

Importance of informal care partner participation in interventions for people living with Parkinson's disease

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BACKGROUND & OBJECTIVE

- Alexander technique (AT) is a cognitive embodiment approach focusing on attention, inhibition, and body schema as a means of improving patient coordination, functional performance, and confidence during daily life.^{1,2}
- We previously reported benefits for people living with Parkinson's disease (PWP) at post-course and at 6 month follow up after adaptive AT group courses delivered both in person and online.^{3,4}
- We included care partners (CPs) in the courses to study their impact of their participation on the dyadic relationship and on PWP symptom management.

DESIGN & INTERVENTION



- 4 in-person courses and 3 online courses for North and South Carolina participants met for 90-105 minutes twice a week for 8-9 weeks.



AT principles were embedded in daily activities: walking, talking, sit-to-stand and floor-to-stand transitions, IADLs.

- Coursework included functional anatomy and self-management skills taught via verbal and manual instruction, demonstration, anatomical models and images, and partnered activities.

PARTICIPANTS

- 35 PWP/CP dyads total (34 married; 1 friend)
- 6 PWP without CP total

Table only includes participants who completed the courses

Demographics	PWP	CP
Age	67 ± 8	66 ± 7.5
Sex	17M 12F	10M 18F
Race (Ethnicity: Non Hispanic)	White (27) Black (1) Asian (1)	White (27) Black (1)
Employment	Retired (19) Working (1) Unemployed (1) Disabled (7) Not reported (1)	Retired (15) Working (12) Unemployed (1)
Hoehn & Yahr	Stages 1-3	N/A
Years Diagnosed	5.3 ± 4 Range: 1-6 (18) 7-10 (6) 11-13 (4)	N/A
Household Income	\$15,000 -- \$49,999 (12) \$50,000 -- \$99,999 (16) \$100,000 -- \$199,999 (25) \$200,000 -- \$399,999 (1) Not Reported (3)	

OUTCOME MEASURES

Functional reach, one-leg stance, TUG, 7-item Physical Performance Test, symptom-management self-report, anonymous course evaluations, and head-neck angles were previously reported.^{3,4}

This report focuses on course attendance and completion, 6-month follow up data results, evaluations, and semi-structured interviews.



Dyad 14



Dyad 17

REFERENCES

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CARE PARTNER ATTENDANCE CORRELATES WITH 6 MONTH FOLLOW UP IMPROVEMENT

Dyad	# CP Attended	# PWP Attended	NM - PWP	NM - CP	M - PWP	M - CP
Dyad 1	18	18	4	-2	8	-1
Dyad 2	17	17	6	3	13	7
Dyad 3	16	17	-1	-3	13	-7
Dyad 4	16	16	2	-2	3	-2
Dyad 5	16	16	4	N/A	1	0
Dyad 6	16	16	1	5	2	4
Dyad 7	15	18	4	0	13	8
Dyad 8	14	14	-1	2	-5	12
Dyad 9	14	16	5	0	10	-3
Dyad 10	13	12	1	-1	2	-4
Dyad 11	13	15	0	N/A	7	0
Dyad 12	12	15	3	-4	3	-4
Dyad 13	12	12	-1	-5	-3	-7
Dyad 14	11	13	1	2	8	-1
Dyad 15	11	12	4	1	12	6
Dyad 16	9	14	-2	-2	-5	-1
Dyad 17	5	14	2	0	0	6
Dyad 18	4	15	-5	6	-17	11
Dyad 19	4	13	1	-2	-8	8

NM = Non motor issues, M = Motor issues.

Positive values show reported improvement at 6 months

Negative values show reported worsening at 6 months

Dark Teal = Online courses. Light Teal = In-person courses.

