2023

THE PERCEPTIONS OF PEOPLE WITH DEMENTIA, CARE PARTNERS, CNAs/SITTERS, AND PROVIDERS DURING THE COVID-19 PANDEMIC UP TO NOW: A MULTIPLE CASE STUDY

Gaudensia Awuor
The University of Texas at Tyler

Recommended Citation

Awuor, Gaudensia, "THE PERCEPTIONS OF PEOPLE WITH DEMENTIA, CARE PARTNERS, CNAs/SITTERS, AND PROVIDERS DURING THE COVID-19 PANDEMIC UP TO NOW: A MULTIPLE CASE STUDY" (2023). *Nursing Theses and Dissertations.* Paper 138.
http://hdl.handle.net/10950/4250

THE PERCEPTIONS OF PEOPLE WITH DEMENTIA, CARE PARTNERS, CNAs/SITTERS, AND PROVIDERS DURING THE COVID-19 PANDEMIC UP TO NOW: A MULTIPLE CASE STUDY

by

GAUDENSIA AWUOR, RN, APRN, FNP-C

A dissertation submitted in partial fulfillment of
the requirements for the degree of
Doctor of Philosophy
Nursing

Beth Mastel-Smith, Ph.D. RN, Committee Chair

School of Nursing

The University of Texas at Tyler
July 2023

This is to certify that the Doctoral Dissertation of

GAUDENSIA AWUOR

has been approved for the dissertation requirement on

July 10, 2023

for the Doctor of Philosophy in Nursing degree

Approvals:

DocuSigned by:
Beth Mastel-Smith
2AA955E90ECA4F3...
Dissertation Chair: Beth Mastel-Smith, Ph.D.

DocuSigned by:
Melinda Hermanns
B4984A0CC808455...
Member: Melinda Hermanns, Ph.D.

DocuSigned by:
Michelle Kimzey
32C3D08835ED496
Member: Michelle Kimzey, Ph.D.

DocuSigned by:
Jenifer Chilton
5B66005C28BE43A...
Chair, Department of Nursing: Jenifer Chilton, Ph.D.

DocuSigned by:
Barbara Haas
985A922F3BF54C7...
Dean, School of Nursing: Barbara Haas, Ph.D.

Dedication

I dedicate this dissertation and my entire journey to God almighty for His love and mercy because without Him, I would not be where I am today. To my late father Mr. Fabian Nicholas Kirario Achilla, thank you baba for your dedication and love for education. You gave me a vision that you never had, and I will cherish you forever. May your soul continue resting in peace and let perpetual light shine upon you.

To my family and friends especially my children Joseph and John Paul, thank you for being by my side from day one and being my greatest cheerleaders. I love you all. To my brother John Nyandenje Achilla, thank you for keeping me going when I had no strength to continue. To my best friend Maureen Osanjo (Yuyu), I will never have enough ways to pay you for the sacrifices you made to see me successful. Thank you from the bottom of my heart. Lastly, I want to appreciate Dr. Osato Osemwengie for the love and support. I hope I can follow in your footsteps and make a change in the world like you have. I love you sweetheart.

ACKNOWLEDGEMENT

I would like to express my sincere gratitude to the outstanding faculty at The University of Texas at Tyler, School of Nursing for their dedication and their love for nursing and research to ensure that every student that is a product of this program emerges as a great scholar. I want to thank Dr. Ellen Fineout-Overholt for her support and knowledge on how to write and publish a paper. That wealth of knowledge will go a long way. To Dr. Barbara McAlister, Dr. Belinda Deal, and Dr. Danita Alfred, thank you for organizing the PhD resources and offering weekly meetings to ensure that we never fell off track especially during the summer.

I want to thank my cohort and fellow nurse practitioner Dr. Kathy Cox. Thank you for your encouragement and for taking extra time in your busy schedule even as we studied to edit my papers. I truly appreciate your love and support. Special dedication and a big thank you to one of the pioneers of the PhD program at UT Tyler Dr. Lynn Wieck for editing the proposal and establishing the yard stick for best qualitative research knowledge. Please know that your feedback and contribution was truly appreciated.

I want to acknowledge my dissertation committee members, Dr. Melinda Hermanns and Dr. Michelle Kimzey. I am grateful for your support, expertise, time, and the wealth of knowledge that you contributed towards my work.

Lastly, I must acknowledge Dr. Beth Mastel-Smith. You are the GOAT (Greatest of All Times). Your love, dedication, and passion for research is unmatched. You have guided my learning and became a key player in shaping my future as a scholar and a nurse scientist. You challenged me, you encouraged me, you supported me, and never quit on me till we reached the finish line. The journey has not been easy, but the end results brought so much joy. Thank you for being my maid of honor that saw me getting married to the world of research. To say I cannot thank you enough is an understatement, but truly know that I immensely appreciate your wealth of knowledge and support yesterday, today, tomorrow, and forever.

I am very grateful to all those who have contributed to the successful completion of this dissertation, and I hope to be an inspiration for others who have lost hope. Specifically, to the girls from my small village in Kigoto Kenya some of whom were given away for marriage at a young age due to poverty and never reached their maximum potential in education.

Table Of Contents

List Of Tables 5

List Of Figures 6

Abstract 7

Chapter 1 9

The Perceptions Of People With Dementia, Care Partners, CNAs/Sitters, and Providers During the COVID-19 Pandemic Up To Now: A Multiple Case Study. 9

- Purpose Statement 10
- Background and Significance 10
- Theoretical Model 11
- Research Questions 13
- Definition Of Terms 13
- Summary 14

Chapter 2: LITERATURE REVIEW 15

- The COVID-19 Pandemic 15
- COVID-19 Effects On People With Dementia 18
  - Physical Effects On People With Dementia 18
  - Psycho-emotional Effects On People With Dementia *19*
  - Social Effects On People With Dementia *20*
- COVID-19 Effects On Care Partners Of People With Dementia 20
  - Physical Effects On Care Partners Of People With Dementia. *20*
  - Psycho-emotional Effects On Care Partners Of People With Dementia *21*
  - Social Effects On Care Partners Of People With Dementia. *22*
  - Provider Perceptions, Experiences and Challenges *22*
- Summary 23

Chapter 3: METHODS 25

- Design ... 25
- Sample ... 26
- Setting ... 27
- Protection Of Human Subjects ... 28
- Data Collection ... 29
- Data Analysis ... 30
- Procedures To Enhance Rigor ... 30
- Summary ... 31

Chapter 4: FINDINGS ... 33

- Health Effects Of COVID-19 ... 37
- Psycho-emotional Effects ... 38
  - Worry And Anxiety ... *39*
  - Care Partner Burnout and Stress ... *40*
  - Loneliness and Depression ... *41*
  - Fear ... *41*
  - Confusion and Behavioral and Psychological Symptoms Of Dementia ... *42*
- Social Isolation and Decreased Social Interaction, and Community Engagement ... 44
- Care Provision ... 45
  - Provider Visits ... *45*
  - Assessment and Diagnosis ... *47*
  - Provider Patient Relationship ... *48*
  - CNA Care ... *49*
- Protective Measures ... 50
- Up To Date ... 51
  - Vaccines ... *52*
  - Life Is Back To Normal ... *53*
- Unexpected Findings ... 54
  - Lack Of Resources and Supplies and Increased Cost Of Living ... *54*
  - Care Partner and CNA Work Burden ... *55*

Chapter 5: DISCUSSION AND SUMMARY ... 57

Health Effects 58
Psycho-emotional Effects 58
Social Isolation and Decreased Social Interaction and Community Engagement 60
Care Provision 60
  Providers *61*
  CNA Care *62*
Protective Measures 62
Up To Date 63
  Vaccines *63*
  Life Is Back To Normal *64*
Unexpected Findings 64
Strength and Limitations 65
Future Research and Practice Recommendations 65
Summary and Conclusions 68

References 70

Appendix A: Recruitment Flyer 83

Appendix B: Demographic Survey-People With Dementia 84

Appendix C: Demographic Survey-CNAs/Sitters 87

Appendix D: Demographic Survey-Providers 89

Appendix E: Demographic Survey-Care Partners 90

Appendix F: Semi-Structured Interview Guide: People With Dementia 93

Appendix G: Semi-Structured Interview Guide: Care Partners 94

Appendix H: Semi-Structured Interview Guide: CNAs/Sitters, And Providers 95

Appendix I: IRB Approval Letter 96

Appendix I Continued 97

Appendix I Continued 98

Appendix J: Approved Consent Form 99

Appendix J Continued.. 100

Appendix K: Permission To Reuse The Need-Driven Dementia-compromised Behavior Model 101

Appendix K Continued 102

Appendix L: Biographical Sketch... 103

LIST OF TABLES

Table 1: Timeline For The COVID-19 Pandemic Sequence.. 16
Table 2: Descriptive Statistics For People With Dementia.. 33
Table 3: Descriptive Statitiscs For Care Partners 35
Table 4: Descriptive Statistics For CNAs/Sitters.. 36
Table 5: Descriptive Statistics For Providers... 37

LIST OF FIGURES

Figure 1: Need-driven Dementia-compromised Behavior Model. 12

Abstract

THE PERCEPTIONS OF PEOPLE WITH DEMENTIA, CARE PARTNERS, CNAs/SITTERS, AND PROVIDERS DURING THE COVID-19 PANDEMIC UP TO NOW: A MULTIPLE CASE STUDY

Gaudensia Awuor

Dissertation Chair: Dr. Beth Mastel-Smith

The University of Texas at Tyler

July 2023

The perceptions of people with dementia, care partners, CNAs/sitters, and providers during the COVID-19 pandemic until now can be useful in formulating better ways to care for people with dementia in future disasters or pandemics. The study explored the perceptions of people with dementia, care partners, CNAs/sitters, and providers during the COVID-19 pandemic, from onset until now, to help formulate better ways to care for people with dementia during a pandemic or disaster. Algase's Need-driven Dementia-compromised Behavior Model guided this comparative, multiple-case study. Six people with dementia, six care partners, five CNAs and one sitter, and six providers were interviewed to gather their perceptions during the COVID-19 pandemic up to now. Findings supported theoretical propositions the four proximal factors: unmet physiological and psychosocial needs and changes in the physical and social environments led to behavioral and psychological symptoms of dementia and might have contributed to care partner burnout. The Need-driven Dementia-compromised Behavior Model provides a foundation for identifying the needs of people with dementia, future research, practice and policy changes during a health or natural disaster.

Keywords: People with dementia; care partners; Certified Nursing Assistants; sitters; providers; COVID-19 Pandemic; *Multiple case study; perceptions, Need-driven Dementia-compromised Behavior Model*

Chapter 1

The Perceptions of people with dementia, care partners, CNAs/sitters, and providers during the COVID-19 pandemic up to now: A multiple case study.

Dementia is a chronic progressive syndrome characterized by cognitive impairment, mood changes, behavior, and lack of emotional control, and motivation (World Health Organization [WHO], 2022). Comprehension, memory, orientation, language, learning capacity, and judgment are also affected (WHO, 2022). Dementia leads to increasing dependency on care partners and healthcare professionals (WHO, 2021). Daily experiences for people with dementia, care partners, and certified nursing assistants (CNA)/sitters worsened with the continuing COVID-19 pandemic.

The COVID-19 virus also known as coronavirus 2 (SARS-CoV-2) spread across the globe infecting people of all ages and affecting more people with disabilities, including people with dementia, compared with people without disability. (WHO, 2020a). Countries worldwide implemented travel bans and isolation protocols, including social distancing, to maintain public safety. People with dementia and their care partners experienced limited support from family members and the community, felt stressed and unsupported while coping with day-to-day activities, and had increased anxiety (Roach et al., 2020). Care partners experienced increased responsibilities and declining mood because of social restrictions (Pentecost et al., 2022). CNAs reported significant exposure to COVID-19 along with emotional and financial strain due to the pandemic (Ecker et al., 2021). Health care providers also reported barriers to dementia care during lockdown (Banerjee et al., 2021). The unexpected and multifaceted intrusion of a pandemic contributed to the already-challenging lives of persons with dementia and their caregivers. No previous studies were identified which examined the pandemic's effect from the perspective of the person with dementia, care partners, CNAs/sitters, and providers.

Purpose Statement

The purpose of this study was to understand the perceptions of people with dementia, care partners, CNAs/sitters, and providers during the COVID-19 pandemic, from onset until now, to help formulate better ways to care for people with dementia during a pandemic or disaster.

Background and Significance

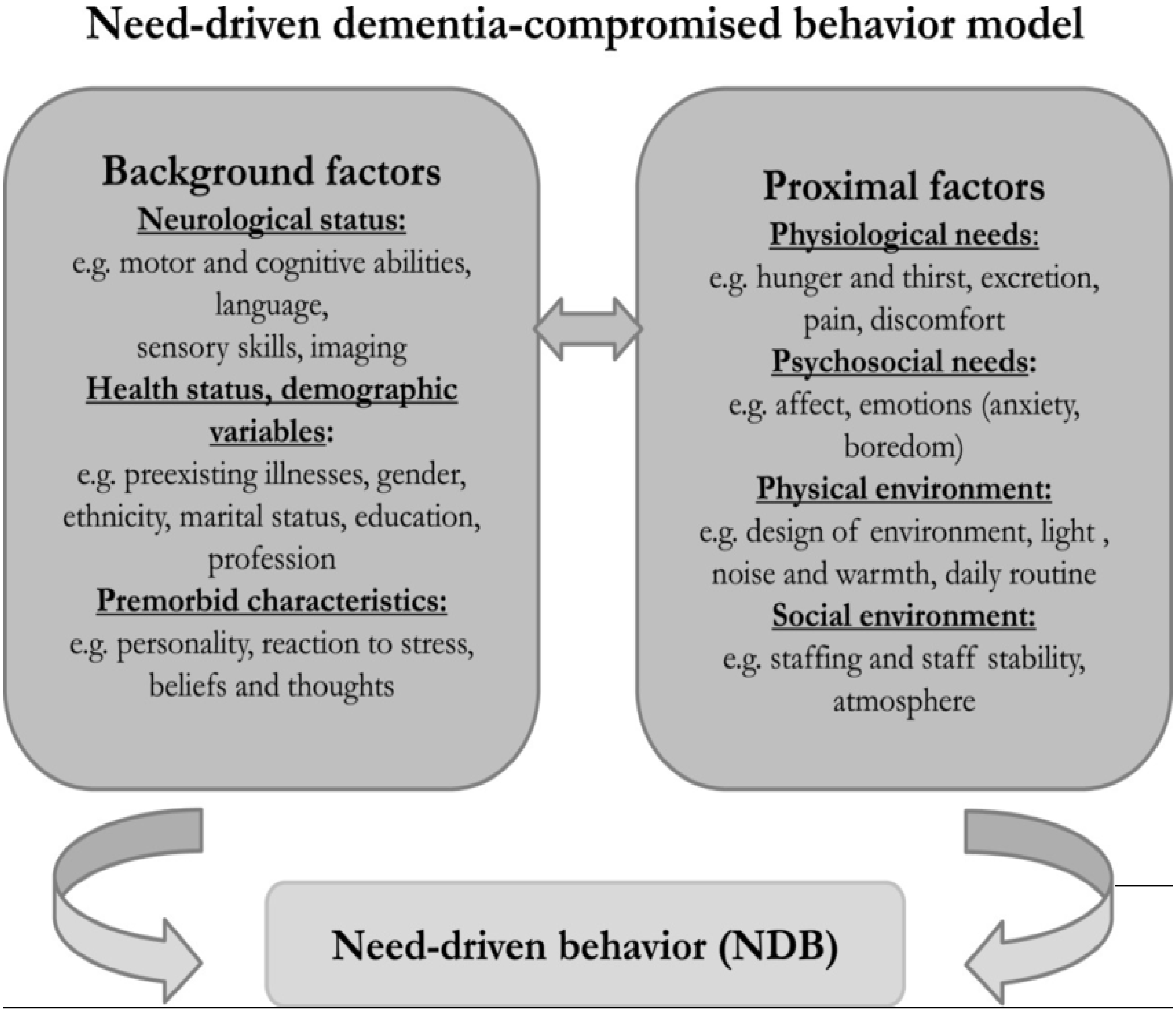
The World Health Organization (2021) projected that the total number of people with dementia worldwide will reach 82 million by 2030 and 152 million by 2050. Currently, the affected population is 50 million people, of whom 60% live in low to middle-income countries (WHO, 2020b). Individuals with dementia were more vulnerable to COVID-19 due to their age, multiple morbidities, and difficulty in maintaining social distancing (Lee et al., 2021; Livingston et al., 2020). People with dementia were disproportionally affected by the pandemic because there were no care plans in place and no educational materials or information for care partners or mechanisms for CNAs/sitters or providers to deliver holistic care (Numbers & Brodaty, 2021). As a result, people with dementia experienced high mortality (Matias-Guiu et al., 2020), and care partners experienced extreme physical and psychological burnout (Cohen et al., 2020a). Quality of life amongst people with dementia and care partners deteriorated during the COVID-19 pandemic (Daley et al., 2022; Livingston et al., 2020). The COVID-19 pandemic led to social isolation prompting increased behavioral and psychological symptoms amongst people with dementia (Azevedo et al., 2021; Kuroda et al., 2022; Portacolone et al., 2021; Talbot et al., 2021). There was a lack of alternative care options such as activity centers or daycares, which was associated with increased depression, anxiety, stress, and burnout in people with dementia and care partners (O'Shea, 2020). One qualitative study presented physician experiences and perceptions focusing on the challenges of caring for people with dementia during the pandemic in India (Banerjee et al., 2021). No previous studies were identified which examined the pandemic's effect from the perspective of the person with dementia, care partners, CNAs/sitters, and providers.

Theoretical Model

The study was guided by Algase's Need-driven Dementia-compromised Behavior Model NDB) Model (Algase et al., 1996), Figure 1. The Model suggests that challenging behaviors experienced by people with dementia result from unmet needs which cannot be communicated directly due to the individual's cognitive status. The model focuses on two factors: (1) Background and (2) Proximal factors. Background factors are those that cannot be changed whereas Proximal factors can be modified to reduce behavioral and psychological symptoms of dementia (BPSDs).

Theoretical propositions suggest that Background and /or Proximal factors have the potential to independently or together cause BPSDs. Background factors focus on three major areas including neurological status (e.g., motor, and cognitive abilities, language, sensory skills, and imaging), health status and demographic variables (e.g., preexisting illnesses, gender, ethnicity, marital status, education, profession), and premorbid characteristics (e.g., personality, reaction to stress, belief, and thoughts). Proximal factors, on the other hand, focus on four areas: Physiological needs (e.g., hunger and thirst, excretion, pain, discomfort), psychosocial needs (e.g., affect, emotions like anxiety or boredom), physical environment (e.g., design of environment, light, noise and warmth, daily routine), and social environment (e.g., staffing, staff stability, atmosphere). For this study, Background and Proximal factors experienced by people with dementia and their relationship with BPSDs during COVID-19 were examined.

Figure 1



Need-Driven Dementia-compromised Behavior Model.

Reprinted from Need-driven Dementia-compromised Behavior: An Alternative View of Disruptive Behavior by D. Algase, C. Beck, A. Kolanowski, S. Berent, K. Richards, & E. Beattie, E., 1996, *American Journal of Alzheimer's Disease & Other Dementia, 11*(10), 10-19. https://doi.org/10.1177/153331759601100603. CC BY 4.0. Used with permission (see Appendix K).

Research Questions

1.What was it like to live with dementia during the COVID-19 pandemic?

2.What was it like to care for a family member with dementia during the COVID-19 pandemic?

3.What were CNAs/sitters' perceptions regarding caring for people with dementia during COVID-19 pandemic?

