

THE IMPACT OF CAREGIVING ON CAREGIVER'S IDENTITY IN DEMENTIA

by

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THESIS ABSTRACT

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Title: The Impact of Caregiving on Caregiver's Identity in Dementia

The purpose of this research was to explore how caring responsibilities impact caregivers' identity over time in first-time caregivers of parents with dementia. Further aims were to gain a deeper understanding of the "invisible second patient" perspective and identify ways to promote reduction of disparities among caregiver identity subgroups.

This was a phenomenological study utilizing semi-structured interviews to capture longitudinal change in caregiver identity over a five-month interview period. Questions arose regarding caregiver identity such as how familial care relationships shape one's caregiver identity.

Participation in this study appears to be therapeutic to participants and appeared to engender greater reflection of self overall. This study promotes further research into the impact of caregiving on caregivers' identity as well as the continued need for support services that are culturally responsive to improve the health and well-being of the caregiver and their recipients.

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CHAPTER I

INTRODUCTION

Definition of Clinical Problem

Informal caregiving is a popular care option for individuals with aging parents, with nearly 17.7 million individuals providing such care in the United States (Alzheimer's Association, 2023). Informal caregiving is defined as the activity of providing care to a member of a vulnerable population (e.g., children, elderly, ill) usually by someone who is known or has a pre-existing relationship with the care recipient (e.g., parent, sibling, friend), and who provides care void of compensation. Nearly half (48%) of the 17.7 million informal caregivers in the United States provide care to older adults with Alzheimer's or other forms of dementia (Alzheimer's Association, 2023). As the prevalence of dementia in the United States is projected to rise from seven million to between nine and twelve million in the next twenty years (Alzheimer's Association, 2023), this number of caregivers is only expected to grow.

Dementia is a group of symptoms highlighted by memory loss, impacted communication, and decline in bodily functions (Centers for Disease Control and Prevention, 2019). The symptoms characteristic of dementia presents themselves when changes occur in the brain's neurons. Changes like loss of neuronal connection and cell death contribute to widespread brain atrophy in the final stages of dementia (U.S. Department of Health and Human Services, 2017). Symptoms are dependent on where the damage within the brain has occurred; therefore, symptoms may be variable. Changes in the brain also happen progressively, or they worsen over time. Given the vast functional impacts and neurodegenerative nature of the disease, people with dementia require high levels of care that increase over time, care which is usually provided by

informal caregivers like family members (Brodaty & Donkin, 2009). The projected rise in dementia cases means there will be an even greater demand for informal caregivers to provide care to these individuals with dementia (Ydstebø et al., 2020). As a result, more family members are likely to be entering a caregiving role for the first time.

With nearly half of the informal caregiving population caring for an older adult with dementia, it is not uncommon for an adult child to take on caring responsibilities for their aging parents. There are several benefits associated with the informal caregiving process, for both the person receiving care and the person providing care. For the individuals with dementia, they get to remain living at home thus reducing burden on the healthcare system and improving their overall quality of life (Lloyd et al., 2016). More generally, older adults who continue to reside at home experience decreased mortality rates, increased feelings of security, and are better able to maintain informal relationships (Elkan et al., 2001; Gardner, 2011; Wiles et al., 2012). Similarly, for caregivers, providing care can be associated with feelings of satisfaction, personal growth, and improved relations between caregiver and care recipient (Onwumere et al., 2008). However, providing such care is not without cost. Recent studies have shown that providing informal care can have negative effects on the health and wellbeing of caregivers (Riffin, 2017; Jennings, 2015). For example, increased depression, decreased quality of life, and poorer health outcomes have been associated with informal caregiving (Jennings, 2015). In light of the benefits of informal caregiving and the clear economic need as the population continues to age, it is important to better understand the contributors to caregiving's costs in order to better mitigate those negative consequences.

Potentially contributing to these negative outcomes is a caregiver's acceptance of and feelings toward this role of "caregiver" (Tatangelo et al., 2018). This may be particularly salient for adult children caregivers. Since the relationship between a child and a parent is often an intimate relationship built from shared experiences and memories, it is highly susceptible to change with the progression of dementia. Due to symptoms like memory loss, dementia may threaten the shared experiences and memories held between a child and their parents (Tatangelo et al., 2018). Further, not all parent-child relationships are positive ones. Adult children may be put into the position to care for a previously neglectful or abusive parent, thus impacting the way they feel towards their caregiving role.

