MOTIVATE PD: Developing a Client-Centered Social Self-Management Program for People with Parkinson's Disease

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Introduction

- **Parkinson's Disease (PD)** is a progressive, neurological condition that affects over 10 million people worldwide[1]
- Current rehabilitation programs for **people with Parkinson's disease (PwPD)** focus primarily on motor symptom remediation[2,3,4]
- **The Tufts Health Quality of Life (HQoL) Lab**, under direction of Linda Tickle-Degnen, identified a lack of PD-specific programs that address biopsychosocial health through what they define as **social self-management (SocM)**[5,6]
- **SocM** = Self-care practices in which one engages one's social resources to manage healthful daily living
- SocM behaviors associated with higher **quality of life (QoL)**[5,6]:

| Engaging in valued home & community activities | Utilizing health resources | Giving and receiving social support |

- Occupational therapy practitioners (OTPs) believe in the **value of participation in meaningful activities;** OTPs can support clients in establishing, restoring, & maintaining social self-management techniques to support long-term health & overall QoL[7,8]

Aims + Methods

Purpose: Develop an OT-based *social self-management manual* for PwPD that is client-centered, addresses biopsychosocial health, & supports long-term motivation & goal-directed behavior

Aim #1: Create Manual

✓ Literature Review
✓ Analyze interview transcripts from the HQOL SocM lab database[9]
✓ Review PD case studies[10,11]
✓ Design 1st draft in Canva

Aim #2: Delphi Method*

Delphi Method: a process by which an interdisciplinary panel of experts provides feedback on a relevant issue, responses are analyzed & interpreted, & process is repeated for 2+ rounds.

	PD Researcher	PD Advocate	Occupational Therapist	Physical Therapist	Activity Instructor	Tufts Faculty
Expert 1	X		X			
Expert 2	X					
Expert 3			X			X
Expert 4		X			X	
Expert 5		X			X	
Expert 6						X
Expert 7			X			
Expert 8				X	X	

✓ Recruit expert panelists (n=8)
✓ Create Qualtrics surveys to gather feedback
✓ Send materials to experts via e-mail   ⎤
✓ Analyze quantitative & qualitative responses ⎬ 2 rounds
✓ Apply revisions to manual   ⎦

Aim #3: Disseminate Manual

✓ Create flyer with QR code to access web-based manual
✓ Distribute flyers at April 2024 Tufts Dance for Parkinson's event
✓ E-mail flyers to clinicians in local PD community

Results

Round 1: Key Themes + Suggestions

Accessibility
- **3/8** discussed concerns re: computer literacy
- **3/8** identified areas of jargon

Activity Suggestions
- **3/8** requested examples & rec'd sourcing examples from Activity Card Sort (ACS)

Barriers
- **7/8** suggested including other barriers (ie. stigma, apathy & depressions, cold weather)

Representation
- **2/8** said biased towards those who are retired/ have discretionary income
- **2/8** requested more opportunities for those who do not have care partners or family

Goal-Setting
- **3/8** people voted to remove PEO explanation
- **2/8** people voted to remove SMART goals
- **2/8** suggested providing more opportunities to grade goals over time

Client Reflection
- **3/8** suggested edits to reflection questions

Social Participation
- **3/8** suggested putting more emphasis on peer support & social participation