4. What were care providers' perceptions of caring for people with dementia during the COVID-19 pandemic?

Definition of Terms

1. **People with dementia:** Individuals with a collection of symptoms caused by several disorders which significantly impairs intellectual functioning and interferes with normal activities and relationships including the ability to solve problems and maintain emotional control, personality changes and behavioral problems, such as agitation, delusions, and hallucinations (https://www.dementiasociety.org/definitions). For this study, self-report of a dementia diagnosis met eligibility criteria.
2. **Care partner:** Family caregiver or friend who provided unpaid care to a person with dementia (https://www.lawinsider.com/dictionary/family-caregiver) for at least five hours per week during the COVID-19 pandemic. The care partner might have or might not have lived with the person with dementia or be directly related.
3. **Certified Nursing Assistant (CNA, commonly referred to as Nurse's Aide, Patient Care Assistant, Nursing Assistant):** A certified personnel who is paid to help with activities of daily living and other healthcare needs under the direct supervision of a Registered Nurse (RN) or Licensed Practical Nurse (LPN).

4. **Sitter:** An individual who is paid to stay with a person with dementia either for companionship or for light duties including housekeeping and running errands but has no certification.
5. **Provider:** Providers included doctor of medicine or osteopathic medicine, an advanced registered nurse practitioner or physician assistant who is licensed to practice medicine according to the statutes of the state in which they are licensed. (https://www.lawinsider.com/dictionary/doctor-of-medicine-or-osteopathic-medicine).
6. **COVID-19:** "The COVID-19 pandemic was a global outbreak of coronavirus, an infectious disease caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) virus" (WHO, 2020, p.1).

Summary

Chapter One presented the background and significance of dementia and general effects of COVID-19 on people with dementia, their care partners, CNAs/sitters, and providers. The purpose statement proposed to explore perceptions of people with dementia, care partners, CNAs/sitters, and providers during the COVID-19 pandemic until now within the context of the Need-driven Dementia compromised Behavior Model. The research questions for the study provided a framework for the literature review exploring empirical evidence about the impact of COVID-19 on people with dementia, care partners, CNAs/sitters, and providers during COVID-19 pandemic.

Chapter 2

Literature Review

A broad review of pertinent literature was undertaken to lay a foundation for exploring the physical, psycho-emotional, and social effects of COVID-19 with a particular emphasis on people with dementia and the persons who strive to help them achieve an optimal state while living with a progressive neurological condition. Databases searched included PubMed, the Cumulative Index of Nursing and Allied Health Literature (CINAHL), Medline Ovid, ProQuest, and Google Scholar. Keywords included dementia, care partners, providers, CNAs/sitters, COVID-19 pandemic, physical effects, psychosocial effects, and psychological effects. The articles ranged from level I-VI, and publications were limited to articles in English published between 2020-2022. Twenty-eight articles examined care partners' perceptions; the experiences of care partners and people with dementia were reported in 10 articles and various sample populations were included in the remaining nine studies. No literature was located that described CNAs'/sitters' perceptions of caring for people with dementia during the pandemic. The literature review therefore focused on people with dementia and care partners living in the community as well as providers during the COVID-19 pandemic.

The COVID-19 Pandemic

The COVID-19 pandemic started in the Wuhan Province of China where the SARS-COV-2 virus was discovered in December 2019. The WHO declared it a global pandemic on March 11, 2020 (WHO, 2020a). The US encountered its first case in the California Bay Area around March of 2020. Since then, the COVID-19 pandemic had spread across nations infecting people of all ages and affecting more people with disabilities like people with dementia (WHO, 2020a). The global chaos surrounding COVID-19 changed everyday life and affected millions of people. The ensuing adaptations and challenges were disruptive, but the impact of COVID-19 on persons with physical and mental health issues has had a devastating effect that continues to this day. Table 1 shows a timeline of events that occurred since the pandemic emerged.

Table 1

Timeline for the COVID-19 Pandemic Sequence

Month/Year	Sequence of events
December 2019	COVID-19 confirmed in Wuhan, China. A new pneumonia-like illness.
February 2020	Cases of COVID-19 spread across the globe.
March2020	WHO declares COVID-19 a pandemic. The first case in the United States was confirmed in the Bay Area of California.
April 2020	Cases continue to surge. Countries implement full lockdown, social distancing, and mandatory mask-wearing. Schools and businesses close.
May 2020	Research on ways to flatten the curve, find treatments, and develop vaccine underway.
June 2020	New cases emerge. Surge of COVID-19 virus.
July 2020	Job losses took a toll. Debates on how to implement safe returns for children to school in the fall.
August 2020	The first documented reinfection reported in Hong Kong. COVID-19 declared third leading cause of death in the United States after heart disease and cancer.
September 2020	Schools reopen, adaptions to in person, remote, and hybrid schooling models.
October 2020	The Federal Drug Administration (FDA) grants full approval to remdesivir as the first drug for treatment of COVID-19.
November 2020	Cases arise due to cold weather and more indoor activities.
December 2020	FDA grants first emergency use authorization for two vaccines (Pfizer and Moderna).

January 2021	The number of COVID-19 cases and deaths began to fall. More variants emerged (Beta, Delta, Alpha, and Gamma).
February 2021	Vaccine supply deficit. Third vaccine (Johnson and Johnson) approved to meet demand. Mask mandate lifted.
March 2021	The mask mandate expired.
December 2021	Centers for Disease Control (CDC) shortened the recommended time for isolations to five (5) days and wearing a mask when around others.
January 2022	A total of 68% Americans are fully vaccinated. Death rates and infection rates have dropped tremendously. Near normalization of activities.
February 2022	CDC release data showing vaccine boosters remains safe. Delta variant surges for everyone age 5 years and older.
March 2022	WHO data showing that the COVID-19 triggered a 25% increase in anxiety and depression worldwide with young people and women at the highest risk. More than 10 billion people received a COVID-19 vaccine with 10,704,043,684 COVID-19 vaccines administered worldwide.
April 2022	Termination of Title 42 by CDC, an order that suspended the right to introduce migrants into the United States due to the public health risk of COVID-19.
May 2022	The number of recorded deaths due to COVID-19 in the United States reached 1 million (1,000,000).
June 2022	The United States recorded a total of 84,145,569 COVID-19 infections and 1,003,571 deaths from COVID-19. The global market to N95 is predicted to reach $11.8 billion by 2026.
July 2022	CDC data showed that the Omicron subvariants BA.4 and BA.5 are now dominant in the United States Making up over 70% of new COVID-19 infection.
August 2022	CDC streamlined COVID-19 guidance to help the public better protect themselves and understand their risks.
September 2022	CDC publishes strategies to mitigate healthcare personnel staffing shortages.

December 2022	WHO reported over 13.7 million cases and over 40,000 new fatalities globally-a 36% increase and 2% decline, respectively compared to statistics for November 2022.
January 2023	President Biden administration extended COVID-19 public health emergency for 90 days.
February 2023	WHO data showed over 757 million confirmed cases and over 6.8 million deaths reported globally.
June 2023-present	COVID-19 rule waiver expired for all healthcare professionals as announced by President Biden.

COVID-19 Effects on People with Dementia

Physical Effects on People with Dementia

COVID-19 posed unique challenges for people with dementia. Deteriorating cognitive function and behavioral and psychological symptoms left people with dementia at higher risk of severe COVID-19 infection (Livingston et al., 2020) because of frailty and medical vulnerability (Keng et al., 2020). In addition, people with dementia had difficulty participating in screening and following prevention instructions such as physical distancing (Keng et al., 2020). Yang et al. (2021) conducted a meta-analysis of 34 studies conducted internationally and concluded that people with dementia had a significantly greater risk for mortality compared to people without a dementia diagnosis (Yang et al., 2021).

The Algase et al. (1996) Need-driven Model suggests that physiologic needs and the environment are Proximal Factors, are modifiable, and thus vulnerable to disruption, such as a pandemic. COVID-19 has had lasting negative physical effects on people with dementia. People with dementia experienced disruptions in sleep (Azevedo et al., 2021), gait and mobility (Cohen et al., 2020a), and decreased physical health (Rusowicz et al., 2021; Tsapanou et al., 2021). In a systematic review involving 15 peer-reviewed articles, Suarez-Gonzalez et al. (2021) concluded that people with dementia experienced functional decline during the pandemic.

Psycho-emotional Effects on People with Dementia

The COVID-19 pandemic had negative psycho-emotional effects on people with dementia who experienced depressed mood, sadness, and mood disorder (Azevedo et al., 2021; Carpinelli et al., 2020; Cohen et al., 2020b); and increased anxiety and fear (Giebel et al., 2020b; Portacolone et al., 2021; Suarez Gonzalez et al., 2021). Maintaining a steady and calming environment is a continuing challenge in dementia care, and the lockdown led to increased incidents of hallucinations, delusions, delirium (Sorbara et al., 2021; Tsapanou et al., 2021), agitation (Rajagopal et al., 2021; Sorbara et al., 2021), obsessive behavior, aggression, and irritability (Azevedo et al., 2021; Pongan et al., 2021), and wandering (Tsapanou et al., 2021). People with dementia also reported reduced meaning and purpose in life during COVID-19 (Talbot et al., 2021) Disruption of schedules can have a profound effect on persons with confusion and dementia. Porock et al. (2015) found that disruptions adversely affected the person with dementia triggering disengaged and distressed behaviors. During the pandemic, everything from short supplies of common products like toilet paper to limitations to going to outdoor venues for daily activities led to a destabilization of the usual routine and contributed to the disruptions of psycho-emotional health of people with dementia. Limitations and disruptions also affected their ability to optimize their social interactions.

Dealing with the ramifications of a lockdown and movement restrictions also increased medication adjustments (Cohen et al., 2020a; Cohen et al., 2020b). Psychotropic medication use increased during quarantine, independently of the dementia severity, "Family members reported an overall increased use of psychotropic medication during the pandemic with the following distribution: 20% increased for antipsychotics, 15% for benzodiazepines, 6% for hypnotics, and 10% for antidepressants" (Cohen et al., 2020a, p.4).

Social effects on People with Dementia

One of the most insidious perils of the COVID-19 pandemic was the negative social effects on people of all ages. This problem was particularly relevant for people with dementia who reported increased loneliness (Azevedo et al., 2021; Talbot et al., 2021), decreased social interaction (Cohen et al., 2020b; Talbot et al., 2021), increased social isolation (Portacolone et al., 2021), and decreased social support (Giebel et al., 2020a). Feelings of security and social interactions were also compromised by COVID-19 as persons with dementia manifested confusion, despair, and abandonment (Bascu et al., 2021a). Lack of interactions with others decreased communication abilities (Talbot et al., 2021; Tsapanou et al., 2020) as routine activity engagement declined (Talbot et al., 2021) and inside activity participation increased (Rajagopal et al., 2021; Sanchez-Teruel., 2021). The Algase et al. (1996) Need-driven Model projects that instability of assistive staff along with altered emotions and environment can lead to need-driven behaviors. Humans are social beings, and the restrictions and dangers of COVID-19 sorely tested the ability to engage in meaningful and sustaining social interactions for people with dementia and those who provided care for them.

COVID 19 Effects on Care Partners of People with Dementia

Physical effects on Care Partners of People with Dementia.

COVID-19 had negative physical effects on care partners of people with dementia. Care partners reported overall decreased physical health (Rusowicz et al., 2021). In addition, care partners experienced an increase in sleep problems, tiredness, and fatigue (Wong et al., 2021) as well as decreased self-care (West et al., 2021). Applying the Algase et al. (1996) Need-driven

Model, it can be assumed that erratic need-driven behaviors by a care recipient would add to the tiredness, fatigue, sleeplessness, and self-care deficits reported by the care partners.

Psycho-emotional Effects on Care Partners of People with Dementia

Being a care partner in a household grappling with dementia is a strain in the best of times. COVID-19 added a negative psycho-emotional dimension to an already strained situation which can lead to need-driven behaviors (Algase et al., 1996). The Need-driven Model (Algase et al., 1996) identifies psychosocial needs as an intervenable aspect for those involved in dementia care. Unmet psychosocial needs can result in need-driven behaviors which may be identified through discussions with persons caring for people with dementia. Rajagopalan et al. (2021) reported increased anxiety and fear as well as depression, distress, sadness, and mood disorders in care partners of people with dementia. Studies by Carpinelli et al. (2020), Hughes et al. (2021), Hwang et al. (2021), Pongan et al. (2021), and Wong et al. (2021) also supported these findings with West et al. (2021) noting similar issues in Black and minority populations. The daily stress of caring for a person with dementia also caused increased irritability and distress (Altieri et al., 2021; Rusowicz et al., 2020; Sriram et al., 2021) and increased burden (Sorbara et al., 2021; Tsapanou et al., 2020; 2021) for some care partners. Feelings of being overwhelmed were found in many care partners (Azevedo et al., 2021) who also reported increased stress resulting in poor coping with daily activities and loss of formal home care services and support that people with dementia had received before the pandemic shut down services (Roach et al., 2021). On a brighter note, some care partners reported increased resilience (Altieri et al., 2020; DeLorito et al., 2021) as well as feelings of self-efficacy/coping (Sanchez-Teruel et al., 2021). However, care partners also experienced financial hardship due to COVID-19 and increased expenses (Hwang et al., 2021; Rusowicz et al., 2021) which posed yet another challenge in a highly restricted environment where psychological and emotional support was difficult to access. An increase in need-driven behaviors (Aglase et al., 1996) by a person with dementia may have added additional stress as care partners attempted to navigate the pandemic period.

Social Effects on Care Partners of People with Dementia.

COVID-19 had negative social effects on care partners of people with dementia. Care partners reported increased loneliness (Carbone et al., 2021), decreased social support (Giebel et al., 2020b; Rusowicz et al., 2021; Sriram et al., 2021), and increased feelings of separation and loss (Bascu et al., 2021b). At the same time, decreased home care and support services (Bascu et al., 2021a; Carpinelli et al., 2020; Giebel et al., 2020a; Rajagopalan et al., 2021; Rusowicz et al., 2021; Sriram et al., 2021; Vislapuu et al., 2021; West et al., 2021; Wong et al., 2021) and social interaction (Rising et al., 2022) were not available to care partners of people with dementia during COVID-19. Daily caregiving for a person with a neurological impairment is difficult and a lonely journey during normal times. In an analysis of 417 lived experience reports, Tam et al. (2021) found care partners were concerned about feeling lonely and more isolated compared with before the pandemic. An increase in need-driven behaviors (Aglase et al., 1996) by a person with dementia may have added additional stress as care partners attempted to navigate the pandemic period. Care partners might have limited social interactions due to their loved one with dementia experiencing increased need-driven behaviors (Aglase et al., 1996).

Provider Perceptions, Experiences and Challenges.

In a qualitative study that spanned between May 2020, after the national lockdown was imposed, and June 2020 in England, Di Lorito et al. (2021) conducted a tele-rehabilitation research exercise program involving 24 participants. Participants included people with dementia, care partners of people with dementia, and therapists. The study was aimed at identifying causes and effects of de-conditioning in people with dementia. Results noted a decrease in motivation, social disengagement, and enthusiasm and increased apathy amongst people with dementia. In addition, care partners and healthcare providers had an increased burden of care, a lack of motivation because of public safety restrictions, depression, and anxiety. Reduced physical activity amongst people with dementia because of lockdown and travel restrictions were reported.

Banerjee et al. (2021) used a qualitative approach to examine the challenges faced by providers during pandemic and their perceptions related to specific facets of dementia care. The study involved 148 providers who were interviewed virtually. Providers reported unmet needs, ambiguity related to newly released telepsychiatry guidelines, high resource constraints and pandemic burden, decreased healthcare access and significant mental health burden on caregivers. General effects included reduced healthcare access, travel restrictions, long-term lockdown, and fear of hospitalization.

It is unclear how the Algase et al. (1996) Need-driven Dementia-compromised Behavior Model applied to the actions of the providers of care to people with dementia. An aspect of this study identified that the model had application to the reported issues brought up by the providers. Research is the laboratory to test theory, so the provider aspect of this study was a good indicator of the applicability and comprehensiveness of the Need-driven Model.

Summary

Chapter Two synthesized the review of literature related to the physical, psycho-emotional, and social effects of COVID-19 for people with dementia, care partners, and providers. It further described how the Need-based Theory (Algase et al., 1996) provided a framework for this study.

Limited research was located regarding provider experiences and no literature reported CNA/sitter experiences caring for people with dementia during the pandemic. None of the research used a multiple-case study design or the Need-riven Dementia Behavior Model to guide data analysis. Further, no study examined participants' experiences from the beginning of the pandemic until now.

Chapter 3

Methods

Design

This study used a comparative, multiple-case design. A case study is considered a suitable research design when the researcher wants to gain contextual, in-depth knowledge about a specific real-world phenomenon or subject (Yin, 2018). Four types of cases; people with dementia, care partners, CNAs/sitters, and providers (*n* = 24) were interviewed to explore what life with dementia was like or what it was like to care for people with dementia during the pandemic up to now, the real-world phenomenon. The Need-driven Dementia-compromised Behavior Model (Algase et al., 1996) was scrutinized to determine whether the model appropriately described how four different groups involved in the management of dementia during the pandemic fit the model framework and assumptions. The use of a multiple, comparative case study allowed for exploration of key characteristics among multiple cases, meanings, and implications of the case where similarities among cases were drawn (Yin, 2018). The approach offered perceptions from the four different cases individually and then compared.

According to Yin (2018, p. 15), a case study approach:

> copes with the technically distinctive situation in which there will be many more variables of interest than points, and as a result, benefits from the prior development of theoretical propositions to guide design, data collection, and analysis, and relies on multiple sources of evidence, with data needing to converge in a triangulating fashion.

Attention is needed to all case study elements, process, and publication to promote authenticity, methodological quality, and visibility (Anthony& Jack, 2009). Case studies can be used to elucidate the theoretical concepts which can be used as the backbone for generalizing findings.

When using a case study design, Yin (2018) suggests that the number of duplicated cases should be considered rather than using actual sample size to accurately represent the population being studied. Multiple-case study designs may be preferred over single-case study because the researcher has the possibility of direct replication (Yin, 2018). Case studies go in depth beyond individual behavior allowing the researcher to access the subjects' thoughts, emotions, past and present activities, and their conditions as they relate to the study focus (Portney &Watkins, 2015). Evidence-based practice requires direct feedback from individuals who experienced the phenomenon to formulate policies, procedures, and guidelines that can be implemented for future pandemics or disasters. Evidence from multiple cases is more compelling and more robust compared with single-case study designs (Yin, 2018). Understanding the perceptions of people with dementia, care partners, CNAs/sitters, and providers and making comparisons between the different cases gave a clear understanding of the best approach to use in tackling the problem for future pandemics.

Sample

The study population included four types of cases. Purposive sampling identified six people with dementia, six care partners, six CNAs/sitters, and six providers (*n* = 24). A recruitment flyer (Appendix A) was distributed by The Rethinking Dementia Center at Harris College of Nursing and Health Sciences at Texas Christian University, doctors' clinics/officers, health care centers, community organizations, and to personal contacts. When using a case study design, Yin (2018) suggests that the number of duplicated cases should be considered rather than using actual sample size to accurately represent the population being studied.

Setting

Interviews were scheduled at a time and location that was convenient to the participants. The location was private or public where participants could freely express their feelings or perceptions with confidence and without fear of being judged. Interviews were conducted in person or via Zoom, an online meeting platform, depending on the participant(s) choice and location.

Inclusion criteria for people with dementia were:

1. Individuals who self-report with dementia prior to COVID-19 pandemic.
2. Are at least 18 years or older.
3. Speak and read English.
4. Are not severely cognitively impaired.

