

Title: Effect of the Life Story Questionnaire on Physical Therapy Participation in Patients with Cognitive Impairment: A Randomized Control Trial

Document date: 04/24/2023

NCT05827276

RESEARCH PROPOSAL

Title: Effect of the Life Story Questionnaire on Physical Therapy Participation in Patients with Cognitive Impairment: A Randomized Control Trial

Principal Co-Investigators: Jonathan Singer, PhD¹
Jean-Michel Brismée, PT, ScD²
Additional Investigators: Megha Shah, PT, DPT^{2,3}
Lisa Brite, OT, BS³

¹Department of Clinical Psychology, Texas Tech University, Lubbock, Texas, USA

²Department of Rehabilitation Sciences, Center for Rehabilitation Research, Texas Tech University Health Sciences Center, Lubbock, Texas, USA

³Peach Tree Place, Department of Rehabilitation, Weatherford, Texas, USA

TABLE OF CONTENTS

Abstract..... v

List of abbreviations.....vii

Background..... 1

Purpose, Aim and Values.....6

Research questions, Hypothesis and Variables.....8

Methods.....11

 Research design.....11

 Research setting/location.....11

 Sampling..... 11

 Sequence12

 Data Analysis.....16

 Descriptive statistics.....16

 Inferential statistics..... 16

References.....17

Research Project Timeline..... 20

Appendix A: Life story questionnaire.....21

Appendix B: Pittsburgh Rehabilitation Participation Scale.....26

Appendix C: Quality of Life Alzheimer’s disease.....27

Appendix D: Cornell Scale for Depression in Dementia.....30

Appendix E: Mini-Mental State Examination.....33

Appendix F: Pre-screening questionnaire..... 35

Consent Form - Participants.....36

Consent Form – Family 38

SCIENTIFIC ABSTRACT

Background: Dementia is characterized by a progressive decline in cognitive function. Dementia disease prevalence is substantially increased among people aged 65 years or older, with a progressive decline in memory, thinking, language and learning capacity. Although physical exercise benefits dementia patients, participation in activities is exceedingly difficult due to communication and cognitive impairments. Several studies demonstrated that life story books usage improved quality of life, depression symptoms, moods and participation in activity in people with dementia. However, these studies did not evaluate the effect of Life Story Questionnaire (LSQ) – a type of life story book - on physical therapy participation, depression symptoms, quality of life.

Objectives: To evaluate the impact of LSQ on (1) participation in physical therapy using Pittsburg Rehabilitation Participation Scale; (2) quality of life using Quality of Life – Alzheimer’s Disease Scale (participant’s version); and (3) depression symptoms using Cornell Scale for Depression in Dementia (CSDD).

Methods: A consecutive sample of convenience of up to 60 patients with mild to moderate cognitive impairment with 44 (22 per group) completing the study will be recruited from a nursing home facility. Patients will be randomly allocated in two groups: (1) *Control group*, which will receive standard physical therapy care without LSQ use; and (2) *Experimental group*, where physical therapists will use the LSQ. Each patient’s family member will receive a LSQ to complete prior to the start of the intervention. Patients’ participation, quality of life and depression symptoms will be measured on day 1 and again after 3 weeks (mid-term), and 6 weeks of intervention. Quality of life and depression symptoms will also be measured 6 weeks following intervention. A licensed occupational therapist blinded to the participants’ group allocation will measure all three dependent variables

Statistical Analysis: Descriptive statistics including means, standard deviations, frequency counts, median, mode, variance and frequency counts will be used to assess sample demographics. The Rank Sum test will be used to assess differences in Pittsburg Rehabilitation Participation Scale between the intervention and control group. Spearman Rank correlations will be used to determine the strength of the correlation between Mini-Mental state examination, Pittsburg Rehabilitation Participation Scale and Quality of Life Alzheimer Disease.

Key words: Dementia, Life story questionnaire, Physical therapy, Participation, exercise

Financial Disclosure and Conflict of Interest: The investigators affirm that they have no financial affiliation (including research funding) or involvement with any

commercial organization that has a direct financial interest in any matter included in this manuscript.

NON-SCIENTIFIC ABSTRACT

Background: Dementia is a general term for difficulties remembering, thinking or making decisions. Dementia increases among people aged 65 years or older. Exercise benefits dementia patients, however participation in activities is very difficult due to difficulties communicating and understanding. Several studies demonstrated that life story books usage improved quality of life, depression symptoms, moods and participation in activity in people with dementia. However, these studies did not evaluate the effect of Life Story Questionnaire (LSQ)– a type of life story book - on physical therapy participation, depression symptoms, and quality of life.

Objectives: To see the benefits of LSQ on (1) participation in physical therapy; (2) depression symptoms; and (3) quality of life.

Methods: Up to 60 patients with mild to moderate cognitive impairment with 44 (22 per group) completing the study will be recruited from a nursing home facility. Patients will be allocated in two groups: (1) *Control group*, which will receive standard physical therapy care without LSQ use; and (2) *Experimental group*, where physical therapists will use the LSQ. Each patient's family member will receive a LSQ to complete prior to the start of the intervention. Patients' participation, quality of life and depression symptoms will be measured on day 1 and again after 3 weeks (mid-term), and 6 weeks of intervention. Quality of life and depression symptoms will also be measured 6 weeks following intervention. An occupational therapist will take the measurements.

Statistical Analysis: Appropriate statistics will be used to analyze the data.

LIST OF ABBREVIATIONS

Cornell Scale for Depression in Dementia.....	CSDD
Life story books.....	LSBs
Life Story Questionnaire.....	LSQ
Mini-Mental State Examination.....	MMSE
Quality Of Life – Alzheimer’s Disease Scale.....	QOL-AD

BACKGROUND

Dementia is a devastating disease that places a significant physical, emotional and financial burden on patients, their caregivers and society¹. In 2015, the number of people living with dementia worldwide was estimated at 46.8 million. This number is expected to increase to 74.7 million in 2030 and 131.5 million in 2050². In the US alone, dementia was responsible for a total expense of US\$277 billion in 2018, and is expected to reach approximately US\$1.1 trillion in 2050³.

