively associated with enjoyment interacting with their partner. This relationship remained when controlling for CP and PD depression.

**Conclusions**—The findings suggest that the experience of facial masking is negatively associated with social wellbeing particularly for the CPs, and especially so for the quality of CPs interpersonal relationship with their partner with PD.

#### Keywords

Parkinson's disease; caregivers; facial expression; quality of life

**Conflict of Interest** The authors have no conflict of interest to report.

Corresponding Author: Sarah D. Gunnery, Department of Occupational Therapy, 574 Boston Avenue, Medford, MA, 02155, 617-627-1099, sarah.gunnery@tufts.edu.

#### Introduction

Hypomimia is a symptom of PD that limits the accurate expression of emotion in the face due to a decrease in the speed and coordination with which the facial musculature is activated [1]. Practitioners and same-aged peers view people with hypomimia as being more depressed and less sociable, less socially supportive, and less cognitively capable, even when the severity of the hypomimia is quite low [2, 3]. Little is known about how self-perceptions of difficulty showing facial expression, also known as *masked face* or *facial masking* in the lay PD community [4], correspond to social wellbeing in people with PD or their care partners (CPs). Though clinician and observer rated measures of facial masking are the current clinical standard, they provide little information about how people with PD experience their symptoms and how their experience of symptoms relates to quality of life and interpersonal relationships [5, 6].

There has been some investigation of convergence between PD and CP report of hypomimia [7] and qualitative research reporting that facial masking can have detrimental effects on marital relationships [8], but to our knowledge no previous study has investigated the relationship between CP perceptions of their partners' facial expressivity and how they report their own social wellbeing. Caregiving for a person with PD can lead to increased stress, depression, and decreased health in CPs [9–11], and these effects could be compounded if the person one is caring for is less able to communicate positive emotions like gratitude and happiness [12]. Understanding how CPs' social lives are associated with their perceptions of their partners' facial expression could give rise to potential ways to improve quality of life and relationships in care partners and people with PD.

The present study measured the relationship between PD and CP experience of PD facial masking and each of their own social wellbeing. Depression was also measured as it can lead to both decreased facial expressivity and decreased social wellbeing [9, 13]. We hypothesized that report of PD facial masking by both the person with PD and their CP is related to their own social wellbeing independent of depression.

#### Method

#### Design

This is a cross-sectional correlational analysis of preliminary data of a subsample from the six months post-baseline assessment of the developing *Emergence and Evolution of Social Self-Management of Parkinson's Disease* database, a three-year longitudinal study (SocM-PD) [14].

#### Participants

Thirteen women and 27 men with PD ( $M_{age} = 66$ , SD = 7.43) participated with their care partner (27 women and 13 men  $M_{age} = 65$ , SD = 7.06). These 40 dyads were the complete sample of dyads who had finished the sixth month assessment at the time of data analysis. Participants were recruited through the Boston University Medical Center's Movement Disorders Clinic and through community outreach throughout the greater Boston area. There were no restrictions on who could participate as a CP, but all CPs in the sample were

spouses. PD inclusion criteria were a diagnosis of idiopathic PD using the UK Brain Bank Criteria [15], Hoehn and Yahr stage between 1 and 4 [16], and an MMSE score greater than or equal to 26. CP inclusion criterion was an MMSE score greater than or equal to 26. Participants with PD had a median Hoehn and Yahr stage of 2 (range: 1 - 4) and a mean MMSE score of 29.18 (SD = 1.11). CPs had a mean MMSE score of 29.20 (SD = 1.02) at the time of screening.

#### **Procedure and Measures**

Participants with PD and their CPs separately completed questionnaires, as described below, as part of the larger SocM-PD protocol [14]. All procedures and measures were approved by the Tufts University and Boston University Medical Center Institutional Review Boards.

Experienced hypomimia was measured by asking the person with PD, "In general, how much difficulty do you have showing expression (emotion) in your face." Separately, care partners were asked, "In general, how much difficulty does your partner have showing expression (emotion) in their face." Both groups answered on a five point Likert scale from 1 (no difficulty) to 5 (very severe difficulty).