Inclusion criteria for care partners were:

1. A care partner for a person with dementia during the COVID-19 pandemic.
2. Provided a minimum of five hours of care per week for a person with dementia during the COVID-19 pandemic.
3. Are at least 18 years or older.
4. Speak and read English.

Inclusion criteria for CNAs/sitters were:

1. Individuals who provided care for people with dementia during the COVID-19 pandemic.
2. Are at least 18 years or older.
3. Speak and read English.

Inclusion criteria for providers were:

1. A provider of primary health care including Medical Doctor, Doctor of Osteopathic medicine, Nurse Practitioner, or Physician Assistant.
2. Are at least 18 years or older.
3. Speak and read English.
4. Provided primary care for people with dementia during the COVID-19 pandemic.

"Snowball sampling is a nonprobability sampling method in which subjects are successively recruited by referral from other subjects" (Portney &Watkins, 2015, p.877). Snowball sampling, a type of convenience sampling, was used to minimize the challenges faced when recruiting participants who might be difficult to access.

Protection of Human Subjects

Institutional Review Board (IRB) approval was obtained from The University of Texas at Tyler to assure compliance with ethical principles and regulations. All participants signed a consent form before being interviewed. For online interviews, participants signed and returned the consent electronically. Truthfulness and full disclosure about the study purpose, methodology and outcomes were explained. Each participant signed two copies of the consent form and one copy was provided to the participant. The participants were notified that the study was voluntary and were able to withdraw from the study at any time without penalty. Participants had a chance to discuss any questions or concerns prior to the interviews.

The primary investigator (PI) ensured that participants with dementia understood the study procedures before signing the informed consent. After reviewing the consent, participants were asked to share their understanding of the study purpose. To avoid conflict of interest, participants with dementia and care partners were not currently enrolled with the organization where the investigator is directly affiliated. Pseudonyms were used for confidentiality, to protect personal identifying information, and when analyzing data. Storing of informed consent was separate from master list of names and pseudonyms. All data was stored on a password-protected computer to which only the PI had access. Only the PI and dissertation chair had access to the data.

Data Collection

Demographic information was collected from people with dementia (Appendix B), CNAs/sitters (Appendix C), providers (Appendix D), and care partners (Appendix E). People with dementia, care partners, CNAs/sitters, and providers were interviewed using a semi-structured interview guide (Appendices F, G, and H). Recordings were transcribed verbatim, and field notes and a reflective journal were documented.

Interviews lasted between 30-45 minutes and occurred in one sitting. The interview process was conducted in a sequential manner. The researcher introduced herself, engaged in a general dialogue to make the participant feel comfortable. Detailed information about the study such as the study purpose, what was expected, and that the interview would be audio recorded was shared. The researcher addressed any questions or concerns before proceeding with the interview. The audio recording was started, and the interview process commenced. The interview ended with a summary of what was discussed. This gave both the interviewer and the participant a moment of reflection and an opportunity for clarification and correction of any misinformation that occurred during the interview. The researcher asked if it was acceptable to contact the participant for additional questions or clarifications. The researcher then ended the interview by thanking the participants for their time and participation. Data collection occurred between December 2022 and March 2023.

Data Analysis

Descriptive statistics were computed to describe the participant characteristics. Algase's Need-driven Dementia-compromised Behavior Model and propositions guided qualitative analysis. Interviews were recorded, transcribed verbatim by a transcription service, and verified for accuracy. Data analysis was an iterative process and occurred after the first interview was completed. This allowed for revision of the interview schedule as needed during data collection. No revisions to the interview guides were required. Raw data was recorded, patterns within cases were grouped and compared across cases. The principal investigator and the committee chair analyzed the data, compared, identified, and resolved any discrepancies. Sub-themes were collapsed into major themes and analyzed.

Procedures to Enhance Rigor

Various methods were used to promote reliability and construct, internal, and external validity. (Creswell & Creswell, 2023) refers to validity and reliability in the context of qualitative analysis. The following validation strategies were employed: triangulation (use of multiple sources of data), multiple researchers analyzing data (the primary investigator and dissertation chair), peer review (the dissertation committee provided an external check of the research process), member checking (select participants were invited to review and judge accuracy of the findings), and rich descriptions of the findings. Reliability was ensured via verbatim transcription as well as multiple researchers coding the data and meeting to resolve discrepancies and coding data based on theoretical concepts and propositions. The use of a code book and an audit trail helped in managing and interpretation of data to ensure consistency and transparency. Inclusion of the major subpopulations, people with dementia, care partners (spouses, relatives, other), CNAs/sitters (from various settings), and providers (Nurse Practitioners and Medical Doctors) benefitted transferability. Participants felt that the interview about their perceptions during COVID-19 was well represented and revisions were not necessary.

Summary

Chapter Three presented the research methodology and rationale. The study sample, protection of human subjects, data collection, and procedures to enhance rigor were detailed. The phenomenon of the COVID-19 pandemic in the context of dementia is climacteric in achieving the best knowledge on how to handle and manage future disasters. Review of literature indicated that the people with dementia and care partners faced social, physical, and psycho-emotional effects during the pandemic. Little is known about provider experiences caring for people with dementia during the pandemic, and no literature was located that presented CNAs/sitters' experiences. To help reduce such effects on a similar population group for future pandemics, policies and procedures must be implemented to help guide and manage those who are vulnerable and support their needs. The proposed study offers a unique approach to providing a comprehensive and multi-faceted view of the challenges encountered in dealing with a rare occurrence, a global pandemic. Retrospective analysis of the impact of such an unusual event is vital in planning for future health needs in a world where world-wide travel and commerce has made containment of communicable diseases more challenging. By studying one of the most vulnerable populations, those with dementia and those involved in their care, the researcher gained insights into positive approaches to minimizing untoward outcomes in these unusual health situations. No amount of planning and preparation readied us for the stresses and outcomes of the COVID-19 pandemic; this study provides insights into what did and did not work in a vulnerable caregiving situation to advise in preparations and management of future global events.

Chapter 4

Findings

The purpose of this study was to understand the perceptions of people with dementia, care partners, CNAs/sitters, and providers during the COVID-19 pandemic, from onset until now, to help formulate better ways to care for people with dementia during a pandemic or disaster. Data was collected from twenty-four subjects (*n* = 24) including six people with dementia, six care partners, six CNA's/sitters (five CNAs and one sitter), and six providers. Participant characteristics were revealed using descriptive statistics (see Tables 2 - 6) and the Need-driven Dementia compromised Behavior Model guided qualitative analysis.

Seven major themes emerged from the data and individual topics were organized into categories under each theme for all four cases. Social isolation, decreased social interactions, and community engagement were collapsed under one major theme. The remaining six major themes included health effects of COVID-19, psycho-emotional effects, care provision, protective measures, up to date, and unexpected findings.

Table 2

Descriptive Statistics for People with Dementia (n = 6)

Variables		Min	Max	M	SD
Age in Years	3	72	85	78.67	5.086
70-80	3				
>80					
Years Diagnosed with Dementia	14	6	20	12.17	5.307
Type of Dementia					
Alzheimer's Disease	5				
Vascular Dementia	1				
Ethnicity					
African American	6				
Gender					
Male	2				
Female	4				
Marital Status					
Widowed	6				
Employment Status					
Retired	6				
Education					
High school	2				
Some College	3				
College	1				
Annual Income					
<$50,000	5				
>$50,000	1				
Current Living Setting					
Private home	4				
Assisted care facility.	2				
Relationship With Care Partner If Any					
Mother	4				
Grand mother	1				
Mother-in-law	1				

The mean age of the subsample of people with dementia was *M* = 78.67, *SD* = 5.086.

Table 3

Descriptive Statistics for Care Partners (n = 6)

Variables	N	Range	Min	Max	M	SD
Age in Years		36	23	59	46.17	12.238
20-29	1					
40-49	2					
>50	3					
Years of Experience with People with		12	3	15	8.50	5.010
Dementia	4					
0-10	2					
10-20						
Annual Income		1	1	2	1.50	.548
<$50,000	3					
>$50,000	3					
Ethnicity						
African American	6					
Gender						
Female	6					
Marital Status						
Single	2					
Married	2					
Divorced	1					
Widowed	1					
Employment Status						
Full-time	4					
Part-time	2					
Education						
High school	3					
Some college	2					
College	1					
Current Living Setting						
Private home	3					
Apartment complex	3					
Relationship With People with Dementia						
Daughter	4					
Granddaughter	1					
Other (daughter-in-law)	1					

Care Partners’ mean age was 46.17 years (*SD* = 12.24).

Table 4

Descriptive Statistics for CNA's/Sitters (n = 6)

Variables	N	Range	Min	Max	Mean	SD
Age in Years		31	24	55	39.67	11.605
21-40	2					
41-60	4					
Year of experience		12	9	21	13.83	5.345
0-10 years	3					
11-20 years	2					
>20 years	1					
Ethnicity						
African American	5					
Hispanic	1					
Gender						
Male	2					
Female	4					
Marital Status						
Single	4					
Married	2					
Current Employment Status						
Full-time	6					
Education						
High school	3					
Some college	3					
Occupation						
Certified Nurse Assistant	5					
Sitter	1					
Workplace setting						
Nursing home	4					
Private duty	1					
Acute care setting	1					

The average age of CNA's/Sitters was 39.67 years (SD= 11.605).

Table 5

Descriptive Statistics for Providers (n = 6)

Variables	N	Range	Min	Max	M	SD
Age in years		25	36	61	48.00	9.338
40-49	4					
50-59	1					
>60	1					
Percentage of direct patient care		10	80	90	81.67	4.082
80 percent	5					
90 percent	1					
Years Working with People with Dementia		13	10	23	16.50	5.357
0-10 years	1					
11-20 years	3					
>20 years	2					
Ethnicity						
African American	5					
Non-Hispanic White	1					
Employment Status						
Full-time	6					
Part-time	0					
Job Title						
Nurse practitioner	4					
Medical doctor	2					

The average age for Providers was 48.00 years (SD= 9.338).

Health Effects of COVID-19

When asked how COVID affected their health, both people with dementia and some care partners stated that COVID-19 had no effect on their health. “It really didn’t affect my health at all”, one person with dementia stated. “Nothing really affected me. I hang in there. Yeah. I wasn’t affected” one care partner reported.

During interviews, other care partners reflected on how the pandemic negatively affected their health. One care partner reported feeling tired, “The start of it was very rough because you couldn’t go anywhere. You couldn’t go outside. So just being in the house with someone with dementia for hours and hours can be tiring". One care partner verbalized increased symptoms of wheezing "I could say I'm wheezing more, uh, than I used to. I have to look after myself now and take vitamins".

Providers and CNAs noted that people with dementia had higher prevalence of COVID-19 because of age and other chronic illnesses. Providers stated, "But most of these patients were catching…getting sick at this time at a higher rate than just anybody…other, patients due to their age, and …they had dementia as well", and "If they should contact it, then it's much easier for it to turn worse or become fatal, uh, for them because they're already compromised, unlike you and me". Another provider recognized that "A lot of dementia patients are older, so… that already puts them at a much higher risk of developing COVID-19 complications than any other set of population". A CNA supported the providers' observations, "People with dementia mostly tend to be the elderly population. So, they come with already chronic illnesses, uh, besides just dementia". Providers reported that death, loss, and the mortality rate including older adults and health professional colleagues was high. "People were dying left and right. Co-workers were dying. Patients were dying. Doctors were dying. People were just dying because we didn't know". One care partner contacted COVID-19 and continued working for financial stability:

> I contracted, uh, COVID, got very sick, and, uh, I could not even work, … I didn't want to go to work anymore. I was like, I, I have to quit this job if …this is the case. And being that that is where I get my daily, daily living and, uh, I have to take care of someone else… and I have just to continue with my job.

Psycho-emotional Effects

Participants were faced with the reality of adapting to a new lifestyle brought on by the pandemic with no prior knowledge and confusing information which resulted in psycho-emotional effects. Psycho-emotional effects included worry and anxiety, care partner burn out and stress, depression, fear, confusion, and behavioral and psychological symptoms of dementia. One care partner stated that she felt she was not herself. “Like, you’re just pressurized to do things. You are not yourself. The pressure is really on because you used to have to be careful. It’s like you’re walking on eggshells”.

Worry and Anxiety

Not knowing what caused COVID-19 brought a lot of worry and anxiety for both care partners and their family members (with dementia). “My family member had increased anxiety” said one care partner. Another added:

> It can also add a little bit of anxiety because no one knew what COVID was. You just saw on the news that people were dying. There was no medicine how we have the flu where…you know, you have the flu, you can take some medicine and it's gone within a week or two. So that added a lot of anxiety due to fear of the unknown and there was no, uh, cure or preventive measures, no medications, and COVID affected just about anybody.

One care partner noted that her anxiety was exacerbated by the fear of the unknown, “But with COVID, you know, you never know. You could be healthy and get it and then you die. There was no like, Oh, you’re healthy. You’re not gonna get it. It's everybody got it across the board”. One person with dementia verbalized feeling worried about other people around the world. “I guess it affected my mind because I… I was just worried about other people in the world”.

One care partner reported that the doctor had to increase hypertension and anxiety medications for their loved one with dementia due to increased symptoms during COVID-19.

"My family member had increased anxiety and even hypertension. Um, the doctor had to increase her medication because, um, wearing a mask or walking around people that were coughing made her very anxious."

Care Partner Burnout and Stress

Care partners felt burnt out and stressed and as if they didn't have a life. Stress was exacerbated by increased dependence on the part of their loved one with dementia. "I felt more stressed out caring for my loved one because she was very dependent on me. I have to pick up her medications. So, the stress was really bad for me". Another care partner explained, "I have to work and go take care of her after work every day. And then my stress was increased". Finally, a care partner put it this way:

> I mean, you…it's all about them (person with dementia). You really don't have a life. It's just everything that you…you know, the breaks and, like, going out and exercise, that's not allowed anymore because I'm just focused on them. It's hard you know. It's, it's a challenge.

Different people experienced different COVID-19 symptoms and not knowing which signs might be indicative of COVID was stressful. One care partner who was the primary caregiver for his dad with dementia and an autistic son noted that when they caught COVID-19, they all presented with different symptoms:

> And COVID did not come with a specific symptom. It came with all sorts of symptoms, so won't really know. Yes, you really didn't know. It was some…you know, some people like me, I had a headache. No…I didn't have any coughing, no fever, just had a headache. My dad didn't have, uh, no fever. He just had…I thought it was his signs which he has it

> every year, but it was COVID. My son had no symptoms and he had it. I mean, it's just…and it, it took a toll. It takes a toll.

Loneliness and Depression

One care partner noted the effect isolation had on their loved one, a long-term care resident with dementia, "They are isolated and lonely because they could not see their loved one or family members which brings other symptoms of depression on top of the dementia, and it's a lot of…absolutely, isolation". Another care partner, described their loved one with dementia:

> But I would say it could have maybe caused a little bit of, maybe depression or sadness as to, they weren't able to just freely go to, you know, family members' houses or even go down to neighbors' houses. That was…you know, not…they weren't allowed to do that. So maybe a little bit sadness due to limited access of visiting with family members and neighbors.

Care partners described feeling depressed and one CNA reported patients with dementia, "were more depressed during COVID than before".

Fear

There was increased fear on the part of CNAs, care partners and providers. One CNA noted, "At the beginning. I was terrified. I had to pray about it". One provider stated that care partners were apprehensive about going to health care facilities for fear they or their loved one would contract COVID-19. "They felt like when you go to a healthcare facility, that's where you get COVID. So, they did not wanna bring their loved ones". Some providers were afraid of being with their spouses for fear of infecting them with the virus. ". . . even as spouses, you were scared …even …to be with your spouse".

Confusion and Behavioral and Psychological Symptoms of Dementia

Ever-changing announcements by CDC caused confusion regarding protective measures. A CNA explained, “Everybody was like, ’What?’ You know, scared. We didn’t have all the information. Every day the CDC was putting out something new. You know? So, we were trying to keep up with all of it at the time”.

Protective measures and lack of socialization contributed to confusion for people with dementia. The use of PPE’s including face shields caused confusion for people with dementia as one provider noted:

> The PPE, um, it also adds to the confusion for them (people with dementia) because they can’t see your whole face. So, like, the PPEs was, like, a barrier to, to physical reflection of a full person or, like, the familiarity of, uh, seeing the full face.

The lack of family visitation was also attributed to confusion for people with dementia. According to a CNA:

> Because patients with dementia are more easily confused, I think that was…that was one of the biggest things that I noticed is not having, um, the ability to have a… family around and people that are familiar to them, I think, um, made them much more easily confused.

Other behavioral and psychological symptoms of dementia and suspected causes were noted. “They (people with dementia) were more aggressive, I guess due to isolation and being that they can’t see their family members” said one CNA. One provider’s perception was that people with dementia felt confined because they were unable to mingle or see their family members:

> They didn’t have their family members there. So, in, in a negative way… because, uh, you know, they’re already compromised. And then now they can’t see their daughter, they can’t see their son. Now, they’re in this confined space, and we want them to stay in bed so we can care for them. So, they feel trapped.

According to one CNA, the mental status for people with dementia declined quickly due to isolation and lack of stimulation. “It’s affected so much in, uh, such a way that they decline easily…(more) than usual due to the isolation and lack of stimulation”. Another CNA noted decreased mobility for people with dementia especially those that were hospitalized for COVID-19, “But some of them were moving around…you know, moving around, and when it hit them, it slowed them down, um, it was where their dementia was just, like, progressed, like 100%”.

Agitation and irritation among people with dementia were reported. A CNA noted that people with dementia easily got agitated. “…they are used to routine, same thing, seeing same faces, doing same things. So, if they deviate from the normal, then they tend to kind of, uh, o-overreact or get agitated”. One person with dementia became irritated according to one care partner who observed, “And just getting a little bit irritated here and there when…uh, especially when the, um, the home help people came in…. she was not getting it”.

CNAs noted increased forgetfulness during the pandemic, “Hmm, no. I think they’re just very forgetful of how serious, uh, the matter was at times”. Another CNA stated:

> All of a sudden, they start forgetting, they can’t remember. It’s just a whole set of things you have to just pay attention to. You know, write a list. Make a note. Putting that down. Watch that… monitor them on a daily activity.

Finally, people with dementia couldn’t remember who their care partners were. “It’s hard when they don’t remember who you are” said one CNA.

Social Isolation and Decreased Social Interaction, and Community Engagement

To prevent contracting COVID-19, people with dementia and care partners living in the community reported that they were unable to go out, visit others and have others visit them (including family), or attend big gatherings. People with dementia stated, “I can’t go out. I have to wear a mask” and “I don’t go, uh, out to big social gatherings anymore. I don’t go out to big dinners anymore”. One care partner verbalized, “(There was an) increase of isolation because we could not visit or be visited”. Large gatherings such as in-person worship was an issue as reported by two people with dementia: “We were out seven, eight months. So didn’t go to church. I just stayed in the house” and “I couldn’t go to church”. People with dementia stated daily outings were limited, “Just not being able to go to the grocery store like I wanted to”, “couldn’t go to the store to get your supplies, couldn’t go get anything”. One care partner reported on how the closure of government offices impacted people with dementia:

> Well, the closure of major government offices, uh, like the social security office. Um, like my mother-in-law she believes in going and talking to an actual person. So, the closure of these major offices made it very difficult for us to coordinate everything virtually or remotely over the phone.

Isolation was experienced by people living in long-term care facilities. People with dementia who lived in long-term care facilities felt isolated because they were unable to see their family members and received care only from staff members. One provider mentioned: “We can’t have their family member come freely like we used to before”.