Dementia is a medical condition in which there is a worsening in a person's cognitive abilities compared with several months or years before. A person with dementia has difficulty with several types of cognitive abilities, most often with memory but also with language, attention, orientation, judgment, and planning⁴. Communication is a major concern for people with dementia^{5,6}. Positive, person-centered communication is important to ensure good quality dementia care^{6,7,8}. In 2016, the American Geriatrics Society Expert Panel developed a summarizing definition of person-centered care: "Person-centered care" means that individuals' values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals. Person-centered care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers. This collaboration informs decision-making to the extent that the individual desires^{2,9}. It can be enhanced by using reminiscence therapy¹⁰.

Life story book (LSB) is a common approach in reminiscence therapy¹¹. Life story books involve events and experience from the past, which can evoke memories, stimulate mental activity and improve well-being¹². Several studies demonstrated that life story books usage improved quality of life, depression and participation in activity in people with dementia in nursing homes¹²⁻¹⁴. Life story books demonstrated positive effects on communication and interaction of persons with dementia immediately after the end of treatment, and also weeks to months later¹². The majority of the life story books were tangible books, although some digital applications exist¹⁵. Qualitative findings demonstrated the value of life story books in triggering memories and in improving the relation with persons with dementia. Learning personal features and life events about dementia residents is beneficial to know actual facts as everything they state is not necessarily true¹⁴. Engaging in life story work, enabled staff to appreciate the person behind the dementia. Understanding (as opposed to knowing) the person with dementia's life story changed staff's thinking on what was important when delivering care to people with dementia².

The Crisis Prevention Institute developed a Life Story Questionnaire (LSQ) (Appendix A), which is a type of life story book for people with dementia. The information about LSQ can be gathered from multiple sources, especially family members. It includes information about preferences and lifestyle. Preferences include coffee vs tea, nickname vs full name, early riser vs night owl, small groups vs large groups, brands of personal care products. Lifestyle examples include culture, faith, family, relationships, job history, home, childhood

home and neighborhood, accomplishments, daily routine, and emotional needs. Understanding patient's preferences, values, and motivation in life is the foundation of person-centered dementia care.

The LSQ allows caregivers to start conversations about topics that are important to each patient, can help establish rapport between caregiver and patient. Clinicians' LSQ knowledge for each patient gives dementia patients security because even when they do not remember life facts, clinicians can still provide relevance to patients, creating a sense of familiarity and personhood. Additionally, the LSQ helps reduce psycho-social behaviors such as anger, agitation and depression when caregivers thoroughly understand patients' likes, dislikes, preferences, interests, and background. The LSQ can be used as a person's identity keeper¹³.

Older people have low levels of physical activity and even lower for people with dementia⁷. Physical activity is a potentially modifiable risk factor to reduce the risk of developing dementia as it can provide beneficial effects on brain health and cognition⁷. Regular exercise can positively impact dementia related symptoms including depression, anxiety, attention-deficit/hyperactivity disorder¹⁶. Additionally, it can relieve stress, improve memory, help sleep quality, and boost overall mood¹⁶. In older dementia adults living in residential care facilities, physical exercise helped patients improve their balance and maintain their independence¹⁷. However, participation in physical therapy for people with dementia is exceedingly difficult due to cognitive impairments. Physical therapists may need to develop other strategies to ensure that people with dementia

receive the input they need, such as improving caregivers' involvement or incorporating exercises into more functional activities that can be undertaken with less supervision, while promoting self-efficacy¹⁸.

Cognitive impairment is the clinical hallmark of dementia; however noncognitive neuropsychiatric symptoms are exceedingly common and dominate the presentation. Neuropsychiatric symptoms such as depression, psychosis, agitation, aggression, apathy, sleep disturbances, and disinhibition are common in people with dementia¹⁹. Non-pharmacologic techniques have substantial scientific evidence but are currently under-utilized in standard care. Kale et al. developed the Describe, Investigate, Create and Evaluate (DICE) approach, which is patient and caregiver centered and has demonstrated better outcome than pharmacological approach with less adverse effects¹⁹.

Dementia and the related neuropsychiatric symptoms affect the quality of life of dementia individuals. Dementia causes a decrease in cognitive function, so quality of life has historically been reported by proxies such as family members or health-care providers²¹. Reminiscence activities/life story book can contribute to cognitive functioning, depression, and quality of life of persons with dementia^{2,12}.

Elfrink et al. researched LSBs/LSQ interventions for people with dementia and confirmed the use of LSBs is promising to support reminiscence and personcentered care. The authors showed that creating and implementing LSBs/LSQ in dementia care seemed beneficial, although their effectiveness and long-term effects have not been investigated².

Dementia - Life Story Questionnaire – Physical Therapy

Therefore, the purpose of this study will be to evaluate the impact of LSQ use on (1) cognitively impaired patients' physical therapy activity participation; (2) quality of life; and (3) depression symptoms.

PURPOSE, AIMS AND VALUES

Purpose: The purpose of this study is to evaluate in patients with cognitive impairment the impact of LSQ on (1) physical therapy participation; (2) quality of life; and (3) depression symptoms.

Aims: The study plans to evaluate the impact of LSQ use on participation in physical therapy, quality of life and depression symptoms in people with cognitive impairment. The intervention will include gathering LSQ information for selected subjects from family patient/family members and then using this information for 6 weeks to evaluate the impact of LSQ on (1) participation in physical therapy using the Pittsburg Rehabilitation Participation Scale (Appendix B); (2) quality of life using the Quality of Life – Alzheimer’s Disease Scale (participant’s version) (Appendix C); and (3) depression symptoms using the Cornell Scale for Depression in Dementia (CSDD) (Appendix D).

Value: Previous studies demonstrated psychosocial life story book usage benefitted people with dementia in nursing homes, their relatives, and staff¹²⁻¹⁴. As per Woods et al. the life story book is beneficial to improve cognitive function, communication, quality of life and mood. However, randomized comparison trials are needed to evaluate the effect of life story book usage on physical therapy participation. People with dementia demonstrate challenges in physical therapy participation due to poor cognition and communication. Physical therapists are challenged to develop plans of care for people with dementia due to poor cognition. The LSQ can help develop individualized and person-centered care. It is hypothesized that the LSQ will help increase physical therapy participation for

Dementia - Life Story Questionnaire – Physical Therapy

people with cognitive impairment and therefore improve their functional mobility, activities of daily living, depression symptoms and quality of life. If LSQ proposed benefits are substantiated, this study could be the first to highlight the importance of LSQ increasing physical therapy participation and improving depression symptoms and quality of life in patients with cognitive impairment.

