

Impact of Isolation During the COVID-19 Pandemic on Non-motor Symptoms of Parkinson's Disease: A PMD Alliance Survey

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INTRODUCTION

» Parkinson's Disease (PD) is estimated to affect approximately 188 per 100,000 people in the United States¹ and its prevalence is projected to continue rising, driven primarily by population aging².

» Non-motor symptoms are common in people with PD (PwP) and may include sleep disturbances, cognitive decline, anxiety, depression, apathy, and psychosis characterized by visual and/or auditory hallucinations, delusions, and illusions³⁻⁶. Burdensome non-motor symptoms such as anxiety and psychosis may affect up to 60% of PwP^{3,6}.

» Non-motor symptoms are associated with reduced quality of life (QoL) in PwP^{7,8} and contribute substantially to caregiver burden^{9,10}.

OBJECTIVE

» This cross-sectional survey aimed to assess the impact of social isolation on self- or proxy-reported PD symptoms during the COVID-19 pandemic. The data presented herein focus exclusively on mood and non-motor symptoms.

PARTICIPANTS AND METHODS

Survey Methodology

» The survey was distributed between January 6, 2021 and February 27, 2021 among 7,109 subscribers of the Parkinson and Movement Disorders Alliance (PMD Alliance) News and Information list using the online Survey Monkey[®] platform.

» Potential respondents were invited to participate via e-mail and no incentives were offered for survey participation. Each respondent could submit only a single questionnaire entry to avoid duplicate responses being included in the analysis.

» The survey was fully anonymous and, as no personal identifiers were collected, no ethical board approval was required as per US regulation 45 CFR §46.104d.

Respondent Population

» Only PwP and their Care Partners (CP) were eligible to respond to the survey. PwP (self-reports) completed the survey based on their own experiences. CPs (defined as a spouse, partner, or non-paid person caring and living with a PwP) served as proxy respondents, completing the survey on behalf of the PwP under their care.

» CPs responding to the survey were not necessarily the CPs of PwP respondents. Neither the survey itself nor the data analysis process attempted to identify PwP and CP pairs from the same household.

Data analysis

» The respondent-perceived impact of the COVID-19 pandemic on PD symptoms was analyzed as a continuous variable using a 3-point Likert scale with "no change" corresponding to 0 points, "slightly" to 1 point, "somewhat" to 2 points, and "significantly" to 3 points. Where self-reported "significant" impact of the pandemic on symptoms is described, the word "significant" is placed in parentheses to distinguish this from references to statistical significance.

» Subgroup analysis is presented by level of social support from outside of the household during the COVID-19 pandemic (decreased or maintained). The latter category comprised the same levels of support as pre-pandemic and increased levels of support, collapsed into a single category due to few respondents reporting increased support level.

» Wilcoxon rank-sum test was used for pairwise comparisons across respondent groups. No adjustment for multiple comparisons was performed.

RESULTS

Respondent Characteristics

» 718 of 7,109 invited participants responded to the survey (response rate of 10.1%). Most respondents were PwP (n=507, 70.6%). More than half of the respondents (61.4%) were aged >70 years and CPs were significantly older than PwP (p=0.006, Chi-square test). Respondent characteristics are presented in Table 1.

Table 1. Demographic and disease characteristics of survey respondents.

	Total sample (n=718)		PwP (self-reports, n=507)		CP (proxy reports, n=211)	
	N	%	N	%	N	%
Age group						
<60 years	74	10.3	57	11.2	17	8.1
60-69 years	203	28.3	159	31.4	44	20.9
70-79 years	356	49.6	232	45.8	124	58.8
≥80 years	85	11.8	59	11.6	26	12.3
Gender						
Female	462	64.3	287	56.7	175	83.3
Male	254	35.4	219	43.3	35	16.7
Missing	2	0.3	1	0.2	1	0.5
Duration of PD						
<5 years	220	30.9	180	35.8	40	19.1
5-10 years	273	38.3	197	39.2	76	36.2
≥10 years	220	30.9	126	25.1	94	44.8
Missing	5	0.7	4	0.8	1	0.5

Abbreviations: CP, Care Partners; PD, Parkinson's Disease; PwP, People with Parkinson's Disease