People with dementia expressed how frustrated they were that they could not do the things they enjoyed doing before COVID-19, “It’s changed. In other words, I don’t do those things I used to do before COVID. I’m more careful”. As an example, one person with dementia lamented, “I don’t do activities anymore. I used to go to the gym. I don’t go to the gym anymore” and another stated, “I could not do the things I loved to do”.

Alternative ways to engage in activities were created. Church services were viewed on television instead of being in-person. “But we weren’t having in-house (church services). We were having . . . televised church”. The tradition of visiting with others in their homes and socializing changed. One person with dementia stated, “drove by and blew horns and they… they know. But before, you used to go in person and share and sit with them and visit”. Care partners created alternative home activities to keep people with dementia engaged. “You had to come up with different measures, maybe more home activities…in the beginning, there was no more going on long walks or going to the store just to pass time. You kinda just stayed indoors”.

Care Provision

Provider Visits

Providers reported that care provision was difficult because of restrictions. “So, in a nutshell, it is more…it was more difficult caring for them because of just the restriction that we had”. For example, a provider who visited patients in their homes shared:

> For us who do direct patient care, it was really difficult because we cannot reach out to our patients. So, um, caring for them was quite difficult because we’re used to going to the patients’ homes and offering, uh, one-on-one care, but this was difficult, and uh, we didn’t know how to get along with it.

People with dementia reported less frequent healthcare visits, "(I go) about every three months” said one participant with dementia and another added, “I was not able to go the doctors”. Missed appointments resulted in patients going “longer without being monitored” acknowledged a provider. Lack of transportation was a barrier to clinic visits for some people with dementia, “A lot of them don’t drive so they have to rely on someone else for transportation” pointed out a provider. Coordinating care with specialists such as dentists was difficult since they only saw people in emergency situations. One care partner stated:

> I had to coordinate a lot of her doctor’s appointments virtually, the dentists, were only seeing people for emergencies. So, this made her (loved one with dementia) feel like she wasn’t important because she wanted to be helped right then and that wasn’t possible.

Providers noted that people with dementia and their care partners wanted tele-consult, “Most of them, in fairness, uh, they wanted to hop in for tele consult”. However, telemedicine visits were not always the provider’s priority; providers were more concerned about stopping the spread of COVID-19 than scheduling visits:

> Just the concern for the patients getting infected, uh, that, um, trying to set them up for zoom meetings was not a priority. So, these patients would even end up going for very prolonged periods of time without being seen.

Telemedicine visits were challenging for several reasons. “You cannot really assess them as you would on a face-to-face basis” reflected one provider. Providers felt that telemedicine services were ineffective and interfered with them doing their jobs: “That’s . . . was really not the same thing. We were not being very effective in our care as we were before. For me, it felt like . . . I could not do my job”.

Telehealth was not a viable substitute for in-person visits for some people with dementia. “They cannot really focus on telemedicine visits” explained a provider who went on:

> Telehealth may cause some confusion. To them, it might just look like another TV or a movie they’re watching versus somebody, um, in their house or, um, or bringing them to the clinic, uh, talking to them physically and, you know, they see multiple staff.

> Somebody is checking their temperature, blood pressure, or exam table. That might encourage their memory to say," Okay. I think I'm at the doctor's office.

When a patient with dementia was unable to initiate a telehealth visit or be an active participant, a care partner served as a proxy. "Most of the time, (healthcare) visits were initiated by family members. They're the ones that kind of ID-ed the symptoms rather than the people with COVID" stated one provider. If a person with dementia was unable to participate in virtual visits, their care partner served as their voice. Providers relied on "their close relative like the daughter to give you the medical history and the condition".

The use of telemedicine and other digital solutions emerged as a critical alternative during the pandemic. People with dementia and care partners had to adapt to the virtual platforms for communication, engagement, and accessing healthcare services. The technology offered some benefits such as maintaining social connections through video calls and virtual gatherings but also presented challenges and limitations.

Assessment and Diagnosis

Symptoms caused by comorbid conditions and / or COVID-19 made it difficult to discern the underlying reason for presenting symptoms:

> They already have a lot of comorbid conditions … besides the dementia . . . it just made everything even worse. A lot of times they already have issues with…um, you know, pulmonary issues and then the COVID on top of that. And then, um, hypoxia contributes to their confusion. So, it's hard as a provider sometimes to figure out if it's their dementia. Are they having delirium on top of dementia or is it hypoxia that's causing them some confusion.

In addition, people with dementia were unable to communicate symptoms which complicated making a diagnosis: “The patient has dementia, unable to . . . express their symptoms. Their temperature could be, um, 102 but they will still say, ‘I am fine’”. A provider noted that often people with dementia will respond that they are fine even after exposure to COVID-19. “You know, a lot of the time, the patient will just say, ’Oh, yeah. I, I’m fine’. And the family might report they have fever, coughing. They’re exposed to granddaughter with COVID”.

Care partners had to be more attentive to symptoms for people with dementia that could be related to COVID-19 and report them to providers promptly for effective diagnosis and treatment. One provider noted:

> So, if, they realize they’re maybe a bit more confused this morning, you know, they seem to be coughing a little and maybe they’re running a fever, then they (care partners) have to be on high alert because some of these patients are not able to voice their concerns or to let us know what kind of symptoms they have.

Provider Patient Relationship

COVID-19 changed relationships between providers and patients and the way they communicate. One provider stated: “COVID ruined the whole world. Everything changed… the way you practice, the way you have to communicate with patients, uh, certainly for the patients, the, the relationships between patients and providers”. Providers faced barriers to patients’ understanding and the ability for the patients to adhere to treatment plans. “There were so many more barriers . . . for the patients to understand us and be compliant with what we need them to do”. Furthermore, providers had to be sensitive to how they talked about COVID-19 with people with dementia so as not to trigger behavioral and psychological symptoms, “You have to be very sensitive on how you explain to these patients about what's going on…just because you do not want to make them more anxious. Providers also assessed "How much, uh, they can actually understand, um, and then how much you're gonna rely on the caregiver to provide that kind of safe care".

CNA Care

CNA's/sitters had increased burden of care during the COVID-19 lock down. "Definitely more time…yeah, spending more one-on-one time and, you know, making sure their personal hygiene is right and, seeing if they had any COVID-19 symptoms" described a CNA. Other CNAs said, "It was harder to gown up and gown out" and:

> Having to monitor them a little bit more so that you normally would, um, under normal circumstances. So those were kind of things that, uh, had to change and make things a little bit . . . I won't even use the word more stressful, but just a little bit more demanding of your time and . . . your attention. As well the monitoring for symptoms that they may have come down because you also have to monitor them for signs and symptoms as well.

Behavioral and psychological symptoms exhibited by people with dementia required extra patience on the part of sitters. One described:

> If you're not a patient person, if you're not a person of patience, that's not a job for you. Because they can say something that they don't mean or voice or do something that they don't mean, and you might well wanna give up on that person or you might not want the job anymore. They might come back later on, might apologize . . . you just have to have an understanding. There's been times I have to cry because I know that's not that person.

Protective Measures

COVID-19 was believed to spread mainly from person to person. The virus could be contracted through close contact with a sick individual within one meter, droplets from someone with COVID-19, objects left on the surface, or poor ventilation. Multiple protective measures were implemented to reduce the spread of COVID-19. People with dementia underscored the importance of masking and safety precautions: “You still wear a mask. You still have to wear masks like in the stores. Uh, when I go to the doctors, you have to wear a mask” and “When I go I, uh, distance myself. Like, I had a mask on, and I distanced myself. I used sanitizer and washed my hands when it’s possible”.

It was difficult to ensure that some people with dementia with more severe cognitive impairment wore their masks or stayed isolated because they were confused and did not understand restrictions. A provider explained:

> Some of them are unable to… they’re unable to do what is needed to keep them safe. So, for example, needing them to have…you know, to wear the masks, needing them to wash their hands, um, that, for some of these patients was, um, was hard, and they may not have the mental capacity to understand why they have to, uh, put on a mask. They, um, don’t have the capacity to understand why they need to use hand sanitizer or clean up more.

A care partner concurred, “They don’t understand why they have…when you are able to go outside, they don’t understand why they have to wear a mask, and it’s difficult trying to redirect them”. One care partner reported that wearing masks caused people with dementia to have panic attacks: “A person . . . that’s not used to . . . something being over their mouth, and that’s being in small places, that can make you, you know, have panic attacks. I mean, it’s crazy”.

Providers were cautious and practiced social distancing, wore their PPE's (personal protective equipment) to be safe and prevented their patients from being sick or contacting COVID-19. One provider stated:

> We have preventative measures that have… I still wear my mask too. To patient care service areas, we try to not to get too close to people. Try to social distance. Being cautious. So, we're wearing our PPE. Even though they say, well, you don't have to. In some hospitals, you don't have to wear PPE, but the hospital I work at, we wear our PPE's. I'm protecting not only my patient but myself and the general…everybody else. So, I think they're aware of infection control.

Some CNA's reported that they used gloves and face shields for extra safety precautions:

> Oh, it was fine. It was pretty much the same, but we just had to use extra safety precautions. You know, with the gloves, the masks, the N-95s and the face shields. So, it was a bit different experience, you know? Working all suited up, you know, with our, uh, PPE.

CNAs went an extra mile disinfecting their work areas and being extra careful "Um, also, you have to . . . really beef up disinfecting. Uh, you have to be extra careful, um, with making sure that you clean behind not only yourself but behind the patients".

Up to Date

Since the beginning of the pandemic, many transitions have taken place. Some people no longer wear masks. People with dementia especially those who were vaccinated did not worry and felt like having some immunity from the vaccine was sufficient and no longer needed to wear a mask, "No worry…we don't have to wear any masks".

Providers noted that more information about vaccines and quarantine requirements has improved healthcare delivery related to COVID. A provider offered:

> We’re more educated now. On what to do and how to handle the vaccine. We were so clueless. And now, when we hear about, you know, COVID, we’re not as scared as we were the first time when we heard about it. So, with more education, more awareness, uh, we have learned how to handle, um, you know, these illnesses . . . we have developed a preparedness plan.

Changes in quarantine requirements and access to vaccinations were recognized as contributing to transitions in protective measures. One provider discussed, “You know, they’ve just put guidelines in place. You know like, I remember back when COVID started, they had, like, quarantine for 14 days or two weeks? Now it has reduced to five”. Another provider added, “We have more technology and more information on how to be safer when it comes to being prepared to whenever somebody is… has contracted COVID … But it’s still hard”.

Vaccines

Vaccines provided hope and reduced mortality and fear. A provider stated:

> Now, when the vaccine started rolling out…with all the controversy around it . . . we felt a sense of hope . . . that at least finally now in research from the CDC showing that vaccinated people are less likely to die from the disease than unvaccinated . . . it made me . . . hope that finally we’re getting somewhere.

Some care partners reported getting the vaccine to protect people with dementia. “But myself and a couple of my family members, we took the shots for precaution for her because we will be around her”.

Providers were concerned that family members refused to have their loved ones with dementia vaccinated:

> When it’s just someone, uh, a typical patient with no cognitive impairment, they decide on their own. Even if their family does not want to be vaccinated, they make their own decision to be vaccinated or not. But when it’s a patient with dementia, someone else is making that decision even though the complications that may be developed would be developed by the patient themselves. The person who might be making this decision for them might be a young person in their twenties, healthy, uh, or even 30, or who is healthy themselves. But the patient is probably older and at higher risk, um, and they decide for them that they’re not gonna get the vaccine.

Life is Back to Normal

People with dementia felt like life is now back to normal, “Things, uh, things are better. You can go out”. Care partners felt less scared compared to when they first learned about the pandemic. “I have realized changes…uh, changes because now, people are not scared like before.” Providers are more comfortable now with the vaccine. “So, we can say, like, with the vaccine, things have changed. There’s more time spent with the patient compared to when it first started just because there was fear of exposure or contacting the virus”. Providers resumed seeing patients in their homes or private settings versus using Zoom or telemedicine that was the norm during the pandemic: “They introduced the vaccine, and then there was the booster shot, and now with wearing the mask, we started doing, uh, more visits in-house. I think we started to see a turn for the better once this happened”.

The CNA's reported that people are more educated, aware, and less fearful. "I think we're a little bit more aware and less fearful". They further noted that medicine is currently available if someone catches COVID, "Um, there's medicine out there now that would help some of them if they were to get it." There is also rapid testing available for screening, "You know, we can catch it in time. Um, we do have the rapid test that we can do too", one CNA noted. One care partner was thrilled that now they are able to celebrate holidays with family:

> I was happy but not 100%. I wouldn't say… because I was not mixing at all, you know, with people, …I'd missed friends. Yes. If you were with friends, you have to wear a mask. You can't, you know, shake hands like that. What… everything was different. But now we can go to parties to…you know. Thanksgiving together with my family members. Everything is back to normal. Christmas, we ate together with the family members, you know, so we are back to normal now. We are getting back to normal.

Unexpected Findings

The sub-themes that were discussed under the major theme unexpected findings included lack of resources and supplies and increased cost of living and care partner and CNA concerns.

Lack of Resources and Supplies and Increased Cost of Living

People with dementia stated. "I couldn't get food" and "had no toilet paper". The cost of living generally increased. One care giver reported that everything including prices for goods and services were very expensive. "Well, I must say that, um, groceries are very expensive. But now, things are very, very expensive. Gas prices are up. Everything is, like, very expensive. And I don't know when things will go back to normal".

Care Partner and CNA Work Burden

The pandemic resulted in a lack of trained personnel to care for people with dementia placing the full responsibility on care partners without support. One care partner stated. "…you can't get out and take a break, or no one can come over and relieve you because it's COVID. So, you're just there. You have to stick in there 24/7…7 days a week". Another care partner reflected, "Uh, and then also on top of that, um, there's basically a lockdown. So, family members had to pretty much take care of their patients who lived in the home with them". Providers noted a lack of trained personnel to care for people with dementia: "Just because as the pandemic progressed, um, we started seeing a lot of shortages in people who are able to work with dementia patients" and "Lack…of manpower. I mean, the nursing shortage reached unprecedented level…". Lack of respite care or caregiver relief concerned providers about "things like abuse and neglect. . . And it was very easy for them (care partners) to experience caregiver burnout. So, we had to watch for that, you know, um, signs of neglect and abuse".

Summary

Chapter Four began by restating the purpose statement which was to explore perceptions of people with dementia, care partners, CNAs/sitters, and providers during the COVID-19 pandemic until now. Description of data collected included the four cases with a sample size n=24. Participants characteristics were revealed using descriptive statistics in table 2-5 and the Need-driven Dementia-compromised Behavior Model which guided the qualitative analysis. A total of seven major themes (emerged from the data which were used to organize data. Social isolation, decreased social interactions, and community engagement were collapsed under one theme. The remaining six themes included health effects of COVID-19, psycho-emotional effects, care provision, protective measures, up to data, and unexpected findings. Some people with dementia and care partners reported no health effect while others reported feeling tired and experiencing increased respiratory symptoms. Worry and anxiety were reported by both people with dementia and care partners. Findings about care partners included care partner burnout and stress. Fear was experienced by CNAs, care partners, and providers. Care partners noted increased loneliness and depressing amongst people with dementia. Results indicated social isolation and decreased social interaction on both people with dementia because they were not able to go out, visit or be visited. Provider had difficulties with care due to restrictions which made assessment and diagnosis challenging. CNA noted increased burden caring for people with dementia due to extra work like gowning in and out. The use of protective measures decreased the spread of COVID-19 even though care partners and CNAs noted that if was hard to redirect people with dementia or make them wear protective measures. Up to date information findings indicated that the vaccine helped in reducing the spread and mortality cases of COVID-19 and other people felt that wearing, masks was no longer necessary. Participants felt they were more educated and aware on how to handle the virus and life is back to normal now. Others felt that there were lack of supplies, resources, and increased cost of living. Findings align with Algase's theoretical model which guided the analysis and significant to support the management of unmet needs for people with dementia to decrease BPSDs.

Chapter 5

Discussion and Summary

The objectives of this study were to understand the perceptions of people with dementia, care partners, CNAs/sitters, and providers during the COVID-19 pandemic, from onset until now, to help formulate better ways to care for people with dementia during a pandemic or disaster. Findings shed light on the distinct challenges faced by people with dementia during the COVID-19 pandemic. In this Chapter, significant findings are compared with results from previous research and interpreted along with unexpected findings. Support for theoretical concepts and propositions are presented and provide the foundation for practice, future research, and policy. Strengths and limitations of the study and discussed.

The study was guided by Algase's Need-driven Dementia-compromised Behavior Model Model (Algase et al., 1996) which suggests that behavioral and psychological symptoms of dementia (BPSDs) result from unmet needs that cannot be communicated directly due to the individual's cognitive status. The model focuses on two factors: (1) Background and (2) Proximal factors. Background factors include neurological and health status, demographic variables, and premorbid characteristics. Changes in neurological and health status for people with dementia were reported by care partners and CNAs; however, it is unknown whether these changes were related to BPSDs. None of the cases referred to premorbid characteristics for people with dementia. Proximal factors within the Need-driven Dementia-compromised Behavior Model include physiological needs, psychosocial needs, and the physical and social environments. Data supported the theoretical propositions that unmet physiological and psychosocial needs and the physical and social environments had the potential to cause BSPDs.

A care partner reported that their loved one with dementia became uncomfortable, a Proximal factor, when wearing a mask which triggered anxiety, a BPSD.

Health Effects

There were mixed responses amongst people with dementia and care partners about the effect of COVID-19 on their health. People with dementia and some care partners reported that they had no health effects while other care partners verbalized increased negative physical health symptoms including increased wheezing and feeling tired, the latter which supports Wong et al.'s prior research (2021). Similar findings were reported in previous literature specifically, increased sleep problems (Wong et al., 2021) and decreased physical health (Rusowicz et al., 2021). In addition, a study by West et al. (2021) reported that care partners reduced self-care activities whereas one participant in the current study reflected that they were consciously taking better care of themselves. It is possible that increased BPSDs experienced by people with dementia caused added responsibilities for care partners which negatively affected their health.

Both providers and CNAs noted that people with dementia were at increased risk of infection and severe illnesses. Matias-Guiu et al. (2020) reported that people with dementia had higher mortality than other groups, findings supported by current participants. While health status serves as a Background Factory within the Need-Driven Dementia-compromised Behavior Model, changes in health for people with dementia did not appear to result in BPSDs in this sample.

Psycho-emotional Effects

The COVID-19 pandemic had a significant and negative impact on the psycho-emotional well-being for people with dementia and care partners. The data supported the theoretical propositions that psychosocial needs and the physical and social environments (Proximal factors) have the potential to cause BPSDs. Strict restrictions on visitations by family members and limitations on social interactions resulted in loneliness, anxiety, and depression for people with dementia, possible precursors to BPSDs.

Disruptions in daily routine and staffing, physical and social environmental Proximal factors respectively, might have increased BPSDs. Current findings support previous literature whereby people with dementia were observed to have depressed mood (Azevedo et al., 2021; Carpinelli et al., 2020; Cohen et al., 2020b); increased anxiety and fear (Giebel et al., 2020b Portacolone et al., 2021; Suarez Gonzalez et al., 2021), agitation (Rajagopal et al., 2021; Sorbara et al., 2021), aggression and irritability (Azevedo et al., 2021; Pongan et al., 2021) all of which were reported by care partners or CNAs. Changes in daily routine and staffing for people with dementia should be limited as much as possible and schedules for mealtimes, bathing, and sleeping maintained.