RESEARCH QUESTIONS, HYPOTHESES AND VARIABLES

RESEARCH QUESTION(s) (RQs)-This project aims to answer the following research questions:

1. **RQ 1:** What is the effect of LSQ usage on physical therapy participation in people with cognitive impairment at 3 weeks(mid-term) and six weeks as compared to a control group?
2. **RQ 2:** What is the effect of LSQ usage on quality of life in people with cognitive impairment at 3 weeks(mid-term), six weeks and six weeks following intervention as compared to a control group?
3. **RQ 3:** What is the effect of LSQ usage on depression in people with cognitive impairment at 3 weeks(mid-term), six weeks and six weeks following intervention as compared to a control group?
4. **RQ 4:** What is the relationship between cognitive impairment severity and physical therapy participation improvement at the end of the intervention (6 weeks)?

RESEARCH HYPOTHESES -This student has devised the following research experimental hypotheses

1. **Research Hypothesis 1:** LSQ usage will increase physical therapy participation in people with cognitive impairment at 3 weeks(mid-term) and six weeks as compared to a control group.

2. **Research Hypothesis 2:** LSQ usage will improve symptoms of depression in people with cognitive impairment at 3 weeks(mid-term), six weeks and six weeks following intervention as compared to a control group
3. **Research Hypothesis 3:** LSQ usage will improve quality of life in people with cognitive impairment at 3 weeks(mid-term), six weeks and six weeks following intervention as compared to a control group.
4. **Research Hypothesis 4:** Mild cognitive impairment will be positively associated with participation in physical therapy at six weeks following LSQ usage as compared to a control group.

COMPARISON VARIABLES

Independent Variable(s)-The student plans to use the following Independent Variable(s) (IV)

1. IV1: physical therapist use of LSQ
 - a. Level 1: LSQ usage
 - b. Level 2: no LSQ usage

Dependent Variable(s)-The Student plans to measure the following dependent variable(s) (DV)

1. DV1: Pittsburg Rehabilitation Participation Scale²⁵(Appendix B)
2. DV2: Quality of Life (quality of life - Alzheimer's disease scale - participant's version)²⁶(Appendix C)

3. DV3: Depression (Cornell Scale for Depression in Dementia (CSDD)²⁷(Appendix D)

Relationship Variable(s)- The investigator plans to use the following variables (RV) for RQ 4

1. RV1: Pittsburg Rehabilitation Participation Scale²⁵(Appendix B)
2. RV2: Mini-mental state of examination (MMSE)^{22,23} = Measure of dementia severity³ (Appendix E)

METHODS

Research Design

Prospective Randomized Control Trial. The trial will be registered on Clinicaltrials.gov.

Research Setting/Location

Peachtree Place (Dementia care facility), Weatherford, Texas. This study will be approved by Texas Tech University (TTU) Institutional Review Board (Lubbock Campus).

Power Analysis

Power calculations were performed to determine the sample size required for the study using the Pittsburgh participation in rehabilitation scale as the primary outcome measure and calculations using Mann-Whitney U test. The study was designed with α value set at 0.05 and Power set at 0.8 (β set at 0.2). The effect size was calculated using G*Power (version 3.1) using differences in the Pittsburgh participation in rehabilitation scale between the experimental versus the control group of 0.5 with a standard deviation of 0.5, based on pilot testing conducted at Peachtree Place, which resulted in effect size of 1 and a sample size of 44 (22 participants in each group) (<http://www.gpower.hhu.de/>).

Sampling

A consecutive sample of convenience of up to 60 patients (44 patients = 22 per group completing the study) with MMSE scale score between 10-18 (moderate cognitive impairment) and 19-23 (mild cognitive impairment), and residing at the Peachtree Place dementia care facility in Weatherford Texas will

be recruited. Patients (or their families) will be asked to participate after explanation of the study.

Subjects

Inclusion Criteria: (1) Patients residing in Peachtree Place in Weatherford, Texas; (2) Age 60-89 years; (2) Diagnosis of dementia disease, in mild to moderate stage using the MMSE (score between 10-23)^{22,23} and (3) attendance to physical therapy for 6 weeks.

Exclusion Criteria: (1) Unable to speak English; (2) blindness; (3) deafness; (4) MMSE score >23 and (5) history of major psychiatric disorder such as schizophrenia and bipolar disorder that required hospital admission within the last year.

Sequence

Reliability Testing

Investigator 2, who is a licensed occupational therapist with 15 years of clinical experience in geriatric population care, will be educated to collect the three dependent variables including the Pittsburg Rehabilitation Participation scale, the quality of life -Alzheimer's disease scale and the Cornell Scale of Depression in Dementia (CSDD) scale to establish intra-rater reliability.

Investigator 1 who is the principal investigator and a licensed physical therapist with 10-year experience treating geriatric population and has experience in using the Pittsburg Rehabilitation Participation scale, the quality of life -Alzheimer's disease scale and the CSDD scale, will explain and educate Investigator 2 in

each scale usage. After demonstration, Investigator 2 will record the three dependent variables measurements on the same patients twice, with at least 48hour interval between measurements. A minimum of five patients will be used. The intra-rater reliability of measurements on the two separate days will be calculated.

Study Sequence

Investigator 1 will conduct patients' screening (Appendix F) before they enroll the study to determine their eligibility. Participants with mild cognitive impairment (MMSE 19-23) demonstrating understanding of the research and the consent decision and indicating a willingness to take part will be asked to sign a consent form. For participants with moderate cognitive impairment (MMSE 10-18), both the potential participants and their legally authorized representatives will be asked to give consent to allow study participation.

Patients will be randomly assigned using block randomization with a 1:1 allocation ratio and randomly permuted block sizes of 2 to 6 based on severity of cognitive impairment. The randomization will be performed in R software (version 4.1.2, R Core Team) using the randomize R package (version 2.0). Each subject will be randomized to one of two interventions: (1) Control group, which will receive standard physical therapy care without LSQ use; and (2) Experimental group, where physical therapists will use the LSQ. The randomization file will be generated by Investigator 1 (Physical therapist) not involved in the data collection process, with the results stored in a spreadsheet accessible only to the investigator responsible for the subjects' group assignment. This investigator will

not participate in any data collection. Due to the nature of the study, participants will not be blinded to the group assignment and to the treatment they will receive. Investigator 2 measuring the dependent variables, however, will be blinded to the group assignment.