As the dementia disease progresses, adult children care partners may also no longer be caring for their "parent" and instead be caring for someone unrecognizable to them. Given the possibility for this stark change, it is possible for care partners to begin viewing their role as well as who they are as a person differently. For example, increased care responsibilities and deterioration of an intimate relationship may reinforce new relationship dynamics thus resulting in possible novel identities (Montgomery & Koloski, 2013). It is both the change in relationship and change in caregiving responsibilities that are suspected to contribute to the caregiver's perception of themselves, and their relationship with their parents. How an individual recognizes and adapts to these new relationships and perceptions may then contribute to positive and/or negative influences of caregiving on their health and well-being (Tatangelo et al., 2018). However, there is limited research on the long-term effects that informal caregiving, particularly when caring for a parent with dementia, has on a caregiver's perception of who they are as a

person. A better understanding of caregiver identity is needed to effectively serve the care partner and their care recipient.

Review of Literature

Caregiver identity in adults' caregiving for their parents with dementia is a multifaceted and complex subject. Firstly, we must understand that factors that may influence caregiving's influence on one's identity. Secondly, we must comprehend the formation and reciprocity of the parent-child relationship, including what it means to be an adult child caregiving for a family member.

Caregiver Identity in Informal Caregivers

A caregiver's identity, or the way in which they perceive themselves, is an area of limited research; however, it is crucial to the wellbeing of caregivers. The identity of "caregiver" may be interpreted differently depending on the level of care that individual is providing, the amount of burden the individual is experiencing, and the relationship the individual has with their care recipient (Montgomery & Koloski, 2013). For example, someone who works at a memory care facility may identify as a caregiver in a different way than someone who cares for their aging parent at home and someone caregiving for their aging parent may identify as a caregiver in a different way from someone who is caring for their aging spouse. Additionally, culture specific norms, cultural and spiritual beliefs, illness beliefs and socialization aim to characterize the way in which the identity of "caregiver" is so vast and variable (Mikolaj et al., 2022). For example, illness beliefs centered around illness timelines and consequences of illness may influence the perspective of a caregiver's role. Given that dementia's illness timeline and consequences are

often intense and strenuous on caregivers, these illness beliefs may have an impact on caregiver identity formation.

It is also important to acknowledge the caregiver disparities across identity groups as it contributes to the way in which one perceives themselves and their role. For example, Black caregivers spend on average 28.5 more hours per month providing informal care than White caregivers including more time providing higher levels of care (Cohen et al., 2019). This example highlights the need to further understand the disparities within identity subgroups and how these identities intersect with gender, race/ethnicity, and socioeconomic status. Understanding how caregiver identity is formed and interplays with other aspects of one's identity can reduce disparities and facilitate better support for caregivers.

Crucial to the discussion of caregiver's identity is the concept of caregivers as the "invisible second patient". The "invisible second patient" is the name bestowed upon informal caregivers of individuals with dementia to reflect the high rates of caregiver burden experienced by informal caregivers and their feelings toward their role in the caregiving process (Engel, 2022). This assigned name implies that informal caregivers often experience a lack of support and harbor unmet needs that may remain unintentionally concealed from others while carrying out primary caring responsibilities. This is consistent with current research on caregiver burden and support accessibility (Macleod et al., 2017; Tatangelo et al., 2018).

One contributing factor to caregiver's unmet needs is their beliefs about their obligations to the caregiving role (Macleod et al., 2017). According to the work by Macleod et al. (2017), the most common belief held amongst informal caregivers to family members with dementia was that asking for help was embarrassing or indicated they were not capable of caring for the person

with dementia. This belief only further engenders invisibility in informal caregiver populations by instilling doubt on the caregiver's capacity for executing the caregiver role. Overall, it is important for health care service providers to understand this belief as it may impact quality of care received by the care recipient as well as the caregiver's thoughts and feelings about themselves.

The Parent-Child Relationship in Caregiving

As noted previously, informal caregivers, particularly those caring for individuals with dementia, are often the adult children. Yet, what drives a child to want to care for their aging parents? There is a limited amount of research in the area of parent-child relationships and their influence on caregiving tendencies. The existing research shows that parent-child relationships are contingent on parent investment and early support (Silverstein et al., 2002). In a study exploring reciprocity in parent-child relationships, researchers found that "social support [was] dependent on earlier financial and emotional investments" (Silverstein et al., 2002, p. 5). For the purpose of the present study, "social support" is defined as providing care to one's parent(s) later in life. Therefore, whether a child provides social support is dependent on the parent's financial and emotional investment into their relationship with their child over time. While this explanation successfully captures the reciprocal relationship between parent and child, it fails to take into account the intersectional factors, such as socioeconomic status, that may contribute to a parent's ability to provide adequate financial and emotional support needed for a child to reciprocate care.