Social wellbeing was measured with three different scales: social isolation, experienced stigma, and enjoyment of interactions with one's partner (partner enjoyment). The Social Isolation domain of the Nottingham Health Profile [17] measured agreement (1 = strongly disagree to 5 = strongly agree) with 5 items assessing social isolation and loneliness. The Stigma Scale for Chronic Illness [18] included 24 items that measured experienced frequency (1 = never to 5 = always) of both enacted stigma, feeling unfavorable attitudes expressed by others, and felt stigma, feeling shame, fear, or self-discrimination as a result of internalizing negative stereotypes about oneself. Both of these scales showed convergent validity with other measures of self-reported health [18, 19]. Because the social isolation and stigma scales were correlated,  $r_{PD} = .57$ , p < .01;  $r_{CP} = .58$ , p < .01, Cronbach's alpha = .72 (PD) and .64 (CP), we created one Social Rejection composite score of these two measures for the person with PD and one for the CP. The composite score was an average of both the social isolation mean score and social stigma mean score and varied from 1 (low) to 5 (high).

We measured partner enjoyment with 3 items from the Medical Outcomes Study: Social Support Survey [20]. These items were (1) Your partner is someone to have a good time with, (2) Your partner is someone to get together with for relaxation, and (3) Your partner is someone to do something enjoyable with. Questions were answered on a Likert scale from 1 (None of the time) to 5 (All of the time). This scale was found to be related to other self-report measures of physical health and quality of life [20].

We measured depression using the 15-item version of the Geriatric Depression Scale (GDS) [21] which employs a dichotomous yes/no response format. As is standard practice, to take into account participants who may not have answered one of the 15 items (there was only one instance of missing data from the GDS in this sample) we created average scores for the GDS (dividing the total by the number of non-missing items). These average scores were then converted back to their original 15 point scale for ease of presentation.

#### **Data Analysis**

Data were managed using Research Electronic Data Capture (REDCap) hosted at Tufts University [22]. Pearson correlations were calculated to investigate the relationships among facial masking, social rejection, partner enjoyment, and depression. For the interpretation of the size of the magnitude of the correlations, we used Cohen's criteria for small (r = .10), medium (r = .30), and large effects (r = .50) [23]. Multiple linear regression tested the hypothesis that report of facial masking predicts social rejection and partner enjoyment independent of depression in people with PD and their CPs. Regression analyses were only conducted for social wellbeing variables that significantly correlated with report of facial expressivity for the person with PD or the CP. Predictor variables were mean centered to account for differences in their scales. Tolerance statistics and variance inflation factors were of suitable levels to indicate a lack of multicollinearity in all analyses.

#### Results

Overall participants reported low levels of difficulty showing expression in their face. Table 1 shows the cross tabulation of PD-reported facial masking and their partners' CP-report of facial masking. Totals for PD and CP report are also presented in Table 1. For ease of presentation we have aggregated ratings of no difficulty and mild for both partners, and moderate and severe for CPs. No PDs self-reported having severe difficulty showing expression in their face.

Replicating Mikos et al. [7], we found no mean difference between PD and CP reported facial masking, t(39) = 1.00, p = .32. There was a correlation of t(38) = .24, p = .14 between the PD and CP indicating a small, though non-significant, size of association according to Cohen's criteria.

Participants with PD who reported less facial expressivity also reported more social rejection at a medium to large and significant level (r = .41) but facial expressivity was unrelated to PDs' enjoyment of their CP (r = -.05). PDs' own depression was positively correlated with both facial expressivity (r = .56, large effect) and social rejection (r = .70, large effect). CPs who rated their partners as having less facial expressivity reported significantly more social rejection (r = .35, medium effect) and significantly less partner enjoyment (r = -.55, large effect). CPs' ratings of their partners' facial expression were not significantly correlated with their partners' depression (r = .27, medium effect), but were significantly correlated their own depression (r = .40, medium to large effect). PD and CP depression were positively correlated with CP social rejection ( $r_{pd} = .48$ , large effect;  $r_{cp} = .70$ , large effect) and negatively correlated with CP partner enjoyment ( $r_{pd} = -.35$ , medium effect;  $r_{cp} = -.55$ , large effect). See Table 2 for descriptive statistics for all measures, correlation coefficients, and corresponding p values.

Multiple linear regression showed facial masking was not a significant predictor of social rejection when controlling for their own self-reported depression for both the people with PD and the CPs (ps > .05). However, for CPs, ratings of their partners' facial masking predicted how much CPs enjoyed interacting with their partners even when PD and CP

depression were held constant (p = .01). It should be noted that CP depression is still a significant predictor in the model as well (p = .02). See Table 3 for all regression statistics.