Care partners shared psycho-emotional effects related to COVID-19. As with previous research, care partners reported increased anxiety and fear (Carpinelli et al., 2020; Hughes et al., 2021; Hwang et al., 2021; Pongan et al., 2021; Rajagopal et al., 2021; Sriram et al., 2021; West et al., 2021), depression and sadness due to added responsibilities (Altieri et al., 2021; Azevedo et al., 2021; Carpinelli et al., 2020; Hughes et al., 2021; Pongan et al., 2021; Rajagopal et al., 2021; Wong et al., 2021), limited access to support services (Bascu et al., 2021a; Carpinelli et al., 2020; Giebel et al., 2020a; Rajagopal et al., 2021; Rusowicz et al., 2021; Sriram et al., 2021; Vislapuu et al., 2021; West et al., 2021; Wong et al., 2021), and concerns about their health and safety and for their loved ones (Rusowicz et al., 2021; Tsapanou, et al., 2021). In support of prior findings, care partners reflected that the daily stress of caring for a person with dementia increased irritability, stress (Azevedo et al., 2021; Rajagopal et al., 2021; Roach et al., 2021) and burden (Sorbara et al., 2021; Tsapanou et al., 2020; Tsapanou et al., 2021).

The majority of study participants were Black, similar to previous research by West et al. (2021) whose subjects included Blacks, Asians, and minority ethnic (BAME) backgrounds. Current study findings support West et al. (2021) work in that both people with dementia and care partners experienced fear and anxiety, social isolation and lack of support structures and medical services.

Social Isolation and Decreased Social Interaction and Community Engagement

Social isolation and decreased social interaction and community engagement are represented in the Proximal Factor, social environment and all were experienced by people with dementia and care partners. For some people with dementia, these experiences resulted in BPSDs such as agitation, confusion, forgetfulness, and aggression. These findings align with previous research by Cohen et al. (2020b), Talbot et al. (2021), and Portacolone et al. (2021). Isolation was experienced by those living in the community as well as long-term care facilities and resulted in frustration because people with dementia were unable to engage in the usual daily activities they loved. Some found alternative ways to remain active such as through online church services or indoor activities initiated by care partners.

Care Provision

Several changes in caring for people with dementia were noted. Providers struggled to assess patients and had to pivot from in-person visits to telemedicine. Sensitivity to the way information was delivered to care partners and people with dementia was necessary. Care partners and providers noted the lack of trained personnel to care for people with dementia which resulted in care partner burnout and vulnerability for neglect and abuse for people with dementia.

These changes in care provision left providers feeling as if they were not delivering effective care.

Providers

Providers verbalized that they faced challenges caring for people with dementia due to restrictions. COVID diagnosis was complicated because of comorbid conditions such as hypoxia and cognitive impairment on the part of the person with dementia which made it difficult for people with dementia to describe symptoms. People with dementia were faced with delayed or less frequent doctor's visits due to fear of infection, lockdown, and lack of transportation. People with dementia reported feeling fine while reports from their care partners or family members indicated signs and symptoms of COVID-19 like temperatures of 102F.

Because providers were unable to see patients in person, telemedicine was instituted as an alternative. However, unexpected difficulties were experienced which led to provider dissatisfaction and perceived low-quality care. Video calls caused confusion for some people with dementia who were unable to focus or participate. Providers relied on care partners during telemedicine visits when people with dementia were unable to share symptoms thus facilitating early diagnosis and prompt treatment, preventing spread of the virus, and decreasing severity of symptoms.

The pandemic significantly altered providers' relationship with patients and how they communicated with them causing concern about their ability to promote treatment adherence for patients with dementia. In disseminating accurate and up-to-date information about COVID-19, providers were sensitive about how they relayed information to care partners for people with dementia so as not to cause anxiety. Providers' awareness of appropriate information and delivery could be considered as a method for preventing emotional reactions (a psychosocial need and Proximal Factor) which might lead to BPSDs.

CNA Care

CNAs reported increased burden because care required more time and there was lack of trained personnel or family members to relieve them or provide respite care. Infection prevention, assessing the resident for COVID symptoms, personal care, and gowning up and out was necessary. Sitters noted that extra patience was required and might have influenced BSPDs by reducing emotional responses and altering the social environment for people with dementia.

Protective Measures

Protective measures played a crucial role in preventing the spread of COVID-19. Some people with dementia understood the importance of using protective measures and reported wearing masks, social distancing, using hand sanitizers, and practicing hand washing. Care partners, CNAs, and providers all reported using some protective measures such as face masks/shields, social distancing, hand hygiene, and respiratory etiquette to decrease the spread of COVID-19. As previously reported, (Sesilia Fransiska & Purnamawati, 2021; Lio et al., 2021) findings indicated that protective measures were hard for people with dementia who had severe cognitive impairments, physical frailty, and older age, hence, they were more at risk than the general population. The use of protective measures had been discussed in previous literature with various samples (Talic et al., 2021); however, this is the first time discussed by all four cases (people with dementia, care partners, CNAs/sitters, and providers). Protective measures likely contributed at least in part to BPSDs in that they caused anxiety and confusion for people living with dementia.

COVID-19 vaccines played a significant role in preventing the spread of the virus. Vaccinated individuals reduced likelihood of transmitting the virus to others and resulted in less severe symptoms than the unvaccinated. Testing and contact tracing identified and isolated infected individuals helped break the chain of transmission and prevent further spread of the virus. Findings indicated that people with dementia who got vaccinated were less worried about contacting the virus. Providers felt like as more information about the vaccine became available, there was improvement in healthcare delivery including more in-person visits, longer time spent with patients, and decreased quarantine time. The vaccine brought a sense of hope for care partners who noted decreased mortality rates and more time spent with family and friends. People with dementia felt that life was back to normal, CNAs/ sitters became less fearful with more available education and availability of rapid testing and medication for COVID-19.

Up to Date

Many changes have taken place since the beginning of the pandemic up to now. People no longer wear masks. There is more information about vaccines, prevention and treatment that has improved healthcare delivery related to COVID-19. The reduction in the number of quarantine days and access to vaccinations were clear indications to alleviate strict rules that governed the use of protective measures.

Vaccines

There is less worry especially for people with dementia who were vaccinated because they felt they had some type of immunity from the vaccine and no longer needed to wear a mask. The introduction of vaccines brought a lot of hope and reduced mortality rates and fear. Care partners got the vaccine as a precaution to protect people with dementia and themselves. Some providers were concerned that family members refused to have their loved ones with dementia get vaccinated.

Life is Back to Normal

People with dementia felt like life was now back to normal after getting the vaccines and they were able to go out more. Care partners felt less scared. Providers were more comfortable because of vaccine availability. Providers were able to spend more time with the patient than when the pandemic first started. Providers resumed in home visits or private settings versus using Zoom or telemedicine that was the norm during the pandemic. CNAs felt that people were more educated and aware about the COVID-19 virus, less fearful, and medications were readily available if someone were infected. The availability of rapid testing for screening made diagnosis quick and geared towards prompt treatment. Care givers felt like things were getting back to normal and celebrated the holidays together with family and friends.

Unexpected Findings

The impact of the pandemic on the cost of living is complex and multifaceted, varying across countries and even within different regions of the same country. Care partners and CNAs reported increased cost of living and inflationary pressure of various goods and services including gas, housing, and grocery items in general. Past literature findings supported this data in that care partners experienced financial hardship due to COVID-19 and increased expenses (Hwang et al., 2021; Rusowicz et al., 2021). People with dementia noted lack of resources and supplies such as toilet paper and groceries which could have been caused by disruptions in supply chains and reduced production.

Strength and Limitations

Strengths of this study include use of a theoretical model (Algase's Need-driven Dementia-compromised Behavior Model). Multiple cases provided an opportunity to triangulate data from diverse perspectives. The research addressed a current and significant phenomenon. The racial make-up of the sample consisting of mostly African Americans population was a strength in that little is known about COVID-19 experiences from this population in the US. Limitations were related to the small sample and participants were recruited from one geographical location. All care partners were females. The study was a qualitative design; qualitative studies focus on depth of understanding rather than generalizability. The majority of participants were female. This study was limited to the perceptions of people with dementia, care partners, CNAs/sitters, and providers from the beginning of the pandemic (2020) up to date and while the study findings can be applied to other pandemic/disasters, additional studies need to be conducted in the near future or in other types of disasters to continue to contribute to science.

Recommendations for Research, Practice and Policy

Future research should include larger samples in various geographical areas, longitudinal, mixed methods, and quantitative studies, and explore strategies to mitigate the negative impact of social isolation on people with dementia and care partners. Randomized controlled trials might examine the effectiveness of diverse interventions to determine the most effective approaches to reducing negative psycho-emotional outcomes for people with dementia and care partners during a pandemic or disaster. The long-term effects of living with dementia or caring for a loved one with dementia should be examined.

In incorporating artificial intelligence (AI) into future research, researchers should design and develop AI algorithms that can analyze the collected data and generate insights to leverage machine learning technologies such as supervised or unsupervised learning to identify relationships between symptoms, triggers, and potential interventions.

Diverse approaches to reducing psycho-emotional effects for people with dementia and care partners are recommended. According to previous research by Bergmann and Wagner (2021), staffing shortages, representative of the proximal factor, social environment, added to the burden of caring for a person with dementia. Care partners in this study did not feel that the lack of personnel increased stress; however, providers were concerned that lack of staff and care partner burnout might lead to abuse of people with dementia. To reduce care partner burden and the psycho-emotional effects of social isolation and BPSDs, virtual education programs (Carbone et al., 2021), counselling (Cohen, Russo, Campos, & Allegri, 2020b) and support groups (DiLorito et al., 2021) could provide creative ideas for engaging loved ones with dementia in activities as well as promote skill building for managing BPSDs (Wong et al., 2021). Online memory cafes were initiated during COVID which provided a reprieve for care partners (Masoud et al., 2021) and have the potential to reduce stress and burden. Phone check-ins by volunteers or students might help to alleviate care partner stress and anxiety. Employers could allow flexible schedules that would support work / life balance for care partners (Suárez-González, Rajagopalan, Livingston, & Alladi, 2021). Finally, nurses must be alert to care partners' physical and mental health and advocate for appropriate and timely care and intervention (Hwang, Connell, Rajpara, & Hodgson, 2021). Online social visits by students for people with dementia can help prevent social isolation (Kimzey, Patterson, & Mastel-Smith, 2021a).

The use of telemedicine and remote support services during the pandemic emerged as a valuable tool for healthcare professionals and caregivers to provide continuous care, support, and monitoring for people with dementia. However, there were challenges and findings are unique to this study. Future telemedicine technologies should be modified to be efficient and easy to use especially for people with dementia. Instructions on how to use telemedicine devices should simple, clear, and include images that can be understood by people with dementia. Volunteer tech support would benefit people with dementia, care partners, and providers (Dowson et al., 2021). Telemedicine providers should offer continuous training for healthcare professionals, people with dementia, their care partners, and CNAs including those that are directly or indirectly involved in the care or services for people with dementia. The unique challenges and limitations that were faced by people with dementia using telemedicine can be addressed by involving care partners during telemedicine visits specifically by helping to set up devices and connecting to the meeting platform, facilitating communication during visits, orienting the person with dementia, and creating a calm and comfortable environment.

Policy changes that address the needs of people with dementia in the community and long-term care are required. A new variant might emerge at any time; therefore, these recommendations should be considered priority and instituted as soon as possible. Emergency plans for people with dementia should be evaluated and updated to include people with dementia and their care partners during a pandemic. Governmental agencies should prepare to provide consistent information that is accessible via reliable and familiar communication delivery methods (Talbot & Briggs, 2021). Increased staffing requirements for long-term and home care services must be anticipated to prevent staff and caregiver burnout. Funding should be allocated for initial and continuing education for CNAs and respite services. Regulatory bodies can monitor long-term care facilities to ensure emergency preparedness plans are current and implemented accordingly. Clear instructions, troubleshooting guides, and helpline assistance for both people with dementia and care partners should be provided. User-friendly platforms with minimal steps and clear instructions will help make set goals and plans attainable. This can be achieved through continuous training, software updates, and evaluation. Care partners (Suárez-González, Rajagopalan, Livingston, & Alladi, 2021), people with dementia, and long-term care residents should be given priority when vaccines are distributed. Given that only two-thirds of the U.S. population has Internet access, resources should be allocated to allow remote consultations and virtual interventions for all Americans using telemedicine (Wong et al., 2021) which have shown promising results in managing symptoms and reducing the risk of infection (Angelopoulou et al., 2022). Ultimately, collaboration across sectors and diverse stakeholders must comprehensively come together to support people with dementia and care partners during future pandemics or disasters (Vislapuu et al., 2021).

Summary and Conclusions

The purpose of this study was to understand the perceptions of people with dementia, care partners, CNAs/sitters, and providers during the COVID-19 pandemic, from onset until now, to help formulate better ways to care for people with dementia during a pandemic or disaster. Algase's Need-driven Dementia-compromised Behavior Model (Algase et al., 1996) guided the study. Theoretical propositions for the four Proximal factors were identified and supported the findings for potential causes of BPSDs. Wearing a mask caused discomfort for people with dementia triggering anxiety. Emotional responses (psychosocial needs), changes in daily routine (physical environment) and staffing changes (social environment) all had the potential to cause BPSDs. Physiological needs, a Proximal Factor, and propositions related to

Background factors were not evident in data collected. The framework was an effective model for examining the impact of COVID-19 pandemic for people with dementia, care partners, CNAs/sitters, and providers. The model identified behavioral expressions of people with dementia is because of unmet needs. During future pandemics or disasters, addressing the needs for people with dementia using person-centered care has the potential to yield better physical and mental health outcomes for both the person with dementia and care partners.

References

Algase, D. L., Beck, C., Kolanowski, A., Whall, A., Berent, S., Richards, K., & Beattie, E. (1996). Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. *American Journal of Alzheimer's Disease*, *11*(6), 10–19. https://doi.org/10.1177/153331759601100603

Altieri, M., & Santangelo, G. (2021). The psychological impact of COVID-19 pandemic and lockdown on caregivers of people with dementia. *The American Journal of Geriatric Psychiatry, 29*(1), 27–34. https://doi.org/10.1016/j.jagp.2020.10.009

Angelopoulou, E., Papachristou, N., Bougea, A., Stanitsa, E., Kontaxopoulou, D., Fragkiadaki, S., Pavlou, D., Koros, C., Değirmenci, Y., Papatriantafyllou, J., Thireos, E., Politis, A., Tsouros, A., Bamidis, P., Stefanis, L., & Papageorgiou, S. (2022). How telemedicine can improve the quality of care for patients with alzheimer's disease and related dementias? A narrative review. *Medicina*, *58*(12), 1705. https://doi.org/10.3390/medicina58121705

Anthony, S., & Jack, S. (2009). Qualitative case study methodology in nursing research: An integrative review. *Journal of Advanced Nursing, 65*(6), 1171–1181. https://doi.org/10.1111/j.1365-2648.2009.04998.x

Azevedo, L. V. dos S., Calandri, I. L., Slachevsky, A., Graviotto, H. G., Vieira, M. C. S., Andrade, C. B. de, Rossetti, A. P., Generoso, A. B., Carmona, K. C., Pinto, L. A. C., Sorbara, M., Pinto, A., Guajardo, T., Olavarria, L., Thumala, D., Crivelli, L., Vivas, L., Allegri, R. F., Barbosa, M. T., & Serrano, C. M. (2021). Impact of social isolation on people with dementia and their family caregivers. *Journal of Alzheimer's Disease, Preprint* (Preprint), 607–617. https://doi.org/10.3233/JAD-201580

Bacsu, J.-D., O'Connell, M. E., Cammer, A., Azizi, M., Grewal, K., Poole, L., Green, S., Sivananthan, S., & Spiteri, R. J. (2021a). Using Twitter to understand the COVID-19 experiences of people with dementia: Infodemiology study. *Journal of Medical Internet Research*, *23*(2). https://doi.org/10.2196/26254

Bacsu, J.-D. R., O'Connell, M. E., Webster, C., Poole, L., Wighton, M. B., & Sivananthan, S. (2021b). A scoping review of COVID-19 experiences of people living with dementia. *Canadian Journal of Public Health*, *112*(3), 400–411. https://doi.org/10.17269/s41997-021-00500-z

Banerjee, D., Vajawat, B., Varshney, P., & Rao, T. S. S. (2021). Perceptions, experiences, and challenges of physicians involved in dementia care during the COVID-19 lockdown in India: A qualitative study. *Frontiers in Psychiatry*, *11*. https://doi.org/10.3389/fpsyt.2020.615758

Bergmann, M., & Wagner, M. (2021). The impact of covid-19 on informal caregiving and care receiving across Europe during the first phase of the pandemic. *Frontiers in Public Health*, *9*. https://doi.org/10.3389/fpubh.2021.673874

Cagnin , A., Di Lorenzo, R., Marra, C., Bonanni, L., Cupidi, C., Laganà, V., Rubino, E., Vacca, A., Provero, P., Isella, V., Vanacore, N., Agosta, F., Appollonio, I., Caffarra, P., Pettenuzzo, I., Sambati, R., Quaranta, D., Guglielmi, V., Logroscino, G., … Bruni, A. C. (2020). Behavioral and psychological effects of coronavirus disease-19 quarantine in patients with dementia. *Frontiers in Psychiatry*, *11*. https://doi.org/10.3389/fpsyt.2020.578015

Carbone, E., Palumbo, R., Di Domenico, A., Vettor, S., Pavan, G., & Borella, E. (2021). Caring for People with Dementia Under COVID-19 Restrictions: A Pilot Study on Family Caregivers. *Frontiers in Aging Neuroscience, 13*(652833), 1–7. https://doi.org/10.3389/fnagi.2021.652833

Carpinelli, M. M., Iavarone, A., Musella, C., De Luca, M., de Vita, D., Branciforte, S., Coppola, A., Scarpa, R., Raimondo, S., Sorrentino, S., Lualdi, F., & Postiglione, A. (2020). Time of isolation, education and gender influence the psychological outcome during COVID-19 lockdown in caregivers of patients with dementia. *European Geriatric Medicine, 11*(6), 1095–1098. https://doi.org/10.1007/s41999-020-00413-z

Centers for Disease Control and Prevention (CDC). (2020). *Understanding risk*. Centers for Disease Control and Prevention. Retrieved September 30, 2022, from https://www.cdc.gov/coronavirus/2019-ncov/your-health/understanding-risk.html

Cohen, G., Russo, M. J., Campos, J. A., & Allegri, R. F. (2020a). Living with dementia: Increased level of caregiver stress in times of COVID-19. *International Psychogeriatrics, 32*(11), 1377–1381. https://doi.org/10.1017/s1041610220001593

Cohen, G., Russo, M. J., Campos, J. A., & Allegri, R. F. (2020b). COVID-19 Epidemic in Argentina: Worsening of behavioral symptoms in elderly subjects with dementia living in the community. *Frontiers in Psychiatry*, *11*(866). https://doi.org/10.3389/fpsyt.2020.00866

Creswell, J. W., & Creswell, J. D. (2023). *Research design qualitative, quantitative, and mixed methods approaches*. SAGE.