Further, if the parent-child relationship is contingent on the parent's availability and resources to invest in their child, what happens if the parent does not invest in their relationship

with their child? Research found that if a parent exhibited unavailability or was viewed from the child's perspective as "ill" or "unstable", then the child was more likely to assume a supportive role to their parent; namely, they still provided social support without reciprocation (Silverstein et al., 2002). This type of relationship, in which an individual feels compelled to maintain a relationship void of reciprocity, is called a "non-voluntary" relationship (Scharp & Thomas, 2016). Children in these relationships were found to continue to care for their aging parents despite the lack of reciprocity between the parent and the child over time.

These relationships are dynamic over time, particularly during the caregiving trajectory. One overarching theory, known as The Caregiver Identity Theory, proposed by Montgomery and Koloski (2013) suggests that the caregiving role emerges from a pre-established familial relationship such as a parent-child relationship. However, as the needs of the care recipient change with the progression of the disease, therefore increasing care responsibilities, the familial relationship is suppressed by a new relationship characterized by caregiving. The impact of this relationship shift on the individual may result in new identity formation (Montgomery & Koloski, 2013). The theory states that there are five phases to one's caregiver identity. In these five phases, the caregiver identity is realized and accepted by the care partner at the start of care responsibilities, then intensified by increasing care responsibilities, and finally disappears with the conclusion of care responsibilities. Such a theory also highlights the observation that for each individual, the caregiver role is uniquely defined, often a product of their familial experiences and cultural norms.

If the emergence of a caregiver identity is dependent on pre-established familial relationships as proposed by Montgomery and Koloski (2013), then the identity of adult children

may change when caring for their parent with dementia (Brodaty & Donkin, 2009). Current literature on adult children caregivers does not often recognize adult children as primary caregivers; rather the literature often recognizes adult children as "care managers", or more secondary/tertiary caregivers who aid the primary caregiver, like the care recipient's spouse, in making care decisions (Brodaty & Donkin, 2009). Further, due to the lack of research centering adult children as primary caregivers, there is limited knowledge on the impact of their identity over time. This is a population of caregivers who may still undergo changes to their identity from being placed in a caregiving role.

Purpose of Current Study

There is limited research on caregiver identity changes over time. This lack of research has only further perpetuated the "invisible second patient" experience as more research is needed on how the healthcare system can better ensure caregivers can access and receive the best support possible. Additionally, the implications of identity change are numerous on the health and well-being of the caregiver and the care recipient. If a caregiver is not feeling secure in their role and views their identity as a caregiver as burdensome, there is a direct line of impact on their care recipient's quality of care. Lastly, it is crucial to better understand how perception of identity may change during the caregiving process. This can dictate the type of support and to what extent of support an individual may require. With better designed supports, caregiver burden can be reduced and quality of care for the care recipient increases.

Thus, the purpose of this research was to facilitate reflection of self-identity in first-time caregivers to their parents with dementia in order to explore how their identity as a caregiver may change over time as predicted by the Caregiver Identity Theory proposed by Montgomery &

Koloski (2013). Additionally, through this research, we hope to gain a deeper understanding of the factors that may influence the invisible second patient perspective and offer hypotheses related to the trajectory of this lived experience that can inform future work. A more nuanced understanding of caregivers' self-identity as well as the invisible second patient perspective over time may impact the way in which accessible and equitable support for caregivers is achieved and promote a person-centric approach to supporting caregivers in the healthcare system.

CHAPTER II

METHODS AND PROCEDURES

All task procedures were approved by the Institutional Review Board at the University of Oregon.

Participants and Recruitment

Participants included four adults ranging in age from late twenties to late fifties ($M = 43.3$ years old; $SD = 13.0$; range = 29-57). Inclusion criteria included: at least 18 years old, are currently or have previously cared for their parent(s) with a formal diagnosis of dementia, were providing care without compensation, and had no previous caregiving training or experience. Participants were also required to have access to a reliable computer, phone, or tablet with the capability of running the virtual meeting platform, Zoom. Participants were recruited via online on social media platforms as well as closed professional groups, through local advertisements, and via word of mouth.