#### Discussion

As predicted there was a positive correlation between experienced facial masking and social rejection in people with PD, but the relationship was stronger between depression and the experience of facial masking, and between depression and social rejection. When both facial masking and depression were added into the regression analysis, depression significantly predicted social rejection but the person with PD's facial masking did not. This finding suggests an overlap in how people with PD report the difficulty that they have showing expression in their face and their own depression, perhaps because people with PD may not experience their physical symptoms and their emotional symptoms as separate [6].

There was no relationship between experienced facial masking and how much people with PD enjoyed interacting with their partners. Theories of mimicry suggest that people often mimic the nonverbal expressions of those they are interacting with [24], and thus CPs might respond to their partners with facial masking with less emotional expression or more negative emotional expression. While this could then lead people with PD to enjoy interacting with their CPs less, data from the current study do not support this. It could also be possible that people with PD are not reading the negative expressions of their partners accurately [25], and this is in turn protecting their perceptions of their relationship.

These data do show a link between CPs experience of their partners' facial masking and how much they enjoy interacting with their partners with PD independent of depression. Although CPs may be familiar with their partners' changing expressive style, these descriptive and correlational data indicate that CPs are also potentially influenced by their partners' loss of facial expression. While CPs reported more partner enjoyment when their partners reported experiencing less depression, the link between CPs' perception of their partners facial expression and their enjoyment of their partner does not appear to be driven by the CPs' or their partners' depression.

These correlational findings, though not providing clear evidence for intervention, suggest that education about hypomimia and strategies for improving communication in the dyad may be beneficial for improving quality of life in people with PD and their CPs. These strategies could be as simple as having CPs focus their attention on their PD partners' verbal rather than nonverbal cues as people with PD do verbalize their positive affect [26].

With some research showing that voice treatment may lead to short term improvement in showing expression in the face [27], future research will investigate ways to reduce hypomimia as well as the relation of reduced hypomimia to PD's and CP's experience of hypomimia. Future research will also aim to replicate these findings in a larger sample size and at a second time point to further investigate the link between self-reported hypomimia, depression, and social wellbeing in people with PD.

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#### Table 1

Cross tabulation table of PD and CP experienced facial masking ratings

	CP Rep		
PD Reported	No Difficulty - Mild	Moderate -Severe	PD Total
No Difficulty - Mild	22	9	31
Moderate	4	5	9
CP Total	26	14	

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# Table 2

Descriptive statistics and correlations between facial masking, depression, and social wellbeing for people with PD and CPs

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	8	M	SD	1.	2.	3.	4	5.	6.	7.
1. PD Facial Masking		1.85	LT.							
2. PD Depression	.80	3.12	2.88	.56***						
3. PD Social Rejection	.72	1.86	.48	.41 **	.70 ***					
4. PD Partner Enjoyment	.94	4.27	88.	05	11	13				
5. CP Facial Masking		2.03	1.00	.24	.27+	.26	.25			
6. CP Depression	80.	1.83	2.97	.29+	.39*	.16	.25	.40 *		
7. CP Social Rejection	.64	1.46	.45	.15	.48 **	.24	14	.35 *	.70***	
8. CP Partner Enjoyment	.95	3.89	.83	11	35 *	 11	02	55 ***	55 ***	73 ***
Note:										
$^{+}_{p < .10}$										
* <i>p</i> < .05										
** <i>p</i> < .01										
p < .001.										
$\alpha$ is Chronbach's alpha. The	re is no	oα for t	the facial	l expressivi	ity self-re,	port me:	asures be	cause ther	e was only o	ne item in th

#### Table 3

Summary of regression analysis predicting social rejection and partner enjoyment in people with PD and CPs

Dependent Variable		Beta	Standard Error	95 % Confidence Interval
PD Social Rejection	$R^2 = .49$			
	PD Facial Masking	.03	.09	1620
	PD Depression	.68 **	.36	.99 – 2.43
CP Social Rejection	$R^2 = .54$			
	CP Facial Masking	.05	.06	0914
	PD Depression	.24	.29	02 - 1.17
	CP Depression	.58**	.30	.73 – 1.94
CP Partner Enjoyment	$R^2 = .45$			
	CP Facial Masking	38 **	.11	5409
	PD Depression	11	.58	-1.6670
	CP Depression	36*	.60	-2.7129

Note:

\* p < .05

\*\* p < .01