Daley, S., Farina, N., Hughes, L., Armsby, E., Akarsu, N., Pooley, J., Towson, G., Feeney, Y., Tabet, N., Fine, B., & Banerjee, S. (2022). COVID-19 and the quality of life of people with dementia and their carers—The TFD-C19 study. *PLOS ONE, 17*(1), 1–13. e0262475. https://doi.org/10.1371/journal.pone.0262475

Di Lorito, C., Masud, T., Gladman, J., Godfrey, M., Dunlop, M., Bosco, A., & Harwood, R. H. (2021). Deconditioning in people living with dementia during the COVID-19 pandemic: qualitative study from the Promoting Activity, Independence, and Stability in Early Dementia (PrAISED) process evaluation. *BMC Geriatrics, 21*(529), 1–10. https://doi.org/10.1186/s12877-021-02451-z

Dowson, B., Atkinson, R., Barnes, J., Barone, C., Cutts, N., Donnebaum, E., Hung Hsu, M., Lo Coco, I., John, G., Meadows, G., O'Neill, A., Noble, D., Norman, G., Pfende, F., Quinn, P., Warren, A., Watkins, C., & Schneider, J. (2021). Digital approaches to music-making for people with dementia in response to the COVID-19 pandemic: Current practice and recommendations. *Frontiers in Psychology, 12*. https://doi.org/10.3389/fpsyg.2021.625258

Ecker, S., Pinto, S., Sterling, M., Wiggins, F., & Ma, C. (2021). Working experience of certified nursing assistants in the greater New York City area during the COVID-19 pandemic: Results from a survey study. *Geriatric Nursing (New York, N.Y.), 42*(6), 1556–1561. https://doi.org/10.1016/j.gerinurse.2021.10.007

Giebel, C., Cannon, J., Hanna, K., Butchard, S., Eley, R., Gaughan, A., Komuravelli, A., Shenton, J., Callaghan, S., Tetlow, H., Limbert, S., Whittington, R., Rogers, C., Rajagopal, M., Ward, K., Shaw, L., Corcoran, R., Bennett, K., & Gabbay, M. (2020a). Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: A qualitative study. *Aging & Mental Health, 25*(7), 1281–1288. https://doi.org/10.1080/13607863.2020.1822292

Giebel, C., Lord, K., Cooper, C., Shenton, J., Cannon, J., Pulford, D., Shaw, L., Gaughan, A., Tetlow, H., Butchard, S., Limbert, S., Callaghan, S., Whittington, R., Rogers, C., Komuravelli, A., Rajagopal, M., Eley, R., Watkins, C., Downs, M., Reilly, S., Ward, K., Corcoran, R., Bennett, K., Gabbay, M. (2020). A UK survey of Covid-19 related social support closures and their effects on older people, people with dementia, and carers. *International Journal of Geriatric Psychiatry, 36*(3), 393–402. https://doi.org/10.1002/gps.5434

Hanna, K., Giebel, C., Tetlow, H., Ward, K., Shenton, J., Cannon, J., Komuravelli, A., Gaughan, A., Eley, R., Rogers, C., Rajagopal, M., Limbert, S., Callaghan, S., Whittington, R., Butchard, S., Shaw, L., & Gabbay, M. (2021). Emotional and mental wellbeing following covid-19 public health measures on people living with dementia and carers. *Journal of Geriatric Psychiatry and Neurology, 35*(3), 344–352. https://doi.org/10.1177/0891988721996816

Hariyanto, T. I., Putri, C., Arisa, J., Situmeang, R. F., & Kurniawan, A. (2021). Dementia and outcomes from coronavirus disease 2019 (covid-19) pneumonia: A systematic review and meta-analysis. *Archives of Gerontology and Geriatrics, 93*, 104299. https://doi.org/10.1016/j.archger.2020.104299

Hughes, M. C., Liu, Y., & Baumbach, A. (2021). Impact of COVID-19 on the health and well-being of informal caregivers of people with dementia: A rapid systematic review. *Gerontology and Geriatric Medicine*, *7*, 1–8. 233372142110201. https://doi.org/10.1177/23337214211020164

Hwang, Y., Connell, L. M., Rajpara, A. R., & Hodgson, N. A. (2021). Impact of COVID-19 on dementia caregivers and factors associated with their anxiety symptoms. *American Journal of Alzheimer's Disease & Other Dementias-*, *36*, 1–8. 153331752110087. https://doi.org/10.1177/15333175211008768

International, A. D., & Organization, W. H. (2016, June 1). ADI - Help for care partners of people with dementia. *Alzheimer's Disease International (ADI)*. https://www.alzint.org/resource/help-for-care-partners-of-people-with-dementia/

Kimzey, M., Patterson, J., & Mastel-Smith, B. (2021a). Nursing students visiting people with dementia online during COVID-19: A qualitative study. *Journal of Intergenerational Relationships*, *20*(1), 1–17. https://doi.org/10.1080/15350770.2021.1985033

Keng, A., Brown, E. E., Rostas, A., Rajji, T. K., Pollock, B. G., Mulsant, B. H., & Kumar, S. (2020). Effectively caring for individuals with behavioral and psychological symptoms of dementia during the COVID-19 pandemic. *Frontiers in Psychiatry, 11*. https://doi.org/10.3389/fpsyt.2020.573367

Kuroda, Y., Sugimoto, T., Satoh, K., Suemoto, C. K., Matsumoto, N., Uchida, K., Kishino, Y., & Sakurai, T. (2022). Factors associated with behavioral and psychological symptoms of dementia during COVID-19. *International Journal of Environmental Research and Public Health*, *19*(16), 10094. https://doi.org/10.3390/ijerph191610094

Lee, J., Baik, S., Becker, T. D., & Cheon, J. H. (2021). Themes describing social isolation in family caregivers of people living with dementia: A scoping review. *Dementia*, *21*(2), 701–721. https://doi.org/10.1177/14713012211056288

Lio, C. F., Cheong, H. H., Lei, C. I., Lo, I. L., Yao, L., Lam, C., & Leong, I. H. (2021). Effectiveness of personal protective health behaviour against COVID-19. *BMC Public Health*, *21*(1). https://doi.org/10.1186/s12889-021-10680-5

Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S. G., Dias, A., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Kivimäki, M., Larson, E. B., Ogunniyi, A., & Orgeta, V. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, *396*(10248), 413–446. PMID: 32738937. https://doi.org/10.1016/S0140-6736(20)30367-6

Matias-Guiu, J. A., Pytel, V., & Matías-Guiu, J. (2020). Death rate due to COVID-19 in Alzheimer's disease and frontotemporal dementia. *Journal of Alzheimer's Disease: JAD, 78*(2), 537–541. https://doi.org/10.3233/JAD-200940

Numbers, K., & Brodaty, H. (2021). The effects of the COVID-19 pandemic on people with dementia. *Nature Reviews Neurology, 17*(2), 69–70. https://doi.org/10.1038/s41582-020-00450-z

Orgeta, V., Mukadam, N., Sommerlad, A., & Livingston, G. (2018). The Lancet Commission on dementia prevention, intervention, and care: A call for action. *Irish Journal of Psychological Medicine, 36*(2), 85–88. https://doi.org/10.1017/ipm.2018.4

O'Shea, E. (2020). Remembering people with dementia during the COVID-19 crisis. *HRB Open Research, 3,* 15. https://doi.org/10.12688/hrbopenres.13030.1

Pentecost, C., Collins, R., Stapley, S., Victor, C., Quinn, C., Hillman, A., Litherland, R., Allan, L., & Clare, L. (2022). Effects of social restrictions on people with dementia and carers during the pre-vaccine phase of the COVID-19 pandemic: Experiences of ideal cohort participants. *Health & Social Care in the Community,* 10.1111/hsc.13863. https://doi.org/10.21203/rs.3.rs-1403858/v1

Pongan, E., Dorey, J.-M., Borg, C., Getenet, J. C., Bachelet, R., Lourioux, C., Laurent, B., Rey, R., & Rouch, I. (2021). COVID-19: Association between increase of behavioral and psychological symptoms of dementia during lockdown and caregivers' poor mental health. *Journal of Alzheimer's Disease, 80*(4), 1713–1721. https://doi.org/10.3233/jad-201396

Portacolone, E., Chodos, A., Halpern, J., Covinsky, K. E., Keiser, S., Fung, J., Rivera, E., Tran, T., Bykhovsky, C., & Johnson, J. K. (2021). The effects of the COVID-19 pandemic on the lived experience of diverse older adults living alone with cognitive impairment. *The Gerontologist, 61*(2), 251–261. https://doi.org/10.1093/geront/gnaa201

Portney, L. G., &Watkins, M.P. (2015). Descriptive research. *Foundations of Clinical Research Aapplications to Practice* (3rd ed, Chapter 14, p. 314-318). Philadelphia, PA: Davis Company.

Rajagopalan, J., Arshad, F., Hoskeri, R. M., Nair, V. S., Hurzuk, S., Annam, H., Varghese, F., BR, R., Dhiren, S. R., Ganeshbhai, P. V., Kammammettu, C., Komaravolu, S., Thomas, P. T., Comas-Herrera, A., & Alladi, S. (2021). Experiences of people with dementia and their caregivers during the COVID-19 pandemic in India: A mixed-methods study. *Dementia, 21*(1), 214–235. https://doi.org/10.1177/14713012211035371

Rising, K. L., Salcedo, V. J., Amadio, G., Casten, R., Chang, A., Gentsch, A., O'Hayer, C. V., Sarpoulaki, N., Worster, B., & Gerolamo, A. M. (2022). Living through the pandemic: The voices of persons with dementia and their caregivers. *Journal of Applied*

Gerontology: The Official Journal of the Southern Gerontological Society, 41(1), 30–35. https://doi.org/10.1177/07334648211036399

Roach, P., Zwiers, A., Cox, E., Fischer, K., Charlton, A., Josephson, C. B., Patten, S. B., Seitz, D., Ismail, Z., & Smith, E. E. (2020). Understanding the impact of the COVID-19 pandemic on well-being and virtual care for people living with dementia and care partners living in the community. *Dementia (London), 20*(6), 2007-2023. https://doi.org/10.1101/2020.06.04.20122192

Rusowicz, J., Pezdek, K., & Szczepańska-Gieracha, J. (2021). Needs of Alzheimer's charges' caregivers in Poland in the COVID-19 pandemic—An Observational Study. *International Journal of Environmental Research and Public Health, 18*(9), 4493–4494. https://doi.org/10.3390/ijerph18094493

Sánchez-Teruel, D., Robles-Bello, M. A., Sarhani-Robles, M., & Sarhani-Robles, A. (2021). Exploring resilience and well-being of family caregivers of people with dementia exposed to mandatory social isolation by COVID-19. *Dementia*, *21*(2), 410–425. 147130122110421. https://doi.org/10.1177/14713012211042187

Sesilia Fransiska, S., & Purnamawati, D. (2021). Compliance with the use of personal protective equipment against the transmission of covid-19 in medical personnel. *Muhammadiyah International Public Health and Medicine Proceeding*, *1*(1), 485–490. https://doi.org/10.53947/miphmp.v1i1.93

Sorbara, M., Graviotto, H. G., Lage-Ruiz, G. M., Turizo-Rodriguez, C. M., Sotelo-López, L. A., Serra, A., Gagliardi, C., Heinemann, G., Martinez, P., Ces-Magliano, F., & Serrano, C. M. (2021). COVID-19 and the forgotten pandemic: Follow-up of neurocognitive disorders during lockdown in Argentina. *Neurología (English Edition), 36*(1), 9–15. https://doi.org/10.1016/j.nrleng.2020.07.014

Sriram, V., Jenkinson, C., & Peters, M. (2021). Impact of COVID-19 restrictions on carers of persons with dementia in the UK: A qualitative study. *Age and Ageing, 50*(6), 1876–1885. https://doi.org/10.1093/ageing/afab156

Suárez-González, A., Rajagopalan, J., Livingston, G., & Alladi, S. (2021). The effect of COVID-19 isolation measures on the cognition and mental health of people living with dementia: A rapid systematic review of one year of quantitative evidence. *EClinicalMedicine, 39*(101047), 1–7. https://doi.org/10.1016/j.eclinm.2021.101047

Talbot, C. V., & Briggs, P. (2021). ‘Getting back to normality seems as big of a step as going into lockdown’: The impact of the COVID-19 pandemic on people with early to middle stage dementia. *Age and Ageing, 50*(3), 657–663. https://doi.org/10.1093/ageing/afab012

Talic, S., Shah, S., Wild, H., Gasevic, D., Maharaj, A., Ademi, Z., Li, X., Xu, W., Mesa-Eguiagaray, I., Rostron, J., Theodoratou, E., Zhang, X., Motee, A., Liew, D., & Ilic, D. (2021). Effectiveness of public health measures in reducing the incidence of COVID-19, SARS-COV-2 transmission, and COVID-19 mortality: Systematic review and meta-analysis. *BMJ*. https://doi.org/10.1136/bmj-2021-068302

Tam, M. T., Dosso, J. A., & Robillard, J. M. (2021). The impact of a global pandemic on persons living with dementia and their care partners: An analysis of 417 survey responses. *Alzheimer's & Dementia, 17*(S7). https://doi.org/10.1002/alz.049480

Thyrian, J. R., Kracht, F., Nikelski, A., Boekholt, M., Schumacher-Schönert, F., Rädke, A., Michalowsky, B., Vollmar, H. C., Hoffmann, W., Rodriguez, F. S., & Kreisel, S. H. (2020). The situation of elderly with cognitive impairment living at home during lockdown in the Corona-pandemic in Germany. *BMC Geriatrics, 20*(540), 1–15. https://doi.org/10.1186/s12877-020-01957-2

Tsapanou, A., Papatriantafyllou, J. D., Yiannopoulou, K., Sali, D., Kalligerou, F., Ntanasi, E., Zoi, P., Margioti, E., Kamtsadeli, V., Hatzopoulou, M., Koustimpi, M., Zagka, A., Papageorgiou, S. G., & Sakka, P. (2020). The impact of COVID-19 pandemic on people with mild cognitive impairment/dementia and on their caregivers. *International Journal of Geriatric Psychiatry, 36*(4), 583–587. https://doi.org/10.1002/gps.5457

Tsapanou, A., Zoi, P., Kalligerou, F., Blekou, P., & Sakka, P. (2021). The effect of prolonged lockdown due to COVID-19 on Greek demented patients of different stages and on their caregivers. *Journal of Alzheimer's Disease, 83*(2), 907–913. https://doi.org/10.3233/jad-210702

Vislapuu, M., Angeles, R. C., Berge, L. I., Kjerstad, E., Gedde, M. H., & Husebo, B. S. (2021). The consequences of COVID-19 lockdown for formal and informal resource utilization among home-dwelling people with dementia: results from the prospective PAN.DEM study. *BMC Health Services Research, 21*(1003), 1–12. https://doi.org/10.1186/s12913-021-07041-8

West, E., Nair, P., Barrado-Martin, Y., Walters, K. R., Kupeli, N., Sampson, E. L., & Davies, N. (2021). Exploration of the impact of the COVID-19 pandemic on people with dementia and carers from black and minority ethnic groups. *BMJ Open, 11*(5), 1–10. e050066. https://doi.org/10.1136/bmjopen-2021-050066

Wong, B. P., Kwok, T. C., Chui, K. C., Cheng, T. S., Ho, F. K., & Woo, J. (2021). The impact of dementia daycare service cessation due to COVID-19 pandemic. *International Journal of Geriatric Psychiatry*, 1–11. https://doi.org/10.1002/gps.5621

Alzheimer’s Disease International. (2016, June 1). *Help for care partners of people with dementia*. https://www.alzint.org/resource/help-for-care-partners-of-people-with-dementia/

World Health Organization. (2022). *Dementia.* World Health Organization. https://www.who.int/news-room/fact-sheets/detail/dementia

World Health Organization. (2021). *Dementia cases set to triple by 2050 but still largely ignored.* World Health Organization. https://www.who.int/news/item/11-04-2012-dementia-cases-set-to-triple-by-2050-but-still-largely-ignored.

World Health Organization. (2020, p.1). *Coronavirus disease (COVID-19) pandemic.* World Health Organization. https://www.who.int/europe/emergencies/situations/covid-19

World Health Organization (WHO). (2021, September 24). *Dementia.* Dementia cases set to triple by 2050 but still largely ignored. https://www.who.int/news/item/11-04-2012-dementia-cases-set-to-triple-by-2050-but-still-largely-ignored

World Health Organization. (2020a). *Background.* https://apps.who.int/iris/bitstream/handle/10665/332197/WHO-2019-nCoV-FAQ-Virus_origin-2020.1-eng.pdf

World Health Organization (2020b). *Genomic sequencing of SARS-COV-2*. https://apps.who.int/iris/rest/bitstreams/1326052/retrieve

World Health Organization. (2019). *Dementia.* World Health Organization. https://www.who.int/news-room/fact-sheets/detail/dementia

Yang, H., Liang, X., Hou, H., Xu, J., Shi, L., & Wang, Y. (2021). The association of dementia with COVID-19 mortality: Evidence based on adjusted effect estimates. *Journal of Infection*, https://doi.org/10.1016/j.jinf.2021.02.013.

Yin, R. K. (2018). *Case Study Research and Applications: Design and Methods* (6th ed.). Sage.

Appendix A

Recruitment Flyer

VOLUNTEERS NEEDED FOR RESEARCH STUDY

I am a nurse working on my PhD at The University of Texas at Tyler. I am recruiting people with **early-stage dementia**, **care partners**, **CNAs/sitters,** and **providers** to share their experiences during COVID-19. I am interested to learn how the pandemic (COVID-19) affected you. The study will take place online or in person. If you want to participate online, you will need:

- Access to the Internet
- A computer, phone or tablet with microphone and camera
- To be able to log onto a video meeting –it is ok to have help logging on.

What you will do:

- Call or email the researcher for information if you're interested.
- Meet with the research nurse (Gaudensia Awuor) for about 30 – 45 minutes.
- Answer some questions about yourself and what it was like for you during COVID-19, lockdown until now.

Please contact Gaudensia Awuor at gawuor@patriots.uttyler.edu or (817-903-7723) if you are interested in participating.

Appendix B

Demographic Survey - People with Dementia

Please complete the following:

What is your age in years: _________

How long have you been diagnosed with dementia? ________________________________

What type of dementia do you have? ________________________

Check ONE box that best describes you:

American Indian or Alaska Native

Hawaiian or Other Pacific Islander

Asian or Asian American

Black or African American

Hispanic or Latino

Non-Hispanic White

What is your gender?

Female

Male

Other: (Please describe) ____

What's your marital status?

Single

Married

Partnered

Widowed

Divorced

Separated

Other: (Please describe) ____

What is your current employment status?

Self-employed

Employed (full-time)

Employed (part-time)

Unemployed

Student

Retired

Other: (Please describe) ____

What is the highest grade or year of school you completed?

Grade 12 or GED (High school graduate) ________________

Associate or higher degree (Some college or technical school) ___________

Bachelor's degree (College graduate) _________________

Master's or higher degree (Advance Degree) ___________________

What is your occupation? ____

Describe your annual income:

<$50,000/year

> $50,000/year

Current living setting?

In a nursing home

Assisted Care Facility

Apartment complex

Private Home

With a relative: specify ________________

Other________________________________

Relationship with care partners if any?

Spouse

Boyfriend/Girlfriend

Brother/Sister

Son/Daughter

Mother/Father

Other____

Appendix C

Demographic Survey - CNAs/Sitters

Please complete the following:

Please write your age in years: _________

Check ONE box that best describes you:

American Indian or Alaska Native

Hawaiian or Other Pacific Islander

Asian or Asian American

Black or African American

Hispanic or Latino

Non-Hispanic White

What is your gender?

Female

Male

Other: (Please describe) ____

What's your marital status?

Single

Married

Partnered

Widowed

Divorced

Separated

Other: (Please describe) ____

What is your current employment status (check all that apply)

Self-employed

Employed (full-time)

Employed (part-time)

Unemployed

Student

Retired

Other: (Please describe) ____

What is the highest grade or year of school you completed?

Grade 12 or GED (High school graduate) ________________

Associate or higher degree (Some college or technical school) ___________

Bachelor degree (College graduate) _________________

Master's or higher degree (Advance Degree) ___________________

What is your occupation? ____

How many years have you worked as a CNA/Sitter? _____months /or/ ____ years

What is your workplace setting?