Round 2: Key Themes + Suggestions

Accessibility
- **2/8** identified further areas of jargon

Barriers
- **2/8** voted to change headings to be more strengths-based

Goal-Setting
- **2/8** provided comments re: simplifying concepts

Expert Testimonials

"This kind of guide - informed by the kind of *inclusive*, *creative* and *accessible* mindset that's part of OT methodology - *fills a much needed void* and provides the Parkinson's community with a *tangible roadmap for managing their wellbeing, health and sense of agency.* Other resources are either too clinical, too simplistic, or too dry. This guide provides really valuable information in a delightful and engaging way that *speaks with, rather than talks down to, the reader.*"
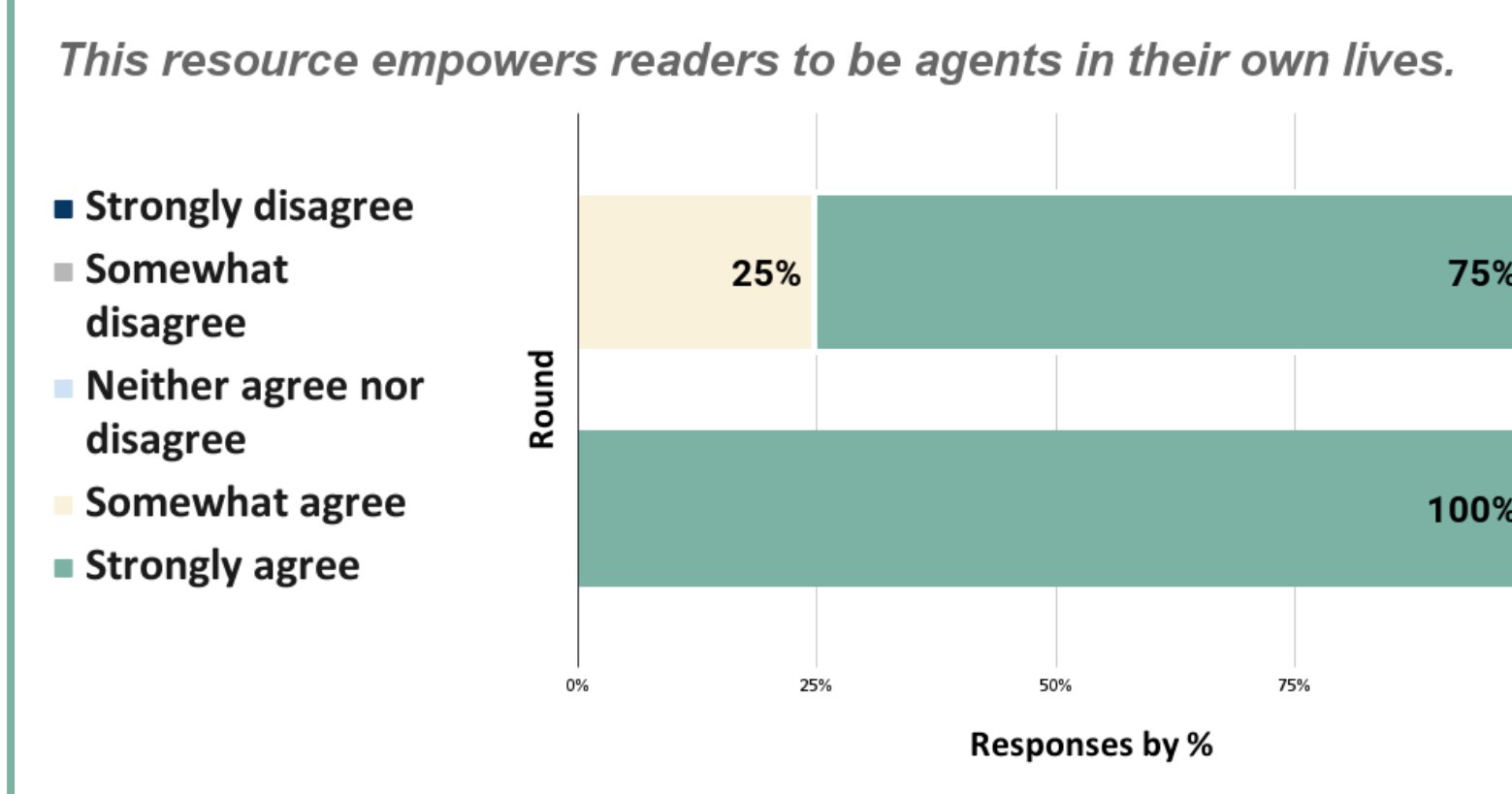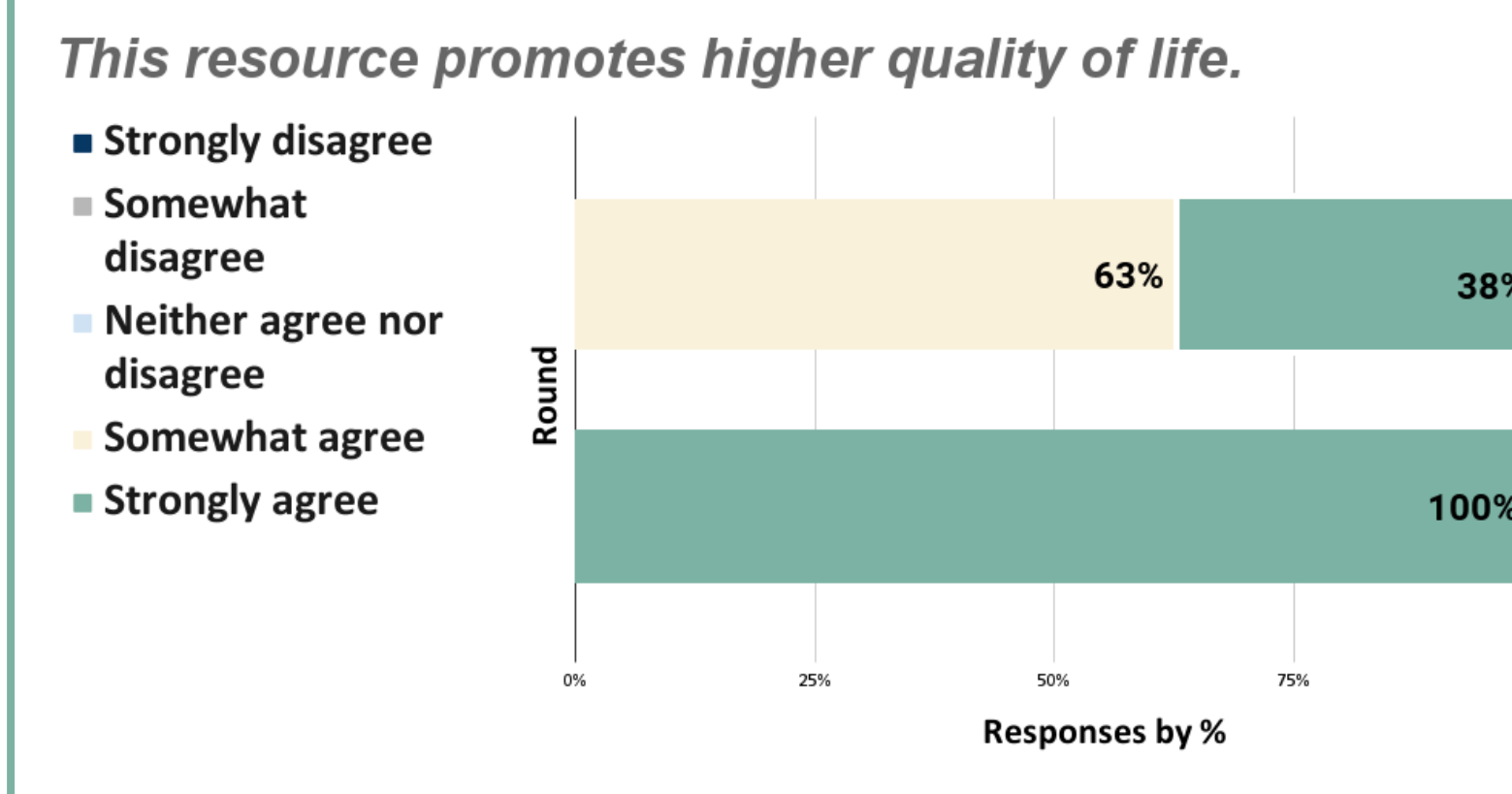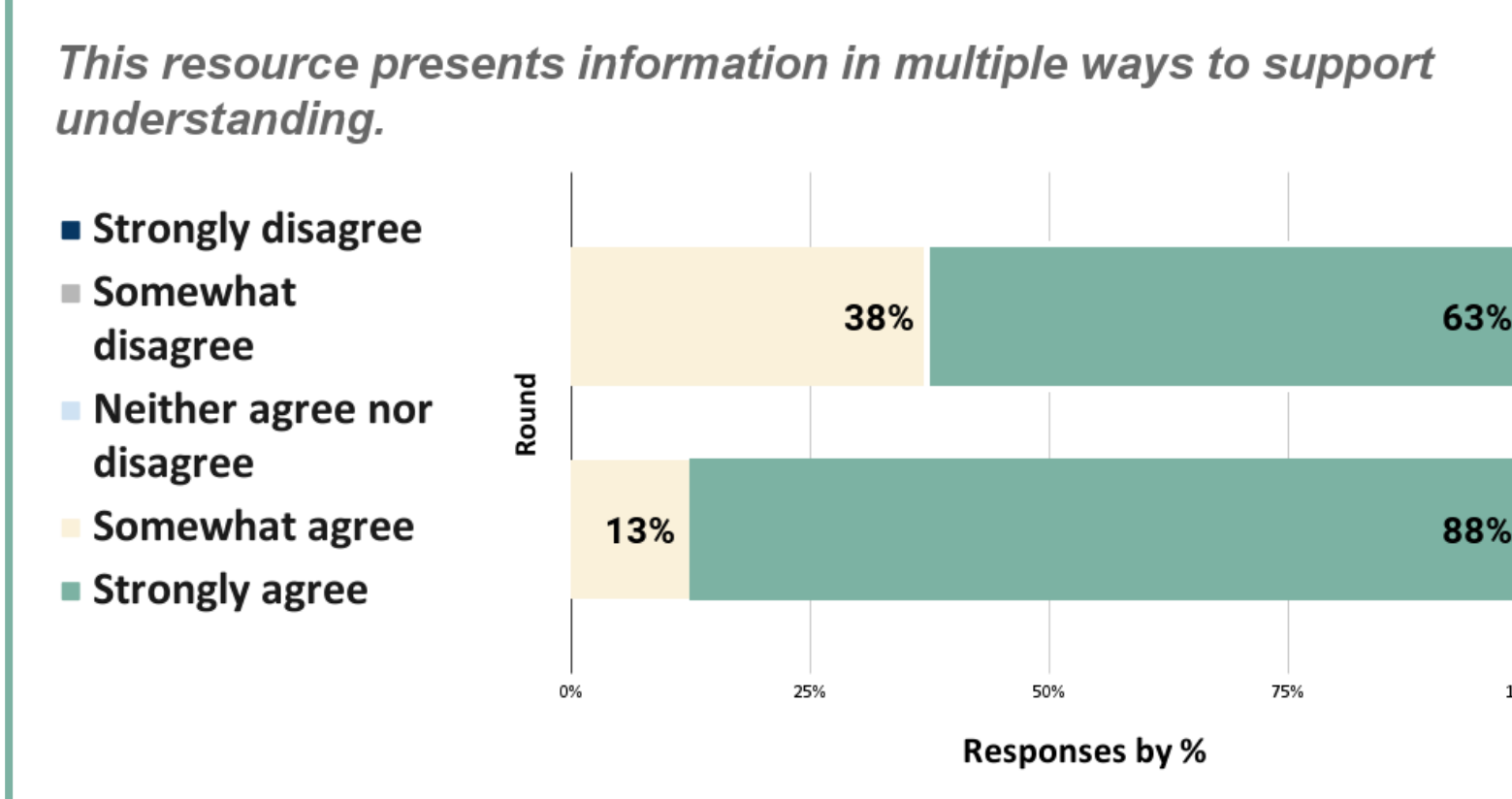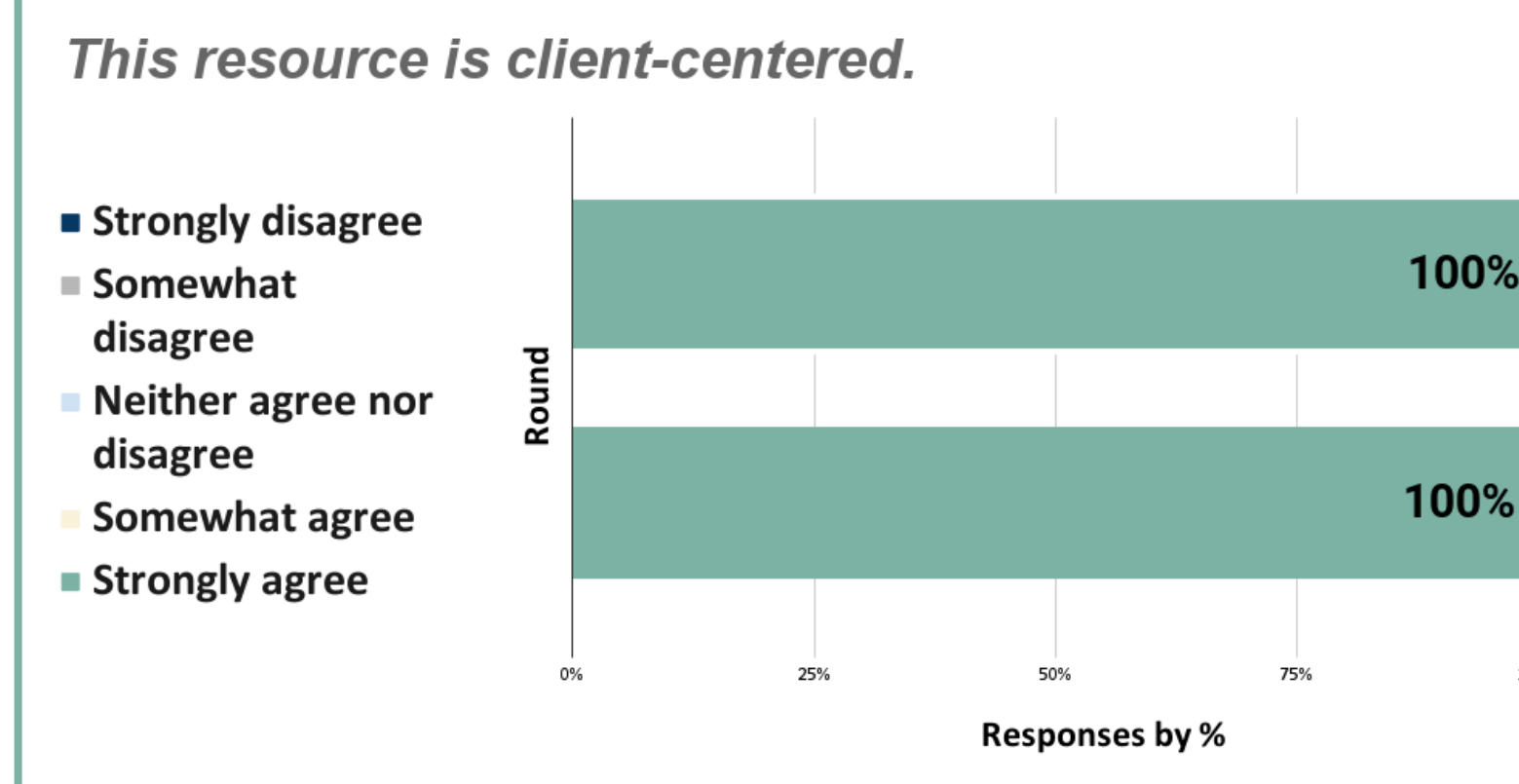
"It's great to see a resource that utilizes an *OT perspective* - something I haven't seen before. This perspective is particularly important because of the focus on *meaningful occupation and engagement*, which encompasses such a *broad range of activities* in different environments - such an important perspective for people with PD, who often get a very narrow view of suggestions from neurologists and PTs."