Family members of each patient will receive an LSQ to complete prior to the start of the intervention (Appendix A). Investigator 1 will conduct all physical therapy sessions for the study patients. Investigator 2, will collect the following dependent variables on day 1 of week 1, and on day 1 of third and sixth weeks:(1) Pittsburg Rehabilitation Participation Scale, which measures patients' participation in therapy; (2) Quality of Life - Alzheimer's disease scale; and (3) depression symptoms (Cornell Scale for Depression in Dementia). Additionally, Investigator 2 will record quality of life and depression at six-week following the intervention. Both investigators will enter their data using Texas Tech University Health Sciences Center password protected Qualtrics platform.

Both control and intervention groups will receive individual exercises that include strengthening, balance, gait, aerobic, endurance, dual cognitive motor tasks and exercises to improve activities of daily living and functional mobility²⁸. A pragmatic exercise program will be used for each participant needs based on physical therapy evaluation and goals. Each session will last approximately 60 minutes with five minutes warm up and five minutes cool down, three to five times per week for six weeks.

All patients will be charged for physical therapy services provided, as these services are standard of care, but there will be no charge for the LSQ use.

Upon completion of the trial, if LSQ results in outcomes improvements, the control group will receive six weeks of physical therapy using LSQ. All licensed therapists who participate in this research completed the Collaborative Institutional Training Initiative (CITI) training.

Example of LSQ usage: Mr. Smith has been diagnosed with dementia and scores 15 (Mild Cognitive Impairment) on MMSE scale. His family has completed LSQ and submitted it to the facility. All Peach Tree Place employees have access to LSQ to facilitate patient care. Patient's LSQ mentioned that patient loves coffee, enjoys playing cards and likes everything about cars. This patient is always excited to come to therapy when physical and occupational therapists (clinicians) mention drinking coffee together. Once patient arrives in therapy room, the clinician plays different card games with this patient in standing, to improve standing tolerance, also use balance board to challenge standing balance and to facilitate functional mobility. The clinician talks about cars, shows variety of car magazines while working on leg exercises. So, this clinician used various information from LSQ for this patient to motivate and improve therapy participation.

Outcome Assessment:

1. Pittsburgh rehabilitation participation scale (Appendix B) – to measure participant's participation in physical therapy
2. Quality of life in Alzheimer's disease – participant's version (Appendix C) – to access quality of life in dementia participants

3. Cornell scale for depression in dementia (Appendix D) – to access depression symptoms in dementia participants

Data Analysis

Descriptive statistics (means, medians, modes, standard deviations, frequency counts, minimum and maximum values) will be calculated using Excel version 2017 and SPSS version 20 (IBM Corp. Released 2011. IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp.) for the subjects' characteristics including age, gender, marital status, education, severity of cognitive impairment (MMSE) and living with family prior to admission to the dementia facility and the dependent and relationship variables.

Inferential statistics: the following statistics will be calculated using Jamovi version 1.6.

Research Questions 1-3: Because the data are ordinal (Pittsburg Rehabilitation Participation Scale, Quality of Life Alzheimer Disease, CSDD), the Mann-Whitney U test will be used to assess differences between the intervention and control group.

Research Question 4: Because the data are ordinal (MMSE, Pittsburg Rehabilitation Participation Scale) Spearman Rank correlations will be used to determine the strength of the correlation between MMSE and Pittsburg Rehabilitation Participation Scale.

Alpha level will be set at $\alpha=.05$ for all analyses.

All statistical analyses will follow the intention-to-treat principle.

REFERENCES

1. Duong S, Patel T, Chang F. Dementia: What pharmacists need to know. *Can Pharm J (Ott)*. 2017 Feb 7;150(2):118-129.
2. Elfrink TR, Westerhof GJ, Zuidema SU, Kunz M. Life story books for people with dementia: a systematic review. *International Psychogeriatrics*. December 2018:1797-1811.
3. Alzheimer's Association. 2018 Alzheimer's disease facts and figures. *Alzheimer's & Dementia* 2018;14:367–429.
4. Arvanitakis Z, Bennett DA. What Is Dementia? *JAMA*. 2019;322(17):1728. doi:10.1001/jama.2019.11653.
5. Machiels M, Metzelthin SF, Hamers JP, Zwakhalen SM. Interventions to improve communication between people with dementia and nursing staff during daily nursing care: A systematic review. *Int J Nurs Stud*. 2017;66:3746.
6. Alsawy S, Mansell W, McEvoy P, Tai S. What is good communication for people living with dementia? A mixed-methods systematic review. *Int Psychogeriatr*. 2017;29(11):1785-1800.
7. Sari YM, Burton E, Lee D-CA, Hill KD. Current physiotherapy practice on delivering treatments for older people with dementia in Indonesia. A cross-sectional study. *Physiotherapy Research International*. 2022:17(1).
8. Hoel V, Feunou CM, Wolf-Ostermann K. Technology-driven solutions to prompt conversation, aid communication and support interaction for people with dementia and their caregivers: a systematic literature review. *BMC Geriatr*. 2021 Mar 4;21(1):157.
9. *J Am Geriatr Soc* 64: 15– 18, 2016.
10. Butler RN. The life review: an interpretation of reminiscence in the aged. *Psychiatry*. 1963;26:65-76.
11. McKeown, J., Clarke, A. and Repper, J. (2006). Life story work in health and social care: systematic literature review. *Journal of Advanced Nursing*, 55, 237–247. 0 reference copied from life story books for people with dementia
12. Woods B, O'Philbin L, Farrell EM, Spector AE, Orrell M. Reminiscence therapy for dementia. *Cochrane Database Syst Rev*. 2018 Mar 1;3(3).
13. Chiusano C, Zarit SH, Krause C, Sewell L, Harrison AS, Liu Y. Rehabilitation of persons living with dementia: Using technology to improve participation. *Alzheimer's & dementia*. 2020;16.
14. Lazar A, Demiris G, Thompson HJ. Evaluation of a multifunctional technology system in a memory care unit: Opportunities for innovation in dementia care. *Informatics for health & social care*. 2016;41(4):373-386.