Private duty

Nursing home/Assisted living

Acute care setting/Hospital

Appendix D

Demographic Survey - Providers

Please complete the following to the best of your ability:

Please write your age in years: _________

What's your current employment status working with people with dementia?

Employed (full-time)

Employed (part-time)

Please estimate the percentage of time you spend in direct patient care: ____________

What is your title?

Medical Doctor

Doctor of Osteopathy

Advanced Registered Nurse Practitioner

Physician Assistant

How many years have you been in your current role working with people with dementia?

____

Appendix E

Demographic Survey - Care Partners

Please complete the following:

What is your age in years: _________

For how long you have been caring for your friend/loved one with dementia?

_________________years/months

Check ONE box that best describes you:

American Indian or Alaska Native

Hawaiian or Other Pacific Islander

Asian or Asian American

Black or African American

Hispanic or Latino

Non-Hispanic White

What is your gender?

Female

Male

Other: (Please describe) ____

What's your marital status?

Single

Married

Partnered

Widowed

Divorced

Separated

Other: (Please describe) ____

What is your current employment status?

Self-employed

Employed (full-time)

Employed (part-time)

Unemployed

Student

Retired

Other: (Please describe) ____

What is the highest grade or year of school you completed?

Grade 12 or GED (High school graduate) ________________

Associate or higher degree (Some college or technical school) ___________

Bachelor degree (College graduate) _________________

Master's or higher degree (Advance Degree) ___________________

What is your occupation? ____

Describe your annual income:

>$50,000 /year

<$50,000 /year

Current living setting?

In a nursing home

Assisted Care Facility

Apartment complex

Private Home

With a relative

Other________________________________

Relationship with Persons with dementia?

Spouse

Boyfriend/Girlfriend

Brother/Sister

Son/Daughter

Mother/Father

Other____

Appendix F

Semi-Structured Interview Guide: People with Dementia

1. Think back to when the COVID-19 pandemic started. The following questions will ask about your experiences. (The question will be directed specifically to the participant being interviewed.)
2. What was it like living with dementia during the pandemic?
3. What kinds of things affected you during COVID-19? Please be specific.
4. How did the pandemic affect your health?
5. How were your everyday activities affected by the pandemic?
6. Can you please explain how your experiences during COVID change from the beginning when we first learned about the virus until now?

Appendix G

Semi-Structured Interview Guide: Care Partners

1. Think back to when the COVID-19 pandemic started. The following questions will ask about your experiences. (The question will be directed specifically to the participant being interviewed.)
2. What was it like caring for your loved one with dementia during COVID-19?
3. What kinds of things affected your caring for someone with dementia during COVID-19?
4. Can you please explain how the pandemic affected the health of your family member with dementia?
5. How did the pandemic affect your health?
6. Did your experiences during COVID change from the beginning when we first learned about the virus until now? Please explain.

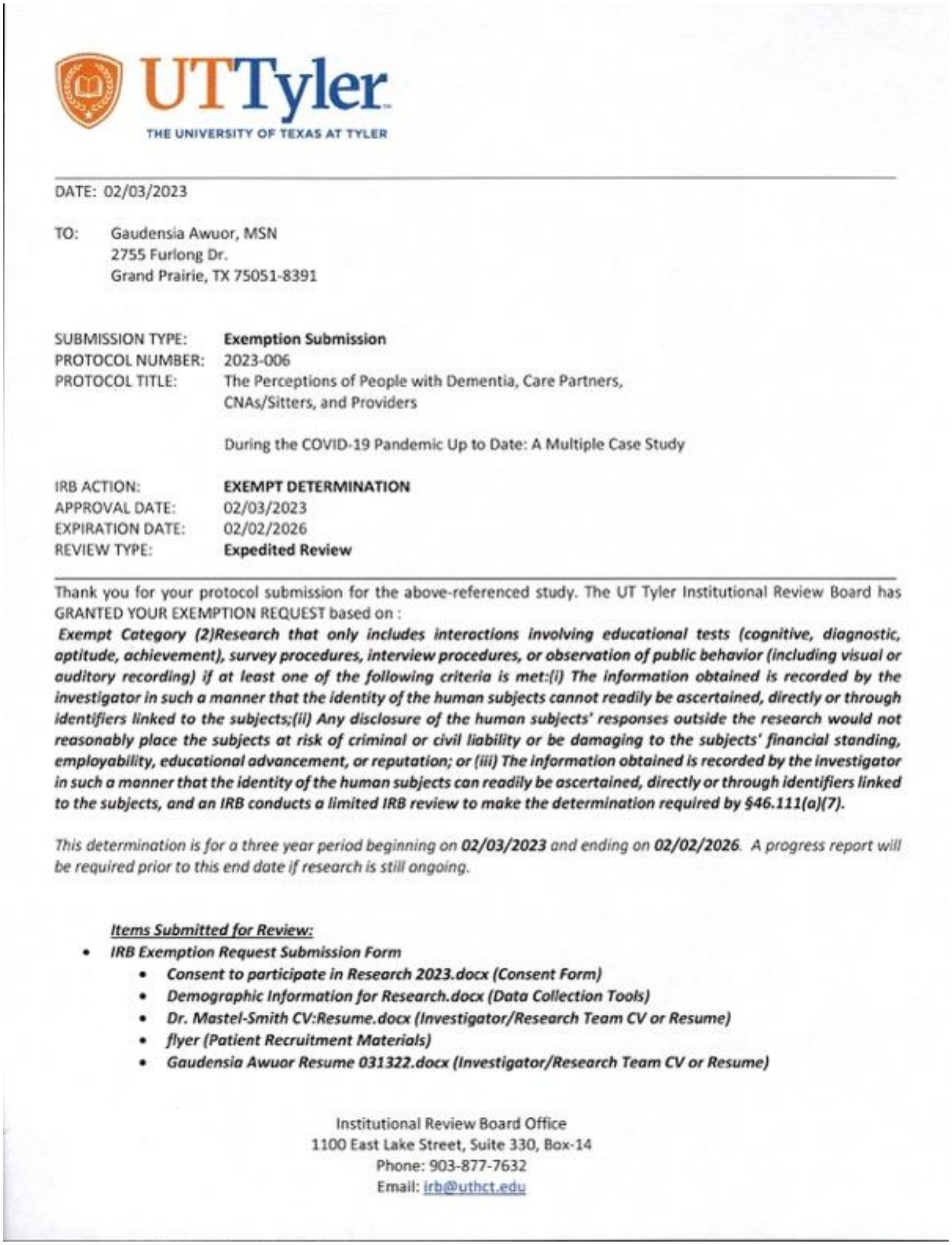
Appendix H

Semi-Structured Interview Guide: CNAs/Sitter, and Providers

1. Think back to when the COVID-10 pandemic started. The following questions will ask about your experiences. (The question will be directed specifically to the participant being interviewed.)
2. What was it like caring for patients with dementia during COVID-19 pandemic`?
3. What kinds of things affected your caring for someone with dementia during COVID-19?
4. Can you please explain how the pandemic affected the health of your clients with dementia?
5. Did your experiences during COVID change from the beginning when we first learned about the virus until now? Please explain.

Appendix I

IRB Approval Letter



UTTyler
THE UNIVERSITY OF TEXAS AT TYLER

DATE: 02/03/2023

TO: Gaudensia Awuor, MSN
2755 Furlong Dr.
Grand Prairie, TX 75051-8391

SUBMISSION TYPE: **Exemption Submission**
PROTOCOL NUMBER: 2023-006
PROTOCOL TITLE: The Perceptions of People with Dementia, Care Partners, CNAs/Sitters, and Providers

During the COVID-19 Pandemic Up to Date: A Multiple Case Study

IRB ACTION: **EXEMPT DETERMINATION**
APPROVAL DATE: 02/03/2023
EXPIRATION DATE: 02/02/2026
REVIEW TYPE: **Expedited Review**

Thank you for your protocol submission for the above-referenced study. The UT Tyler Institutional Review Board has GRANTED YOUR EXEMPTION REQUEST based on :
Exempt Category (2)Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met:(i) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects;(ii) Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or (iii) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by §46.111(a)(7).

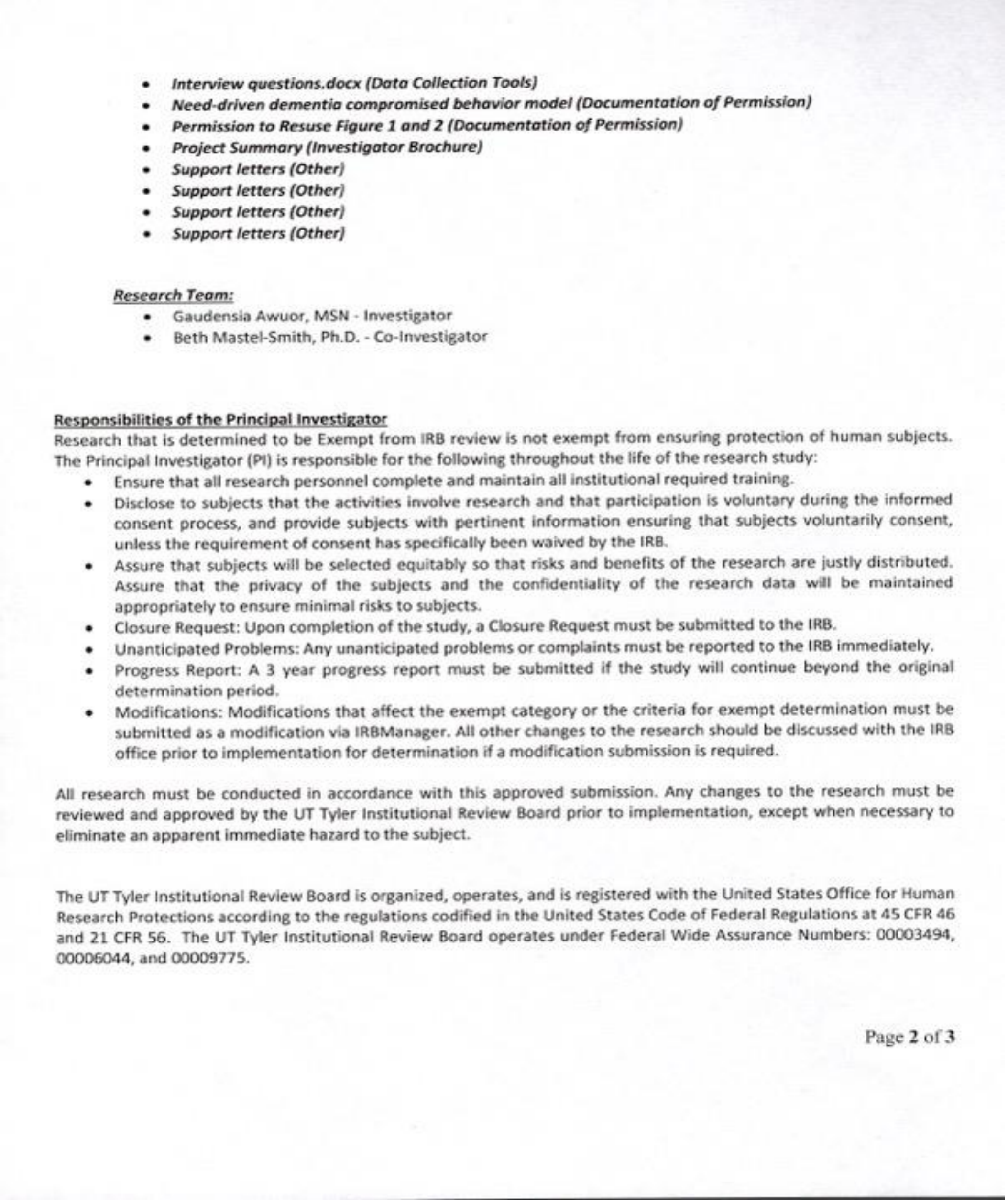
This determination is for a three year period beginning on ***02/03/2023*** *and ending on* ***02/02/2026****. A progress report will be required prior to this end date if research is still ongoing.*

Items Submitted for Review:

- ***IRB Exemption Request Submission Form***
  - ***Consent to participate in Research 2023.docx (Consent Form)***
  - ***Demographic Information for Research.docx (Data Collection Tools)***
  - ***Dr. Mastel-Smith CV:Resume.docx (Investigator/Research Team CV or Resume)***
  - ***flyer (Patient Recruitment Materials)***
  - ***Gaudensia Awuor Resume 031322.docx (Investigator/Research Team CV or Resume)***

Institutional Review Board Office
1100 East Lake Street, Suite 330, Box-14
Phone: 903-877-7632
Email: irb@uthct.edu

Appendix I continued



- ***Interview questions.docx (Data Collection Tools)***
- ***Need-driven dementia compromised behavior model (Documentation of Permission)***
- ***Permission to Resuse Figure 1 and 2 (Documentation of Permission)***
- ***Project Summary (Investigator Brochure)***
- ***Support letters (Other)***
- ***Support letters (Other)***
- ***Support letters (Other)***
- ***Support letters (Other)***

Research Team:

- Gaudensia Awuor, MSN - Investigator
- Beth Mastel-Smith, Ph.D. - Co-Investigator

Responsibilities of the Principal Investigator

Research that is determined to be Exempt from IRB review is not exempt from ensuring protection of human subjects. The Principal Investigator (PI) is responsible for the following throughout the life of the research study:

- Ensure that all research personnel complete and maintain all institutional required training.
- Disclose to subjects that the activities involve research and that participation is voluntary during the informed consent process, and provide subjects with pertinent information ensuring that subjects voluntarily consent, unless the requirement of consent has specifically been waived by the IRB.
- Assure that subjects will be selected equitably so that risks and benefits of the research are justly distributed. Assure that the privacy of the subjects and the confidentiality of the research data will be maintained appropriately to ensure minimal risks to subjects.
- Closure Request: Upon completion of the study, a Closure Request must be submitted to the IRB.
- Unanticipated Problems: Any unanticipated problems or complaints must be reported to the IRB immediately.
- Progress Report: A 3 year progress report must be submitted if the study will continue beyond the original determination period.
- Modifications: Modifications that affect the exempt category or the criteria for exempt determination must be submitted as a modification via IRBManager. All other changes to the research should be discussed with the IRB office prior to implementation for determination if a modification submission is required.

All research must be conducted in accordance with this approved submission. Any changes to the research must be reviewed and approved by the UT Tyler Institutional Review Board prior to implementation, except when necessary to eliminate an apparent immediate hazard to the subject.

The UT Tyler Institutional Review Board is organized, operates, and is registered with the United States Office for Human Research Protections according to the regulations codified in the United States Code of Federal Regulations at 45 CFR 46 and 21 CFR 56. The UT Tyler Institutional Review Board operates under Federal Wide Assurance Numbers: 00003494, 00006044, and 00009775.

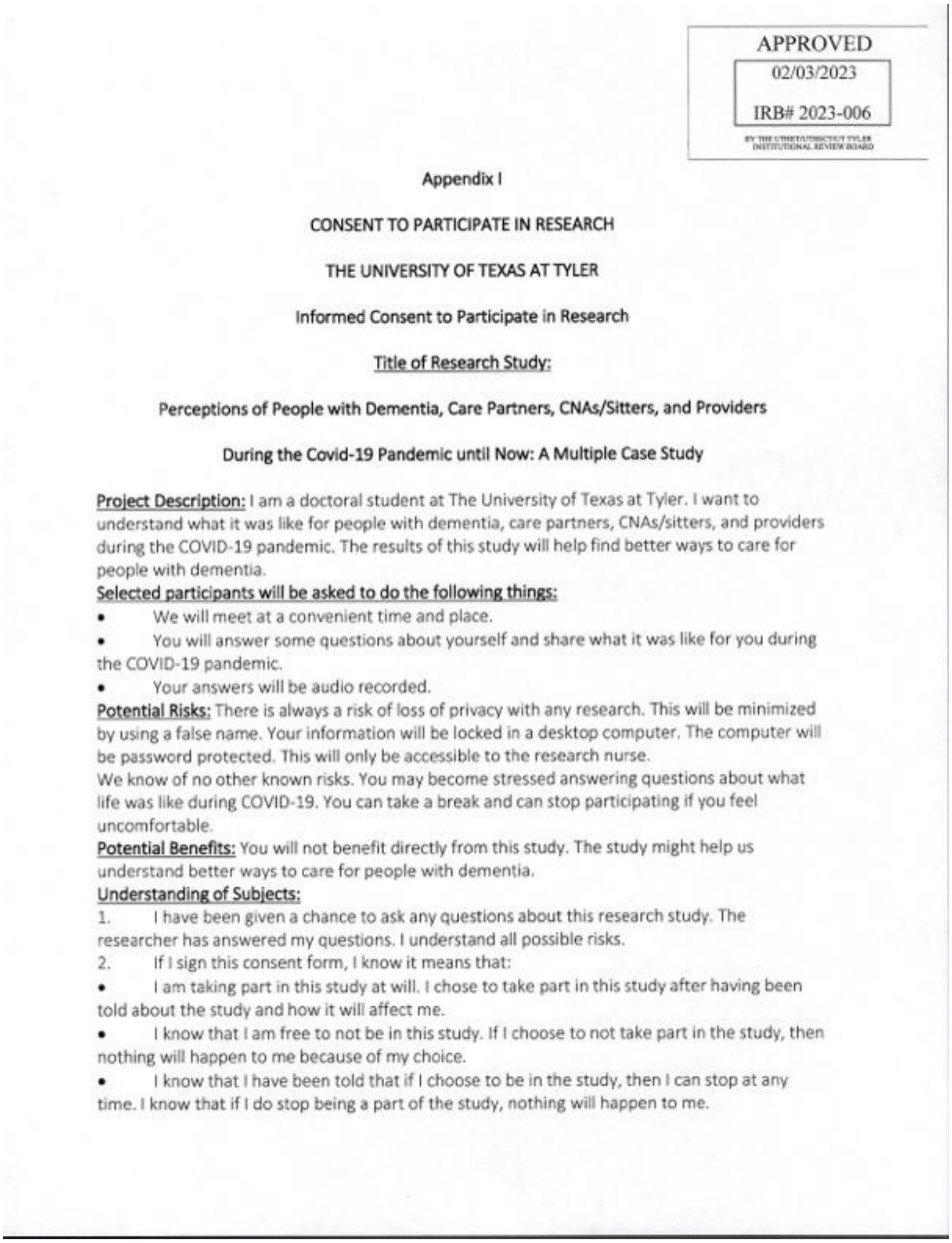
Appendix I continued

Any complaints or issues of non-compliance must be immediately reported to this office. If you have any questions or comments about this correspondence, please contact the IRB Office at 903-877-7632 or irb@uthct.edu

Sincerely,
The Institutional Review Board

Appendix J

Approved Consent Form



APPROVED
02/03/2023
IRB# 2023-006
BY THE [illegible] TYLER
INSTITUTIONAL REVIEW BOARD

Appendix I

CONSENT TO PARTICIPATE IN RESEARCH

THE UNIVERSITY OF TEXAS AT TYLER

Informed Consent to Participate in Research

Title of Research Study:

Perceptions of People with Dementia, Care Partners, CNAs/Sitters, and Providers During the Covid-19 Pandemic until Now: A Multiple Case Study

Project Description: I am a doctoral student at The University of Texas at Tyler. I want to understand what it was like for people with dementia, care partners, CNAs/sitters, and providers during the COVID-19 pandemic. The results of this study will help find better ways to care for people with dementia.

Selected participants will be asked to do the following things:

- We will meet at a convenient time and place.
- You will answer some questions about yourself and share what it was like for you during the COVID-19 pandemic.
- Your answers will be audio recorded.