"I love that [Motivate PD] is so *comprehensive*. Its a great *go-to resource* for people with PD, their caregivers and their therapists. I feel like I could refer patients/families to this for any question/issue and they would find *quick and appropriate answers*."

Sample Survey Responses

Round 1 (Top Line) vs. Round 2 (Bottom Line)

"Please indicate whether you agree or disagree with the following statements…"

This resource is client-centered.

Legend:
- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Round 1: 100% (Strongly agree)
Round 2: 100% (Strongly agree)

This resource presents information in multiple ways to support understanding.

Round 1: 38% (Somewhat agree), 63% (Strongly agree)
Round 2: 13% (Somewhat agree), 88% (Strongly agree)

This resource promotes higher quality of life.

Round 1: 63% (Somewhat agree), 38% (Strongly agree)
Round 2: 100% (Strongly agree)

This resource empowers readers to be agents in their own lives.

Round 1: 25% (Somewhat agree), 75% (Strongly agree)
Round 2: 100% (Strongly agree)

Final Impressions

- **100%** of experts said they would **recommend Motivate PD** to a friend or client
- **100%** of experts said that Motivate PD **fills a gap in practice**

Discussion

Manual Strengths

- *Accessibility features*
  - Simple design
  - Approachable length
  - No medical jargon
  - Compatible with PDF screen-readers
  - Audiobook option
- *Fills multiple gaps in practice*
  - OT-specific
  - Client-centered
  - Emphasis on activities & social participation
  - Holistic approach to health
  - Supports long-term problem-solving & goal-setting
  - Supports independence, self-efficacy, and autonomy

Manual Limitations

- **Language accessibility:** Currently available in English only
- **Computer accessibility:** Currently available online only
  - Requires computer, phone, or tablet to access
  - Requires moderate level of computer literacy
- **Region-specific:** Most resources pertain to New England area
- Intended for **community-dwelling PwPD**; less applicable to those with higher physical and cognitive needs

Conclusions

- Motivate PD has been **evaluated & endorsed** by an interdisciplinary panel of experts in the Parkinson's community; **it is ready for piloting** to determine its effectiveness in supporting PwPD & care partners over time

Future Directions

- **Pilot manual**: Obtain feedback from PwPD & care partners via survey or focus group regarding:
  - Helpfulness
  - Usability
  - Whether supports goal-setting & motivation
  - Whether promotes biopsychosocial health
- **Expand access:**
  - Translate manual into other languages
  - Get funding to print materials in hard-copy
  - Create Motivate PD website
  - Consolidate into pamphlet for doctor's offices
- **Expand audience:**
  - Differentiate based on stage of PD
  - Adapt for non-community dwelling PwPD
  - Adapt for region-specific resources outside of New England or worldwide

Contacts & References

Contacts

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References + More

Scan to view the Motivate PD manual, poster references, & other materials