The purpose of the study was to engage participants in reflection regarding their caregiver identity. Given the stages predicted by the Caregiver Identity Theory (Montgomery & Koloski, 2013), we felt that the perspective of those who previously cared for a parent was also valuable to include alongside current caregivers. Although these individuals were not currently in a caregiving role, we wanted to see how former caregivers viewed themselves post caregiving involvement. The Caregiver identity Theory states that if a caregiver is no longer providing care for the care recipient with dementia, then they will no longer hold a caregiver identity. However, former caregivers may still view themselves through the lens of a caregiver and maintain a portion of their caregiver identity, which would be important to understand further.

The final participant sample included 3 females and 1 male from Oregon and Pennsylvania. A majority of participants were white ($n = 3$). Participants were caring for or had provided care for either their biological parent ($n = 3$) or stepparent ($n = 1$). See Table 1 below for an overview of participant demographic information. Three of the care recipient parents were still living, with two residing in a nursing facility and one at home. None of the care recipient parents were currently residing with their child who participated in the study. Three of the four participants identified care coordination or making long-term care decisions as their primary care responsibilities to their parent. The fourth participant, P4, reported taking on all care responsibilities for both their parents when they were alive and noted that their parents died in their home. Table 2 outlines the demographics available for the care recipient parents for each participant. The demographic information collected for both the participants and their parents represents the information self-disclosed by the participants to the researcher during the interview process. Therefore, demographic information is limited to what was said by participants. The researcher intentionally did not probe for demographic information beyond what was offered up by participants during the interviews in order to maintain participant-driven conversation and allow them the autonomy to share their stories.

Table 1. Participant demographic characteristics							
Participant ID	Sex	Race/Ethnicity	Age	Occupation	Relationship with Parent	Length of Time Caregiving for Parent	Other
P1	F	White/Caucasian	29	PhD Student	Stepdaughter – Stepfather	2 years	Married
P2	F	White/Caucasian	51	Undergraduate Student	Daughter – Biological Mother	4 years	Married Children over 18 Disabled
P3	F	White/Caucasian	36	Educational Assistant	Daughter – Biological Mother	22 years	Married Children under 18
P4	M	Asian	57	Police Officer	Son – Biological Father	12 years	Married Immigrant

Table 2. Parent demographic characteristics				
Parent ID	Sex	Age	Length of Time with Diagnosis	Current Status
P1- Parent	M	Not Available	2 years	Living at home not with participant
P2- Parent	F	Not Available	4 years	Living in nursing facility
P3- Parent	F	Not Available	3 years	Living in nursing facility
P4- Parent	M	Not Available	12 years	Deceased

Procedures and Analysis

The study took place virtually on Zoom. Prior to beginning the study, the principal investigator (PI) described the study details to the participants in a telephone screener. Due to the low-risk nature of this study, the investigators obtained only verbal consent from all participants during the screening phone call. Participants took part in five 1:1 interviews over a five-month period; one participant missed an interview resulting in a total of 19 interviews being completed. Upon completion of the study, participants received a \$150 gift card, or a prorated amount, as compensation.

All interviews were conducted by the PI, a female who, at the time of data collection, was a master's student in speech-language pathology with experience in facilitating conversations regarding personal identity. Each interview was scheduled with the PI via email 1-2 weeks prior to the interview, and a secure Zoom link was sent to participants 10-minutes before each interview. The PI sat in a secure and private location for the interviews. Participants were encouraged to join the interview from a private location. Each interview was recorded using the record feature on Zoom and uploaded to the PI's secure computer. Prior to the beginning of each recorded interview, the PI prompted the participants if they had any questions about the preceding interview or the interview process and obtained verbal consent from the participant to begin recording. Interview questions were presented one at a time, and terms were defined if the participant did not understand the question. Interviews typically ran 30-45 minutes in length. A semi-structured interview guide (see Table 3 below) was used during the interviews to facilitate open-ended conversation between the PI and the interviewees.