Potential Risks: There is always a risk of loss of privacy with any research. This will be minimized by using a false name. Your information will be locked in a desktop computer. The computer will be password protected. This will only be accessible to the research nurse.

We know of no other known risks. You may become stressed answering questions about what life was like during COVID-19. You can take a break and can stop participating if you feel uncomfortable.

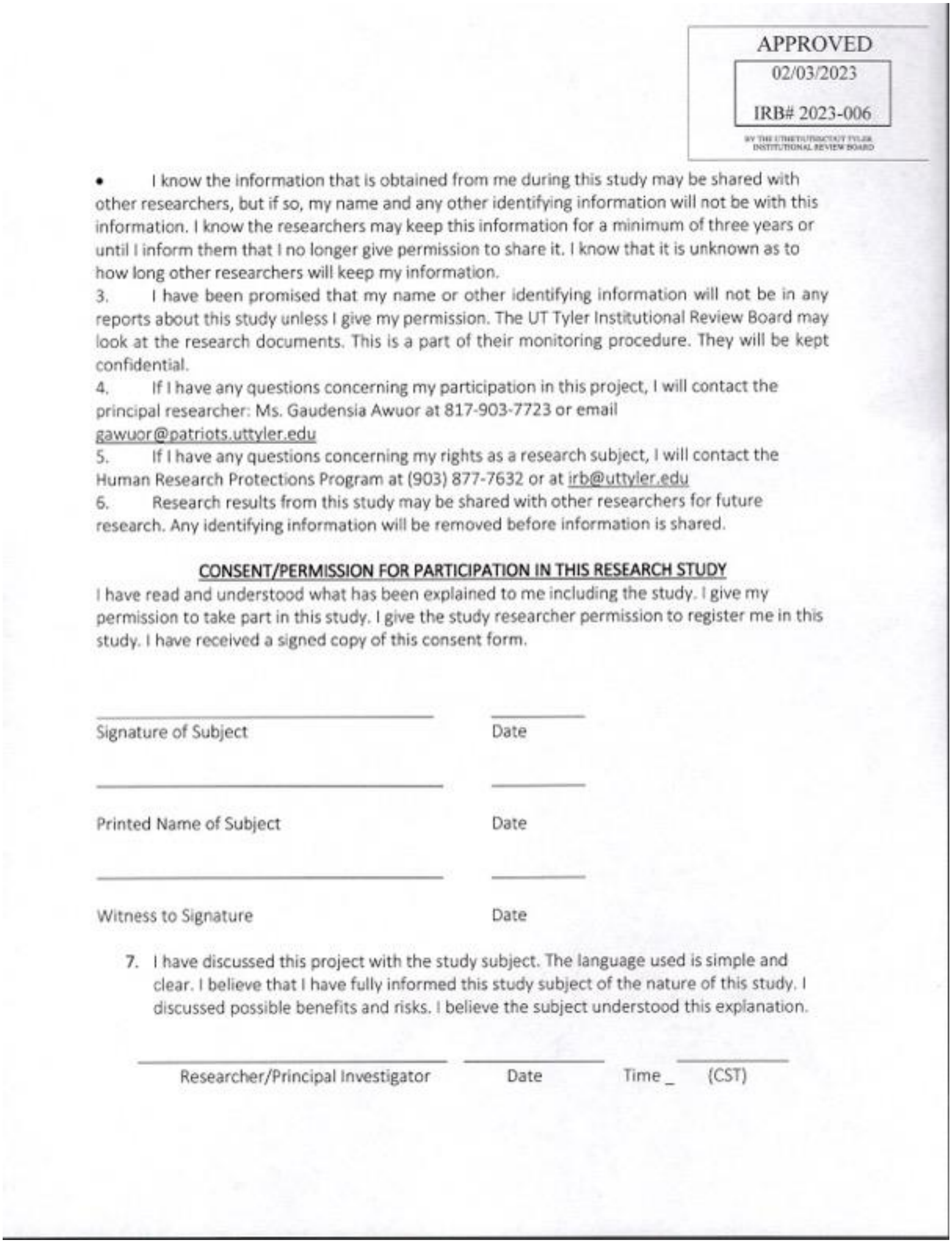
Potential Benefits: You will not benefit directly from this study. The study might help us understand better ways to care for people with dementia.

Understanding of Subjects:

1. I have been given a chance to ask any questions about this research study. The researcher has answered my questions. I understand all possible risks.
2. If I sign this consent form, I know it means that:

- I am taking part in this study at will. I chose to take part in this study after having been told about the study and how it will affect me.
- I know that I am free to not be in this study. If I choose to not take part in the study, then nothing will happen to me because of my choice.
- I know that I have been told that if I choose to be in the study, then I can stop at any time. I know that if I do stop being a part of the study, nothing will happen to me.

Appendix J continued



APPROVED
02/03/2023
IRB# 2023-006
BY THE [illegible] TYLER
INSTITUTIONAL REVIEW BOARD

- I know the information that is obtained from me during this study may be shared with other researchers, but if so, my name and any other identifying information will not be with this information. I know the researchers may keep this information for a minimum of three years or until I inform them that I no longer give permission to share it. I know that it is unknown as to how long other researchers will keep my information.

3. I have been promised that my name or other identifying information will not be in any reports about this study unless I give my permission. The UT Tyler Institutional Review Board may look at the research documents. This is a part of their monitoring procedure. They will be kept confidential.
4. If I have any questions concerning my participation in this project, I will contact the principal researcher: Ms. Gaudensia Awuor at 817-903-7723 or email gawuor@patriots.uttyler.edu
5. If I have any questions concerning my rights as a research subject, I will contact the Human Research Protections Program at (903) 877-7632 or at irb@uttyler.edu
6. Research results from this study may be shared with other researchers for future research. Any identifying information will be removed before information is shared.

CONSENT/PERMISSION FOR PARTICIPATION IN THIS RESEARCH STUDY

I have read and understood what has been explained to me including the study. I give my permission to take part in this study. I give the study researcher permission to register me in this study. I have received a signed copy of this consent form.

Signature of Subject Date

Printed Name of Subject Date

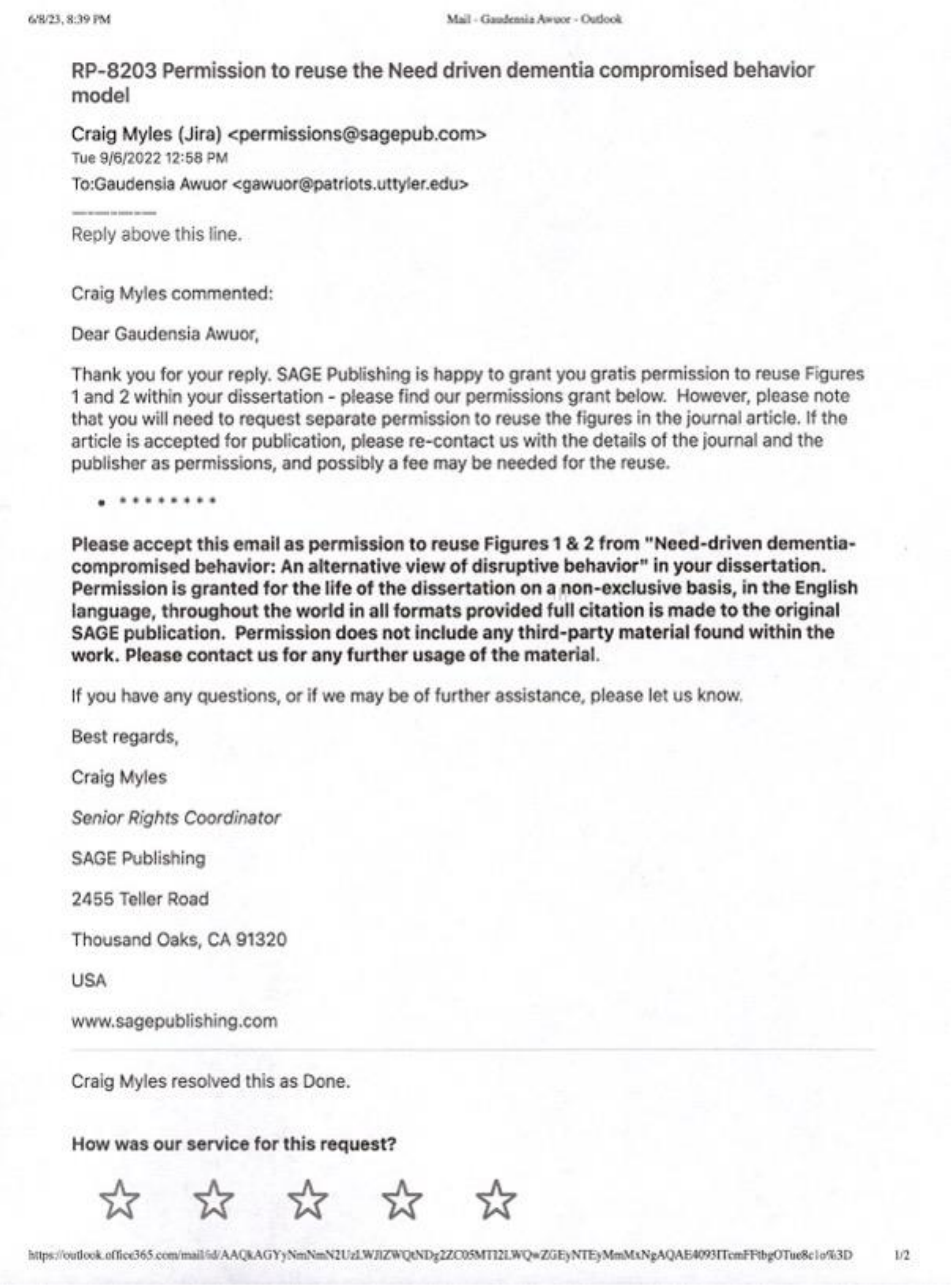
Witness to Signature Date

7. I have discussed this project with the study subject. The language used is simple and clear. I believe that I have fully informed this study subject of the nature of this study. I discussed possible benefits and risks. I believe the subject understood this explanation.

Researcher/Principal Investigator Date Time _ (CST)

Appendix K

Permission to Reuse the Need-driven Dementia-compromised Behavioral Model.



6/8/23, 8:39 PM Mail - Gaudensia Awuor - Outlook

RP-8203 Permission to reuse the Need driven dementia compromised behavior model

Craig Myles (Jira) <permissions@sagepub.com>
Tue 9/6/2022 12:58 PM
To:Gaudensia Awuor <gawuor@patriots.uttyler.edu>

———

Reply above this line.

Craig Myles commented:

Dear Gaudensia Awuor,

Thank you for your reply. SAGE Publishing is happy to grant you gratis permission to reuse Figures 1 and 2 within your dissertation - please find our permissions grant below. However, please note that you will need to request separate permission to reuse the figures in the journal article. If the article is accepted for publication, please re-contact us with the details of the journal and the publisher as permissions, and possibly a fee may be needed for the reuse.

- * * * * * * * *

Please accept this email as permission to reuse Figures 1 & 2 from "Need-driven dementia-compromised behavior: An alternative view of disruptive behavior" in your dissertation. Permission is granted for the life of the dissertation on a non-exclusive basis, in the English language, throughout the world in all formats provided full citation is made to the original SAGE publication. Permission does not include any third-party material found within the work. Please contact us for any further usage of the material.

If you have any questions, or if we may be of further assistance, please let us know.

Best regards,

Craig Myles

Senior Rights Coordinator

SAGE Publishing

2455 Teller Road

Thousand Oaks, CA 91320

USA

www.sagepublishing.com

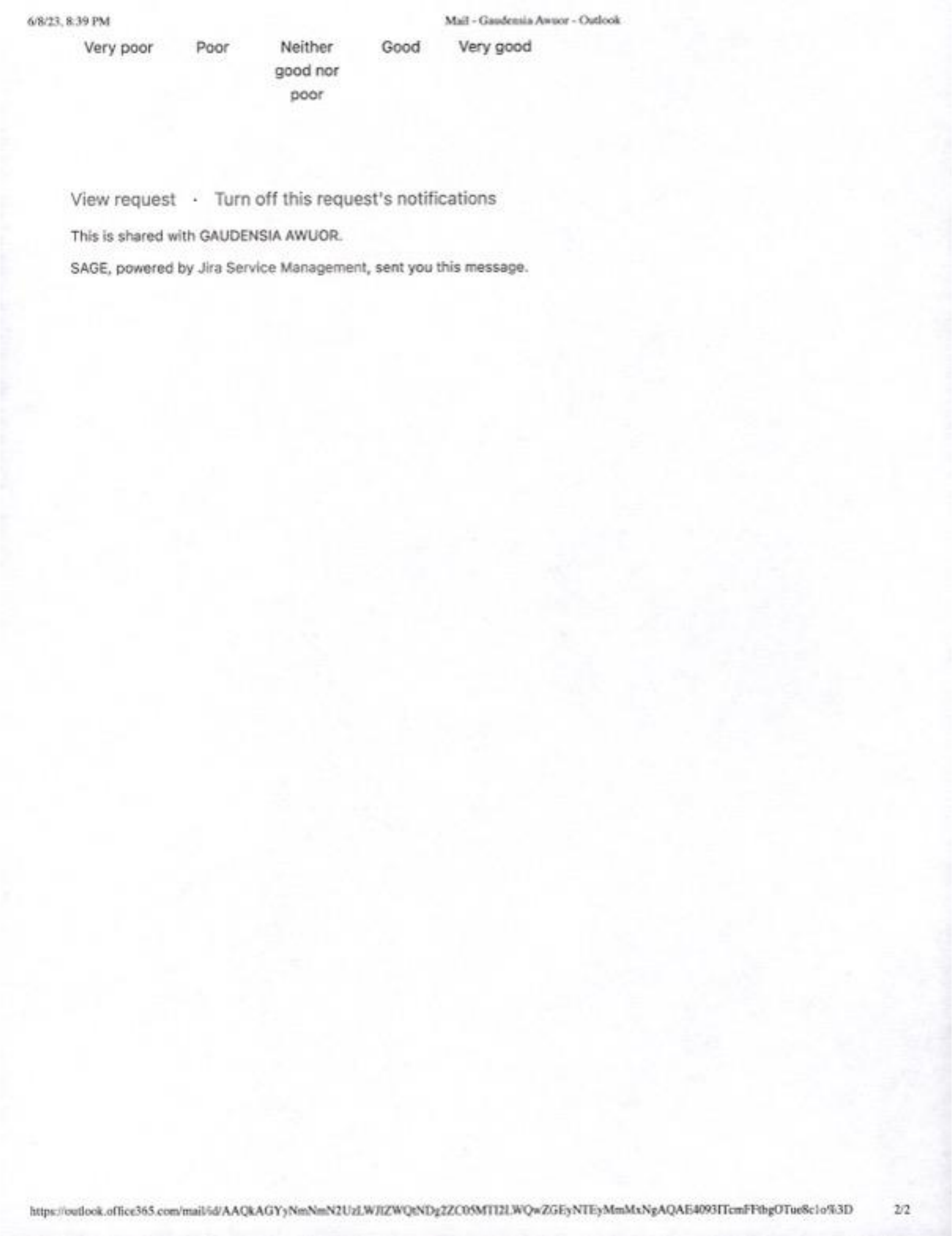
Craig Myles resolved this as Done.

How was our service for this request?

☆ ☆ ☆ ☆ ☆

https://outlook.office365.com/mail/id/AAQkAGYyNmNmN2UzLWJlZWQtNDg2ZC05MTI2LWQwZGEyNTEyMmMxNgAQAE4093ITcmFFtbgOTue8c1o%3D 1/2

Appendix K continued



6/8/23, 8:39 PM Mail - Gaudensia Awuor - Outlook

Very poor	Poor	Neither good nor poor	Good	Very good

View request · Turn off this request's notifications

This is shared with GAUDENSIA AWUOR.

SAGE, powered by Jira Service Management, sent you this message.

https://outlook.office365.com/mail/id/AAQkAGYyNmNmN2UzLWJlZWQtNDg2ZC05MTI2LWQwZGEyNTEyMmMxNgAQAE4093ITcmFFtbgOTue8c1o%3D 2/2

Appendix L

Biographical Sketch

NAME: Gaudensia Awuor

POSITION TITLE: Family Nurse Practitioner

EDUCATION/TRAINING

INSTITUTION AND LOCATION	DEGREE	END DATE	FIELD OF STUDY
El Centro College (Dallas County Community College, Dallas, Texas	ADN	2006	Nursing
Texas Tech University Health Sciences Center, Lubbock, Texas	BSN	2007	Nursing
The University of Texas at Arlington, Arlington, Texas.	MSN	2011	Advanced Practice Nursing –FNP-C
University of Texas at Tyler, Tyler, Texas	PhD	2023	Nursing

Personal Statement

My experience in nursing covers a period of 22 years when I started as a home health aide, then certified nursing assistant, medical aide, later on to a licensed vocational nurse, to a registered nurse up to my current position as a PhD candidate. I have worked in various clinical settings including intensive care unit, medical-surgical, emergency room, doctors' offices, home health services and hospice. I enjoy direct patient care and the additional knowledge that contributes to better quality of health.

Throughout my life, I have been captivated by the wonders of science and the potential it holds to transform lives. As a young girl, I volunteered to work at a local hospital where I worked in an AIDS unit to provide direct patient care. I developed a keen interest in patient care and the intricate mechanisms that govern life on earth. This fascination led me to pursue a career in nursing, where I aspire to contribute to the advancement of knowledge and the development of innovative healthcare solutions.

During my undergraduate studies in Nursing, I gained clinical experience, working alongside medical professionals and nurses in various clinical settings including emergency rooms, intensive care units, medical-surgical units, labor and delivery, post-partum units, psychiatrist nursing and operation units. These experiences allowed me to delve into the world of nursing, where I honed my practical skills, developed a meticulous approach to documentation, and learned to navigate the complexities of various hand-on skills. I was particularly drawn to the field of intensive care and worked as a registered nurse in the intensive care unit most part after my graduation.

I pursued a master's degree in nursing, with a certificate specializing in family practice. My project work focused on identifying the most preferred bowel cleansing product for individuals going for a colonoscopy. Through this project, I gained valuable expertise in conducting research studies as a principal investigator by interviewing over 300 patients prior to their colonoscopy to get their perception about the kind of bowel prep product they used.

Besides my expertise in clinical nursing, I am a strong believer in the power of collaboration and interdisciplinary approaches. I thrive in team environments where diverse perspectives converge to solve complex problems. I am eager to work alongside experts from various disciplines, bridging the gap between the current technology, science, and clinical application.

My journey has been defined by a deep passion for direct patient care, treatment regimen using a holistic approach and a commitment to scientific research and a drive to make a tangible impact in the field of nursing and beyond. I am excited to continue with the next chapter of my professional journey, where I hope to contribute to groundbreaking discoveries and improve the lives of patients through innovative discoveries in combination of new scientific technologies like artificial intelligence (AI), ChatGPT5, and LangChain.

Positions and Employment

2021–Current	Nurse Practitioner, North Texas Medical Specialists, Plano, TX
2014-2016	Nurse Practitioner, Esteem Hospice LLC, Carrollton, TX
2017–Current	Administrator/DON, Perfection Hospice Care Inc, Grand Prairie, TX
2014–2019	Nurse Practitioner, Perfection Housecalls of Texas, Grand Prairie, TX
2013–2015	Nurse Practitioner, Per Diem, Care Now, Dallas/Fort Worth, TX
2012-2015	Nurse Practitioner, Premier Housecalls Physicians, Dallas, TX.

Professional Memberships

2012–Current	American Association of Nurse Practitioners
2006- Current	Texas Nurses Association

Honors

2008	Magna Cum Laude, Texas Tech University Health Sciences Center