15. O'shea E, Cooney A. The impact of life story work on person-centered care for people with dementia living in long-stay care setting in Ireland. *Dementia*.2019;18(7/8):2731-2746.
16. Rashid MH, Zahid MF, Zain S, Kabir A, Hassan SU. The Neuroprotective Effects of Exercises on Cognitive Decline: a Preventive Approach to Alzheimer Disease. *Cureus*. 2020;12(2).
17. Crocker T, Forster A, Young J, et al. Physical rehabilitation for older people in long-term care. *Cochrane database of systematic reviews*. 2013;(2).
18. Hall AJ, Burrows L, Lang IA, Endacott R, Goodwin VA. Are physiotherapists employing person-centered care for people with dementia? An exploratory qualitative study examining the experiences of people with dementia and their carers. *BMC geriatrics*. 2018;18(1):63.
19. Kales HC, Gitlin LN, Lyketsos CG; Detroit Expert Panel on Assessment and Management of Neuropsychiatric Symptoms of Dementia. Management of neuropsychiatric symptoms of dementia in clinical settings: recommendations from a multidisciplinary expert panel. *J Am Geriatr Soc*. 2014;62(4):762-769.
20. Kitching D. Depression in dementia. *Australian Prescriber*. 2015;38(6):209-211. Accessed August 26, 2022.
21. Burks HB, des Bordes JKA, Chadha R, Holmes HM, Rianon NJ. Quality of Life Assessment in Older Adults with Dementia: A Systematic Review. *Dementia and geriatric cognitive disorders*. 2021;50(2):103-110.
22. Creavin ST, Wisniewski S, Noel-Storr AH, et al. Mini-Mental State Examination (MMSE) for the detection of dementia in clinically unevaluated people aged 65 and over in community and primary care populations. *Cochrane database of systematic reviews*. 2016;(1).
23. Folstein MF, Folstein SE, McHugh PR. "Mini-Mental State": A Practical method for grading cognitive state of patients for the clinician. *Journal of Psychiatric research*. 1975;12(3):189-198.
24. <https://www.crisisprevention.com/Blog/Use-This-Life-Story-Questionnaire-for-More-Person>. Accessed August 28, 2015.
25. Lenze EJ, Mnin MC, Quear T, et al. The Pittsburgh rehabilitation participation scale:reliability and validity of a clinician-rated measure of participation in acute rehabilitation. *Archives of physical medicine and rehabilitation*. 2004;85(3):380-384.
26. Weyer G, Erzigkeit H, Kanowski S, Ihl R, Hadler D. Alzheimer's Disease Assessment Scale: Reliability and Validity in a Multicenter Clinical Trial. *International psychogeriatrics*. 1997;9(2):123-138.
27. Kørner A, Lauritzen L, Abelskov K, et al. The Geriatric Depression Scale and the Cornell Scale for Depression in Dementia. A validity study. *Nordic journal of psychiatry*. 2006;60(5):360-364.

28. Gbiri CAO, Amusa BF. Progressive task-oriented circuit training for cognition, physical functioning and societal participation in individuals with dementia. *Physiotherapy research international*.2020;25(4).
29. Asano T, Wang C-W, Tsugaru M, Ishikawa T. Effectiveness of high-frequency individual reminiscence interventions using life story books on person with dementia. *British Journal of Occupational therapy*. 2021;84(5):317-326.
30. Folstein MF, Folstein SE, McHugh PR. "Mini-Mental State": A Practical method for grading cognitive state of patients for the clinician. *Journal of Psychiatric research*. 1975;12(3):189-198.
31. <http://www.gpower.hhu.de/>, accessed XXXXXX
32. The jamovi project (2021). Jamovi (version 1.6) (computer software). Retrieved from <https://www.jamovi.org>

RESEARCH PROJECT TIMELINE

Submission to Texas Tech University IRB	January 2023
IRB Approval	March 2023
Prospective Trial Registration	March 2023
Trial Registration approved	May 2023
Data collection	May 2023 – September 2024
Data Analysis	October - November 2024
Writing	December 2024
Submit for publication	Spring 2025

APPENDIX A: Life Story Questionnaire

Professional Care Partners: Use this questionnaire to learn about the clients you work with. Complete one questionnaire with each client and/ or the client's loved ones. This great resource will provide you with helpful information as you get to know your clients and encourage their interests and abilities.

Family Care Partners: Use this questionnaire to help others learn about your loved one. Complete this questionnaire with your family member or on her behalf. With this valuable tool in hand, everyone who cares for your loved one will have the information they need to engage her likes and interests.

Background:

Full name _____

Does your name have a special significance?

Do you have a nickname?

Where did your nickname come from?

Where were you born?

What was your father's name?

Please describe your father.

What was your mother's name?

Please describe your mother.

Do you have brothers and/or sisters?

If yes, please describe your siblings.

Did you know your grandparents?

If yes, please describe your grandparents.

Where did you grow up?

Please describe the house you lived in.

What was your neighborhood like?

Who were your neighbors?

What games did you play?

Are/were you married?

If yes, please describe your spouse.

you have children and grandchildren?

If yes, please describe your children and grandchildren.

Daily Routine

What time do you like to get up in the morning?

Do you prefer to stay in your pajamas for a while?

Describe your routine after waking (e.g., brushing your teeth, doing your hair, dressing).

Do you prefer showers or baths?

At what time of day do you take a shower/bath?

Do you eat breakfast?

If yes, what do you like to eat for breakfast?

What's your typical lunch and afternoon routine?

Do you like to take naps?

Do you like a big meal at noon or in the evening?

Please describe your typical evening routine.

What time do you like to go to bed?

What hygiene products do you prefer?

Education Where did you go to school?

How did you get there?

What did you like about school?

Also ask questions about high school and college, if appropriate.

Work

What was your first paid job?

What kind of job was it?

What were your duties/responsibilities?

What were your accomplishments?

Leisure

What are your hobbies/interests?

What are your favorite movies/books?

Do you enjoy music? If yes, what kind?

Did you have pets? If so, what kind, and what were their names?

Are you afraid of or allergic to any pets?

Did you travel, and if so, where did you go?

What have been some special events in your life?

What's your favorite time of year?

Do you prefer solitary activities, small groups, or large groups?

Religion/Faith

Did you attend a place of worship?

Did you have a role in the services? If so, please describe.

How did you spend your day of worship?

Do you have a prayer book?

Emotional Needs What makes you feel happy?

What makes you feel safe?

What makes you feel sad?

Is there anything that helps you alleviate this feeling?

What makes you feel anxious, angry, or frustrated?

Is there anything that helps you alleviate these feelings?

Please describe your bedroom at home.

Please describe the room in your home where you relaxed.

Additional Information

Please note other important likes and interests.

APPENDIX B: PITTSBURGH REHABILITATION PARTICIPATION SCALE

Patient name: _____

Date: _____

Instructions to therapist: for each therapy session, please circle one of each of the following to assess the patient’s participation (effort and motivation as perceived by you) in the therapy session.