The interview guide was curated based off leadership facilitation best practices that the researcher was trained in prior to the creation of this study (Van Knippenberg & Hogg, 2003; Social Identity Wheel, 2021). The guide was made to aid the researcher in facilitation of identity related conversation. The researcher placed an emphasis on participant-driven conversations in order to adequately capture the unique experiences of each participant. Therefore, the questions on the interview guide were not piloted nor were they static. Questions were flexible and subject to change between participants and across the multiple interviews, depending on individual participant conversation with the researcher. Additionally, when framing the interview questions, the term “caregiver” was purposefully avoided. The researcher intentionally avoided the use of “caregiver” as this term assumes that participants identify with being a caregiver. Given the purpose of the study, it was essential that participant’s name their own identity/identities to capture verbatim the identity they resonate with in their caregiving role.

Structurally, the interview guide consisted of four initial interview questions, four recurrent interview questions, and two final interview questions. The recurrent interview questions were routinely asked at each interview with variation depending on the nature of the given interview. All recurrent interview questions were developed from the Social Identity Wheel framework put forth by University of Michigan’s Inclusive Teaching Program (Social Identity Wheel, 2021).

Table 3. Semi-Structured Interview Guide	
Initial Interview	Tell me about your current relationship with your parent(s).
	What was your relationship like growing up with your parent(s)?
	How would you describe yourself to others (outside the context of caregiving)?
	How would you have described yourself to others prior to caring for your parents?
Recurrent Questions	What part of your identity do you think about most often?
	What part of your identity do you think about least often?
	Of the identities you hold, which do you think have the strongest effect on how you perceive yourself?
	Of the identities you hold, which do you think have the greatest effect on how others perceive you?
Final Interview	How has it been to reflect on your identity over the past five months?
	What has your experience been like engaging in these interviews over the past five months?

Data from the interviews were transcribed verbatim using Word's dictation feature and refined manually using the meeting recording by the PI and an undergraduate research assistant. Qualitative research is dependent on the PI's judgement and is therefore more susceptible to influence by personal biases and idiosyncrasies. To increase the trustworthiness of the findings, the transcripts were interpreted using the bracketing method (Anderson, 2010). The bracketing method of data interpretation was used in order to (a) safeguard data against PI's personal biases therefore increasing the rigor of the study, (b) allow for the collection of emotionally complex and challenging material over time, and (c) engender deeper levels of reflection across all stages of the research process (Tufford & Newman, 2010). All this ensured that the data were gathered, interpreted, and presented without biased preconceptions or judgements from the PI.

Because the goal of the study was to capture potential change in caregiver identity over time, thematic analysis was used to identify, analyze, and report patterns or themes within the data (Anderson, 2010). Additionally, thematic analysis is often used to organize and describe large quantities of information, like interview responses. All transcripts were uploaded to Delve, an online thematic analysis tool. Transcripts were coded in order of participant identification. Each transcript was initially coded using the spoken words of the participants (*in-vivo codes*). This way of coding was helpful in highlighting the specific terms, words and phrases used by the participants to describe their experiences (Manning, 2017). Additionally, it allowed for the researcher to reduce subjectivity during the coding process and increases the study's integrity by relying on the participants themselves for giving meaning to the data. Codes were collated and examined for (a) overlap with other coded sections, and (b) a given code's occurrence across participants over time. Using an excel spreadsheet, codes were tallied for overlap with other

codes. Codes that overlapped with another code more than four times across all transcripts and participants were considered significant and highlighted. Coded sections were then reviewed and themes were developed based on overlapping codes. Additionally, codes were tallied across interviews by participants. The number of times a given code appeared in a singular interview for one participant was tallied and listed next to the participant's ID. If the participant's interview did not include a given code, the participant's ID was highlighted as absent.

CHAPTER III

RESULTS

Based on the data extracted from the 19 participant transcripts, several codes were identified and combined into two primary overarching themes: *The Parent/Caregiver Identity* and *Reflection of Self in Caregiving Role*. In this chapter, the codes are first defined, and the code collation process outlined to highlight the formation of the overarching themes. Themes are then described, using the participants' own words to illustrate their meanings.

Identification of Codes and Themes

All 19 transcripts were thoroughly read by the PI prior to the curation of codes to reappraise interview content that was collected multiple months prior. The PI utilized the participants' own words for the initial code creation, starting with all initial interviews across participants. Initial code creation yielded 25 codes. The process was repeated with all 19 interviews and existing codes were supported with excerpts from the interviews. A couple of the codes with similar semantic meaning were combined and refined in order to concisely capture feelings towards care provision. Four codes did not have sufficient evidence across all 19 transcripts and were discarded. Twenty-one codes remained after revision to the initial codes. A total of 215 excerpts were coded. The PI analyzed the excerpts for two or more "overlapping" codes or multiple codes assigned to the same excerpt. Each code was charted on an excel sheet and tallied for overlap. Ultimately, 6 codes appeared the most frequently in excerpt citations, and consistently overlapped within a given excerpt, forming the basis of two overarching themes described in this thesis.