Only participants that completed 6-month follow-up were included

- Dyads are arranged in descending order according to how many classes the CP attended in the table to the left.
- The difference between pre-course and 6-month follow-up scores was totaled based on PWP and CP responses to symptom management surveys using a Likert scale.
- Non-motor issues (NM) of confidence, independence, emotional self-control, anxiety, and pain were selected due to their impact on dyadic relationships.
- Motor issues (M) included bradykinesia, tremor, rigidity, shuffling gait, balance, upright posture, vocal volume, fine motor skills, handwriting, and rolling over.
- Data indicates long-term retention of benefits for PWP at 6 months is associated with how many times the CP attended the course.
- A stronger correlation was found for CP attendance than for PWP attendance.

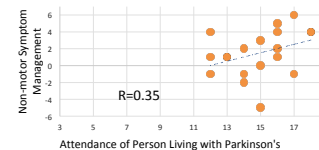
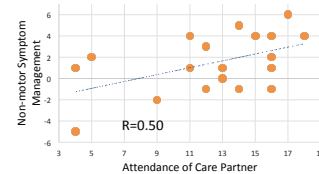
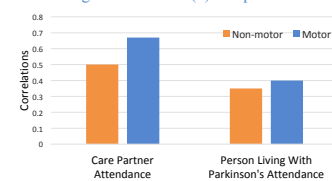


ATTENDANCE CORRELATED WITH 6-MONTH SYMPTOM MANAGEMENT IMPROVEMENT

	PWP - Dyad	PWP - Single
*Attendance	89%	81%
Completion	82%	33%

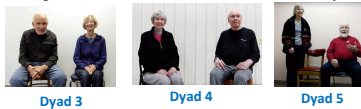
*Only participants who completed the study are included

- Overall Course Completion: 80%
- All single PWP in person (4) dropped out
- All single PWP online (2) completed course



RESULTS - SEMI-STRUCTURED INTERVIEWS

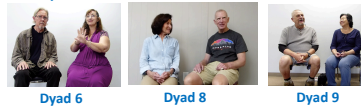
At 6-month follow up, most dyads reported better communication, patience, and compassion for each other, as well as a greater understanding of the impact living with Parkinson's had on both of their daily lives.



Dyad 3

Dyad 4

Dyad 5



Dyad 6

Dyad 8

Dyad 9

CP: There's a different interplay... We know we're there for each other. There's less of that awkwardness about it. The dance is more graceful between us.

PWP: She's been a lot more understanding. It's great... She's also gotten more of an awareness of things that are specific to Parkinson's. Being in a group, she saw the patterns in other people as well, and it kind of forces the reality of what is actually going on.

CP: I could see that with the other couples, too. I could see how they were trying to adapt depending on the situation. I had more compassion for myself and more compassion for him).

CARE PARTNERS

It can help you to understand some of the things the PWP faces physically and emotionally... and you also know that you can remind them to use, in their daily life while living with PD. And the fact that both of you are going through it together, you are both kind of on the same page.

I realize more of the affects of the PD on her than I did before, both emotionally and physically.

PEOPLE LIVING WITH PARKINSON'S

It can help you to understand... I think this is very important that the partner is involved... He doesn't know what I go through during the day. And if you are active together you see it in a different way.

I think it would have been great if my husband could have done it with me.

RESULTS - POST COURSE EVALUATION FORMS

Post course, both PWP and CPs expressed improvement in their relationship on 0-10 Likert scale. Higher score means greater statement agreement.

Anonymous Evaluation Form Results	PWP Avg.	CP Avg.
The class was enjoyable.	7.8	8.4
I feel better prepared for the daily demands of living with Parkinson's/being a care partner.	8.1	8.7
I feel my care receiver is better prepared for the daily demands of living with PD.	N/A	8.4
*I feel my partner is better prepared for the present and future daily challenges of being my care partner.	8.4	N/A
*I feel my partner has a better understanding of my experiences and challenges while living with PD.	8.4	6.2
*I feel I have a better understanding of my partner's experiences and challenges while living with PD.	8.6	8.0
*I feel we have a new shared vocabulary to meet the present and future challenges of living with PD.	8.1	8.7

*only 7 Dyads were asked these questions

CONCLUSIONS

Including care partners in interventions for people living with Parkinson's disease can improve course attendance, course completion, longterm symptom management, and foster better dyadic relationships.

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