Social support during the COVID-19 pandemic

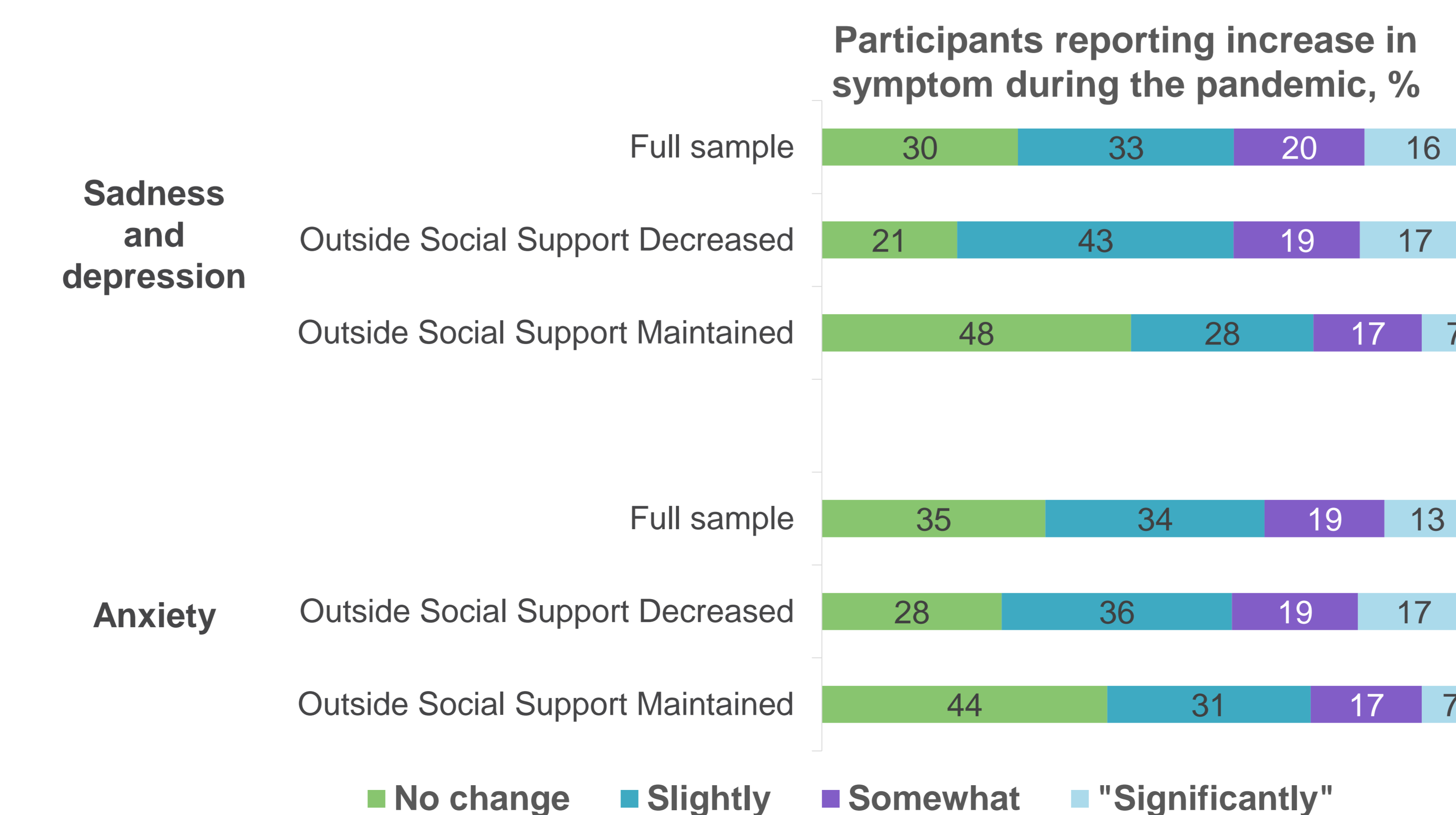
» Decreased social support from outside of the household during the COVID-19 pandemic was reported by 58.5% of respondents. The remaining 41.5% reported maintained social support from outside of the household (31.1% the same as pre-pandemic and 10.5% increased).

Mood symptoms

» During the pandemic, 69.6% of respondents (70.7% among PwP and 66.9% among CP) reported an increase in sadness and depression.

» Increase in anxiety was reported by 65.5% of respondents (63.1% among PwP and 71.3% among CP).

Figure 1. Association between the change in social support from outside of the household during the pandemic and mood symptoms.