Please rate as follows:

None: patient refused entire session, or did not participate in any exercises in session. (see Note below)

Poor: patient refused or did not participate in at least half of session. **Fair:** patient participated in most or all of exercises*, but did not show maximal effort or finish most exercises*, or required much encouragement to finish exercises*.

Good: patient participated in all exercises* with good effort and finished most but not all exercises* and passively followed directions (rather than actively taking interest in exercises* and future therapy).

Very good: patient participated in all exercises* with maximal effort and finished all exercises, but passively followed directions (rather than actively taking interest in exercises* and future therapy).

Excellent: patient participated in all exercises* with maximal effort, finished all exercises*, and actively took interest in exercises* and/or future therapy sessions.

Note: if patient was unable to attend therapy because of medical test, bed rest order, illness, or scheduling conflict, do not mark any score. Note: in cases of doubt, choose the lower rating, eg, “good” rather than “very good.”

Participation:

Session Number	Date	Therapist Initials	None	Poor	Fair	Good	Very good	Excellent
1 – prior to intervention			1	2	3	4	5	6
2 – 3-week			1	2	3	4	5	6
3 – 6-week			1	2	3	4	5	6
4 – 6-week following end intervention			1	2	3	4	5	6

* This version is specifically for physical therapists. For the occupational therapy form, “exercises” should be replaced by “activities”.

Source: <https://www.sralab.org/sites/default/files/2017-06/PITTSBURGH%20REHABILITATION%20PARTICIPATION%20SCALE.pdf>

APPENDIX C: Quality of Life in Alzheimer's Disease Instruction for interviewers

The Quality of Life in Alzheimer's Disease (QOL-AD) is administered in interview format to individuals with dementia, following the instructions below. The interview is carried out with the subject and/or an informant. The subject should be interviewed alone. Hand the form to the participant, so that he or she may look at it as you give the following instructions (instructions should closely follow the wording given in bold type): **I want to ask you some questions about your quality of life and have you rate different aspects of your life using one of four words: poor, fair, good, or excellent.** Point to each word (poor, fair, good, and excellent) on the form as you say it. When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I'm going to ask you to rate each of these areas. We want to find out how you feel about your current situation in each area. If you're not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess. It is usually apparent whether an individual understands the questions, and most individuals who are able to communicate and respond to simple questions can understand the measure. If the participant answers all questions the same, or says something that indicates a lack of understanding, the interviewer is encouraged to clarify the question. However, under no circumstances should the interviewer suggest a specific response. Each of the four possible responses should be presented, and the participant should pick one of the four. If a participant is unable to choose a response to a particular item or items, this should be noted in the comments. If the participant is unable to comprehend and/or respond to two or more items, the testing may be discontinued, and this should be noted in the comments. As you read the items listed below, ask the participant to circle her/his response. If the participant has difficulty circling the word, you may ask her/him to point to the word or say the word, and you may circle it for him or her. You should let the participant hold his or her own copy of the measure, and follow along as you read each item.

1. **First of all, how do you feel about your physical health?** Would you say it's poor, fair, good, or excellent? Circle whichever word you think best describes your physical health right now.
2. **How do you feel about your energy level?** Do you think it is poor, fair, good, or excellent? If the participant says that some days are better than others, ask him or her to rate how she/he has been feeling most of the time lately.
3. **How has your mood been lately?** Have your spirits been good, or have you been feeling down? Would you rate your mood as poor, fair, good, or excellent?
4. **How about your living situation?** How do you feel about the place you live now? Would you say it's poor, fair, good, or excellent?
5. **How about your memory?** Would you say it is poor, fair, good, or excellent?

6. **How about your family and your relationship with family members?**
Would you describe it as poor, fair, good, or excellent? If the respondent says they have no family, ask about brothers, sisters, children, nieces, nephews.
7. **How do you feel about your marriage?** How is your relationship with (spouse’s name). Do you feel it’s poor, fair, good, or excellent? Some participants will be single, widowed, or divorced. When this is the case, ask how they feel about the person with whom they have the closest relationship, whether it’s a family member or friend. If there is a family caregiver, ask about their relationship with this person. If there is no one appropriate, or the participant is unsure, score the item as missing.
8. **How would you describe your current relationship with your friends?**
Would you say it’s poor, fair, good, or excellent? If the respondent answers that they have no friends, or all their friends have died, probe further. Do you have anyone you enjoy being with besides your family? Would you call that person a friend? If the respondent still says they have no friends, ask how do you feel about having no friends—poor, fair, good, or excellent?
9. **How do you feel about yourself?** —when you think of your whole self, and all the different things about you, would you say it’s poor, fair, good, or excellent?
10. **How do you feel about your ability to do things like chores around the house or other things you need to do?** Would you say it’s poor, fair, good, or excellent?
11. **How about your ability to do things for fun, that you enjoy?** Would you say it’s poor, fair, good, or excellent?
12. **How do you feel about your current situation with money, your financial situation?** Do you feel it’s poor, fair, good, or excellent? If the respondent hesitates, explain that you don’t want to know what their situation is (as in amount of money), just how they feel about it.
13. **How would you describe your life as a whole?** When you think about your life as a whole, everything together, how do you feel about your life? Would you say it’s poor, fair, good, or excellent?

Scoring instructions for QOL-AD:

Points are assigned to each item as follows: poor = 1, fair = 2, good = 3, excellent = 4. The total score is the sum of all 13 items.

Participant Last Name: _____ **First Name:** _____

Date: __/__/202__

QOL: Alzheimer Disease (Participant’s version)

Instruction:					Score
1. Physical health	Poor	Fair	Good	Excellent	

Dementia - Life Story Questionnaire – Physical Therapy

2. Energy	Poor	Fair	Good	Excellent	
3. Mood	Poor	Fair	Good	Excellent	
4. Living situation	Poor	Fair	Good	Excellent	
5. Memory	Poor	Fair	Good	Excellent	
6. Family	Poor	Fair	Good	Excellent	
7. Marriage	Poor	Fair	Good	Excellent	
8. Friends	Poor	Fair	Good	Excellent	
9. Self as a whole	Poor	Fair	Good	Excellent	
10. Ability to do chores around the house	Poor	Fair	Good	Excellent	
11. Ability to do things for fun	Poor	Fair	Good	Excellent	
12. Money	Poor	Fair	Good	Excellent	
13. Life as a whole	Poor	Fair	Good	Excellent	
Comments:					

Source: <https://www.cogsclub.org.uk/professionals/files/QOL-AD.pdf>

APPENDIXE D: Cornell Scale for Depression in Dementia

The scale is designed as a screening tool and is not diagnostic.

