THE NARRATIVE MEDICINE "TOOLBOX": LITERARY MINDFULNESS, ACTIVE REFLECTION AND PDPR

- •We define "Literary Mindfulness" as reading something and entering the mindset of what you have read; staying in that moment, and you will achieve a temporary but beneficial calmness. Living with Parkinson's disease (PD) can give moments of negative thoughts and times of increased doubt. Likewise, the "care partner" is under different stressors but is also facing life-altering circumstances.
- •We define "Active Reflection" to be focusing your mind for a moment and then writing your thoughts about the reading(s) into a journal or cell phone app. The mindfulness journey begins by reading, pausing to think, and then it ends by actively reflecting on your thoughts in writing a response.
- •We describe the "Parkinson's Disease Progress Report" (PDPR) as a <u>balance</u> sheet created to give a <u>weekly-mental</u> health score. The PDPR will be a 10-question survey about QoL with PD. Stress, life-work-exercise balance, and overall wellness will be monitored.



Literary Mindfulness for Building Resilience in Parkinson's Disease: A Pilot Study

MARY-FRANCES E. HALL, JESSICA SHURER, AND FRANK C. CHURCH UNC SCHOOL OF MEDICINE, CHAPEL HILL, NC

OVERALL GOAL

Our <u>goal</u> is to build resilience, reduce stress, and improve the quality-of-life (QoL) in a person-with-Parkinson's (PwP) <u>and</u> their care partner. Practicing <u>Literary Mindfulness</u> and <u>Active Reflection</u> will require the participant to <u>read</u>, <u>react</u>, <u>reflect</u>, and to <u>respond</u> (which we call the 4R's of literary mindfulness).

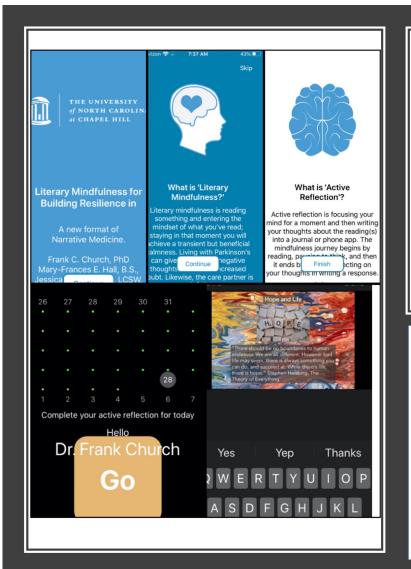
CENTRAL HYPOTHESIS

Our <u>central hypothesis</u> is by practicing <u>Literary Mindfulness</u> will help to reduce stress and smooth out the rough edges of life <u>both for a PwP and for a care partner</u>. Responding to what we term, <u>Active Reflection</u> will help sustain and solidify the moment. Finally, we will produce a weekly life-stress-related ledger using what we named the <u>PDPR</u> (<u>Parkinson's Disease Progress Report</u>). Thus, in our Narrative Medicine study, <u>both</u> the PwP and care partner would build resilience and improve their QoL.

LITERARY MEDICINE AND ACTIVE REFLECTION ARE INNOVATIVE TOOLS In searching Google Scholar, we find no prior studies using literature quotes/artwork/reflection by writing to reduce stress, build resilience, and improve QoL fin Parkinson's for either PwP or their care partners.

SPECIFIC GOALS AND VISION

- •The goal of <u>Literary Mindfulness</u> is to read 1-3 quotes on topics like Hope, Positivity, and Persistence for 1-2 minutes, you are breathing slowly, deeply thinking, and becoming one with the readings (and accompanying artwork). You are focused on this specific moment, and if you have accomplished the goal, then you have become mindful of the words.
- •The goal of <u>Active Reflection</u> is the exercise of writing about what you are currently feeling after reading. Expression of your thoughts is very important; these thoughts may reflect your overall sense of wellness, mental mood, and mental healthfor-the-moment. Writing the active reflection will likely take 2-5 min/quote.
- •Frequency: Literary mindfulness and active reflection will be done 5 times/week; you will be given the readings and space to read, react, reflect, and to respond. The <u>PDPR</u> will be given weekly, focusing in on your overall physical and emotional wellness: e.g., how your week was balanced with work-working out-sleepingeating, stress at work/home, and how the PwP and care partner are dealing with PD.
- •All responses will be blinded, but will be collected; thus, an IRB will be obtained.
- •On Day 1 and on Day 60, a "Coping" assessment will be given to all participants; and the PwP will complete the PDQ-39.
- •Results will compare participants who do Literary Mindfulness to none (Control).



Literary Mindfulness iPhone App (v1.0)

Deepak H. Melwani and
Frank C. Church
Left/below left- early prototype
iPhone app, and below/rightexamples of quotes.

Hope

"Once you choose hope, anything's possible."
Christopher Reeve

"The thought of hope is the seed to healing."
Shilpa Menon

"What oxygen is to the lungs, such is hope to the meaning of life." Emil Brunner

"Never give up. It's like breathing—once you quit, your flame dies letting total darkness extinguish every last gasp of hope. You can't do that. You must continue taking in even the shallowest of breaths, continue putting forth even the smallest of efforts to sustain your dreams. Don't ever, ever, ever give up." Richelle E. Goodrich

"Resolve never to quit, never to give up, no matter what the situation." Jack Nicklaus

"If you want to hit it farther, hit it better." Jack Nicklaus

"Focus on remedies, not faults." Jack Nicklaus

Mindfulness for Living in the Moment and Mindfulness for Parkinson's Disease

"Much of our lives are led at a pace where we fret for the future, are remorseful of the past, and frequently, we remain oblivious and out of touch to the current moment. Some experts argue that one needs to practice mindfulness meditation for at least 20 minutes to achieve a positive return. ^{86,87} Other experts would suggest that even if you can do it for 5 minutes, there are rewards for such calming thoughts. ⁸⁸ We reason, if you can focus your mind on the current moment and maintain yourself in that moment for 60 sec, a transient but a quality and beneficial calmness will be achieved. Centering yourself within the moment and your current environment and surroundings alters your life-perspective temporarily, allowing your mind to maintain focus not only on one event but also on an awareness of self." Excerpt from Mary-Frances E. Hall and Frank C. Church, (2020) "Integrative Medicine and Health Therapy for Parkinson's Disease", Topics. in Geriatric Rehabilitation; 36.3 (2020): 176-186. Open access:

https://bit.ly/3kIDY2K