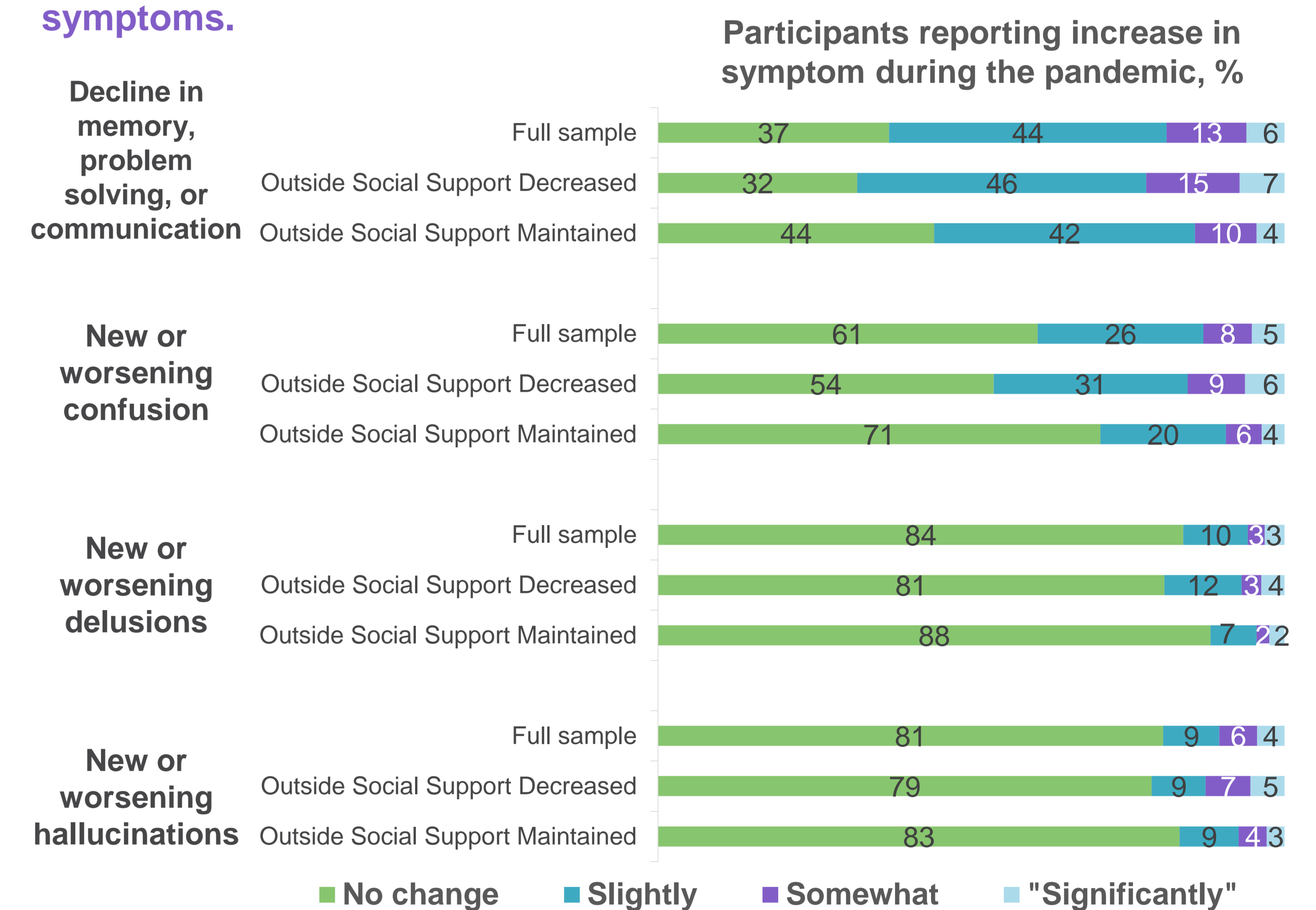
» Decreased social support from outside of their home or primary relationship during the COVID-19 pandemic was significantly associated with increased levels of both sadness and depression and anxiety, compared with maintained levels of social support (p<0.0001 for both comparisons, Figure 1).

Other non-motor symptoms

» A decline in memory, problem solving, or communication during the COVID-19 pandemic was reported by 63.1% of respondents. Other non-motor symptoms were less frequently exacerbated during the pandemic. New or worsening confusion was reported by 39.4% of respondents, new or worsening hallucinations by 19.4%, and new or worsening delusions by 16.2%.

» Decreased social support from outside of the home or primary relationship was significantly associated with decline in memory, problem solving, or communication (p=0.0009), new or worsening confusion (p<0.0001), and new or worsening delusions (p=0.018) (Figure 2). There was no significant association between a decline in this type of social support and the onset of new worsening of hallucinations (p=0.1278) (Figure 2).

Figure 2. Association between the change in social support from outside of the household during the pandemic and non-motor symptoms.



CONCLUSION

» During the COVID-19 pandemic, PwP experienced a decline in social support, which showed a statistically significant and negative association with the burden of mood and other non-motor symptoms of PD, including neuropsychiatric symptoms.

» These results call for increased vigilance towards non-motor symptoms in PwP experiencing social isolation and for stronger provider focus on encouraging PwP and their CPs to build and maintain social connections and engagements.

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