The Cornell Scale for Depression in Dementia (CSDD) was specifically developed to assess signs and symptoms of major depression in demented patients. Because some of these patients may give unreliable reports, the CSDD uses a comprehensive interviewing approach that derives information from the patient and the informant. Information is elicited through two semi-structured interviews; an interview of an informant and an interview of the patient. The interviewer should assign preliminary scores to each item of the scale on the basis of the informant's report in the "Informant" column. The next step is for the rater to interview the patient using the Cornell scale items as a guide. The interviews focus on depressive symptoms and signs occurring during the week preceding the interview. Many of the items during the patient interview can be filled after direct observation of the patient. If there are discrepancies in ratings from the informant and the patient interviews, the rater should re-interview both the informant and the patient with the goal to resolve the discrepancies. The final ratings of the CSDD items represent the rater's clinical impression rather than the responses of the informant or the patient. The CSDD takes approximately 20 minutes to administer.

Cornell Scale for Depression in Dementia

Participant Last Name: _____ First Name: _____

Date: __/__/202__

Scoring System:

- a = unable to evaluate 0
- = absent
- 1= mild or intermittent
- 2 = severe

Ratings should be based on symptoms and signs occurring during the week prior to interview. No score should be given if symptoms result from physical disability or illness.

A. Mood-Related Signs

- | | | | | |
|---|---|---|---|-------|
| 1. Anxiety | a | 0 | 1 | 2 |
| anxious expression, ruminations, worrying | | | | |
| 2. Sadness | a | 0 | 1 | 2 sad |
| expression, sad voice, tearfulness | | | | |
| 3. Lack of reactivity to pleasant events | a | 0 | 1 | 2 4. |
| Irritability | a | 0 | 1 | 2 |
| easily annoyed, short-tempered | | | | |

B. Behavioral Disturbance

- | | | | | |
|--|---|---|---|--------|
| 1. Agitation | a | 0 | 1 | 2 |
| restlessness, handwringing, hairpulling | | | | |
| 2. Retardation | a | 0 | 1 | 2 |
| slow movements, slow speech, slow reactions | | | | |
| 3. Multiple physical complaints | a | 0 | 1 | 2 |
| 4. Loss of interest | a | 0 | 1 | 2 less |
| involved in usual activities (score only if change occurred acutely, i.e.in less than 1 month) | | | | |

C. Physical Signs

- | | | | | |
|--|---|---|---|---|
| 1. Appetite loss | a | 0 | 1 | 2 |
| eating less than usual | | | | |
| 2. Weight loss | a | 0 | 1 | 2 |
| score 2 if greater than 5 lb. in one month | | | | |
| 3. Lack of energy | a | 0 | 1 | 2 |
| fatigues easily, unable to sustain activities (score only if change occurred acutely, i.e., in less than 1 month) continued on reverse | | | | |

D. Cyclic Functions

- | | | | | |
|-------------------------------|---|---|---|---|
| 1. Diurnal variation of mood | a | 0 | 1 | 2 |
| symptoms worse in the morning | | | | |

Dementia - Life Story Questionnaire – Physical Therapy

- | | | | | |
|--|---|---|---|---|
| 2. Difficulty falling asleep
later than usual for this individual | a | 0 | 1 | 2 |
| 3. Multiple awakenings during sleep | a | 0 | 1 | 2 |
| 4. Early-morning awakening
earlier than usual for this individual | a | 0 | 1 | 2 |

E. Ideational Disturbance

- | | | | | |
|--|---|---|---|---|
| 1. Suicide
feels life is not worth living, has suicidal wishes or makes suicide attempt | a | 0 | 1 | 2 |
| 2. Poor self-esteem
self-blame, self-depreciation, feelings of failure | a | 0 | 1 | 2 |
| 3. Pessimism
2 anticipation of the worst | a | 0 | 1 | 1 |
| 4. Mood-congruent delusions
2 delusions of poverty, illness or loss | a | 0 | 1 | 1 |

Scoring: A score >10 probably major depressive episode

A score >18 definite major depressive episode

Source:

Alexopoulos GA, Abrams RC, Young RC & Shamoian CA: Cornell scale for depression in dementia. Biol Psych, 1988, 23:271-284.

<https://dementiaresearch.org.au/wp-content/uploads/2016/06/CSDD.pdf>

APPENDIX E: Mini-Mental State Examination

Patient's Name: _____ **Date:** __/__/202__

Instruction: Ask the questions in the order listed. Score one point for each correct response within each question or activity.

Maximum score	Patient's Score	Questions
5		"What is the year? Season? Date? Day of the week? Month?"
5		"Where are now: state? Country? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats then until patient learns all of them, if possible. Number of trials:
5		"I would like you to count backward from 10- by sevens." (93,86,79,72, 65...) stop after five answers. Alternative: "spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: No ifs, ands, or buts."
3		Take the paper in your right hand, fold it in half, and put it on the floor." (the examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.) 
30		Total

Interpretation of MMSE Scores:

Score	Degree of Impairment	Formal Psychometric Assessment	Day-to-Day Functioning
24-30	Questionably significant	If clinical signs of cognitive impairment are present, formal assessment of cognition may be valuable.	May have clinically significant but mild deficits. Likely to affect only most demanding activities of daily living
19-23	Mild	Formal assessment may be helpful to better determine pattern and extent of deficits.	Significant effect. May require some supervision, support and assistance.
10-18	Moderate	Formal assessment may be helpful if there are specific clinical indications.	Clear impairment. May require 24hour supervision.
0-9	Severe	Patient not likely to be testable	Marked impairment. Likely to require 24-hour supervision and assistance with ADL.

Source:

Adapted from Folstein MF, Folstein SE, McHugh PR: "Mini-mental state: A practical method for grading the cognitive state of patients for the clinician." J Psychiatr Res 1975;12:189-198

APPENDIX F

PRE-SCREENING QUESTIONNAIRE

Patient: Last name: _____ First name: _____
Phone #: _____ Subject #: _____

1. **For Family Member:** Do you prefer to be contacted in regard to research study?
morning afternoon evening no preference

2. **For patient or Family member to answer depending on severity of cognitive impairment:** Are you interested to participate in a research project related to cognitive impairment disease and their participation in therapy in which patients will receive physical therapy service 5 days a week with or without use of Life story questionnaire? You will be selected for this study if you score >10 on MMSE which is a scale to measure cognitive impairments. There is no extra charge for this service. Yes /
No

3. Are you between the ages of 60 and 89 years old?
 - a. Yes
 - b. No

4. Can you speak English?
 - a. Yes
 - b. No

5. Are you deaf or blind?
 - a. Yes
 - b. No

<u>FRONT OFFICE USE ONLY</u>		
History of Psychiatric disorder:	Yes	No
Diagnosis of Dementia:	Yes	No Patient's
MMSE score between 10-23:	Yes No	
Patient referral for Physical Therapy:	Yes	No

CONSENT FORM

PATIENT CONSENT FORM

Effect of the Life Story Questionnaire on Physical Therapy Participation in Patients with Dementia: A Randomized Control Trial

What is this research studying?

This study will help us to investigate the effect of Life Story Questionnaire in physical therapy participation in people with milder forms of dementia. Communication, problem solving, impaired understanding and memory are common problems in people with dementia. This can affect quality of life, participation in activities and can eventually lead towards depression. The study is being done to see if using your Life Story Questionnaire during physical therapy will improve your participation and social life.

What would I do if I participate?

In this study, you will be asked to answer questions about your life experiences, cognitive ability, daily routine, religion/faith, leisure preferences, and quality of life. You will be randomly assigned to either receive the intervention during your physical therapy sessions (experimental group), or not receive the intervention during these sessions (control group). Both groups will receive individual exercises and tasks to improve activities of daily living and mobility, but only the experimental group will be given the Life Story Questionnaire (LSQ) which is a type of life story book that gathers information on preferences and lifestyle (e.g., coffee vs. tea, early bird vs. night owl). Family members of participants in both groups will be asked to complete this questionnaire prior to the start of participation. Upon completion of the intervention, if the LSQ results in improved outcomes, the control group will receive the LSQ for their next 6 weeks of physical therapy.

Can I quit if I become uncomfortable?

Yes, absolutely. Dr. Jonathan Singer and Texas Tech University's Institutional Review Board have reviewed this research project and think you can participate comfortably. However, you can skip parts of the research you are not comfortable with and stop at any time. You will keep all the benefits of participating even if you stop. Participating is your choice.

How long will participation take?

We are asking for 6 weeks of your time. You will attend 60-minute physical therapy sessions 2-5 times a week for the duration of this study.

How are you protecting privacy?

Your name will not be linked to any material in reports, publications or presentations. No one other than the researchers associated with this project will have access to the raw data. All related documentation will be stored in the researcher's locked office **and** on a password protected computer.

Dementia - Life Story Questionnaire – Physical Therapy

What will happen to my data?

Your information collected as part of the research, even if identifiers are removed, will not be used or distributed for future research studies.

What are the benefits and risks of participating in this research?

There are no known risks other than soreness during or after physical therapy treatment. There are no direct benefits for participating in this research. We appreciate your time and effort with this research study.

I have some questions about this study. Who can I ask?

The study is being run by Dr. Jonathan Singer from the Department of Psychological Sciences at Texas Tech University and Megha Shah from Peach Tree Place. If you have questions, you can call them at 770-241-4526.

Texas Tech University also has an Institutional Review Board that protects the rights of people who participate in research. You can contact them at 806-742-2064 or hrpp@ttu.edu.

Signature of Participant

Date

Printed Name of Participant

FAMILY CONSENT FORM

Effect of the Life Story Questionnaire on Physical Therapy Participation in Patients with Dementia: A Randomized Control Trial

What is this research studying?

This study will help us to investigate the effect of Life Story Questionnaire in physical therapy participation in people with milder forms of dementia. Communication, problem solving, impaired understanding and memory are common problems in people with dementia. This can affect quality of life, participation in activities and can eventually lead towards depression. The study is being done to see if using your Life Story Questionnaire during physical therapy will improve your participation and social life.

What would I do if I participate?

In this study, your family member will be asked to answer questions about their life experiences, cognitive ability, daily routine, religion/faith, leisure preferences, and quality of life. They will be randomly assigned to either receive the intervention during their physical therapy sessions (experimental group), or not receive the intervention during these sessions (control group). Both groups will receive individual exercises and tasks to improve activities of daily living and mobility, but only the experimental group will be given the Life Story Questionnaire (LSQ) which is a type of life story book that gathers information on preferences and lifestyle (e.g., coffee vs. tea, early bird vs. night owl). You, a family member of a participant in either the experimental or control group, will be asked to complete the LSQ about your loved one prior to the start of their participation. Upon completion of the intervention, if the LSQ results in improved outcomes, the control group will receive the LSQ for their next 6 weeks of physical therapy.

Can I quit if I become uncomfortable?

Yes, absolutely. Dr. Jonathan Singer and Texas Tech University's Institutional Review Board have reviewed this research project and think you can participate comfortably. However, you can skip parts of the research you are not comfortable with and stop at any time. You will keep all the benefits of participating even if you stop. Participating is your choice.

How long will participation take?

We are asking for about an hour of your time. This may vary depending on how in-depth you want to go with the LSQ. Your family member will be in the study for about 6 weeks and will attend 60-minute physical therapy sessions 2-5 times a week.

How are you protecting privacy?

Your name will not be linked to any material in reports, publications or presentations. No one other than the researchers associated with this project will have access to the raw data. All related documentation will be stored in the researcher's locked office **and** on a password protected computer.

What will happen to my data?

Dementia - Life Story Questionnaire – Physical Therapy

Your information collected as part of the research, even if identifiers are removed, will not be used or distributed for future research studies.

What are the benefits and risks of participating in this research?

There are no known risks other than soreness during or after physical therapy treatment. There are no direct benefits for participating in this research. We appreciate your time and effort with this research study.

I have some questions about this study. Who can I ask?

The study is being run by Dr. Jonathan Singer from the Department of Psychological Sciences at Texas Tech University and Megha Shah from Peach Tree Place. If you have questions, you can call them at 770-241-4526

Texas Tech University also has an Institutional Review Board that protects the rights of people who participate in research. You can contact them at 806-742-2064 or hrpp@ttu.edu.

Signature of Family Member Participant

Date

Printed Name of Family Member Participant

Please check this box and sign below if acting as the Legally Authorized Representative of the participant

Signature of Family Member on behalf of Physical Therapy Participant

Date

Printed Name of Physical Therapy Participant