Naming and Defining Codes

Codes Contributing to Theme 1

In exploring the shared experience across participant interviews, three interrelated codes frequently overlapped: “I am always the caregiver”, “I like to take care of people,” and “it’s my responsibility”. The code “I am always the caregiver” was assigned to excerpts in which the participant explicitly referred to themselves as a caregiver to their parents. At some point across the series of interviews, all participants explicitly referred to themselves as a “caregiver” or reframed the word “caregiver” to fit their perception of the role. For example, P2 reframed “caregiver” as “mom” or “momming” as this was a role they more closely related to and which held the same caregiving connotations to them. The reframing of the term “caregiver” was accepted under this code. The code “I like to take care of people” was assigned to sections in which the participant mentioned taking care of someone other than their parents with dementia. Each participant mentioned fulfilling a commitment to care responsibilities or relationship maintenance outside their responsibilities for their parents with dementia. For example, P2 and P3 both cited parenthood and their responsibility to their children. P1 consistently noted their responsibility to collaborate with their mother on care decisions, and P4 noted taking care of their mother, who had a stroke prior to their father’s diagnosis of dementia. Lastly, the code “it’s my responsibility” was assigned to excerpts that included details about care provision and/or outlined commitments the participant had to their parent’s care. These three codes contributed to the broader theme of *The Parent/Caregiver Identity*.

Codes Contributing to Theme 2

The three codes that overlapped the second most included: “just doing my best”, “take a minute to talk,” and “describing myself”. The code “just doing my best” was assigned to excerpts that contained mention of situational impacts or limitations on the participants’ ability to engage in care responsibilities. Additionally, excerpts were assigned to this code when the participant verbally acknowledged these impacts or limitations. For example, P1 stated in response to traveling four hours regularly to care for their parent with dementia, “This is like a fire drill, but I have to deal with it, and then it’ll be hopefully solved.”. The code “take a minute to talk” was assigned to excerpts that included the participant's reflection on their experience as a caregiver, to their parent or to others, and/or on the interview process. Finally, the code “describing myself” was assigned to excerpts in which the participant spoke about another aspect of their identity or an experience outside of taking care of their parent. These three codes contributed to broader theme of *Reflection of Self in Caring Role*.

Theme 1 and Theme 2 will be defined and elaborated upon in the following section, using quotes from the participants to illuminate their different experiences throughout the five-month interview process.

The Parent/Caregiver Identity: Participants’ Care Responsibilities to Their Family Contribute to Their Caregiver Identity

Theme 1 encompasses the formation of a unique caregiver identity through care provision responsibilities to family members including, but not limited to, their parent with dementia. This section is divided into collective experiences across all participants and then the unique experiences of the individual participants.

All participants referred to themselves as a “caregiver”, or caregiver equivalent, to their parent with dementia at least once over the five-month interview period. The proclaimed self-identification of the label “caregiver”, or caregiver equivalent, was always mentioned in participant quotes containing care commitments to their family members. This was evident in quotes regarding both the care of their parent with dementia, and in quotes regarding other individuals with whom the participants either provided support or interacted with frequently to coordinate parent with dementia’s care. These other individuals were always another family member (e.g., niece, children, mother) to the participant.

While all participants referred to themselves as a “caregiver”, each participant professed their caregiver identity differently across the five-month interview process. In order to capture each individuals’ experience and accurately depict their journey over the five-month interview periods, excerpts from each participant accompany the data below.

Across all interviews, P1 explicitly referred to themselves as a “caregiver” the most out of the other participants. In total, they referred to themselves as a caregiver to parent with dementia eleven times, mostly in their second, third and fourth interviews. They also cited taking on the most care responsibilities out of the other participants. Demographically, P1 was the youngest caregiver and lived the furthest away from their parent with dementia. Notably, P1 was a PhD student in speech language pathology with an interest in aging research. P1 often spoke about their research and how they felt about their involvement in aging research while caring for a parent with a progressive disease. When speaking about the intersection of their research and their care responsibilities, they stated,

I'm definitely more aware of like his general safety and his overall like well-being...because we talk about a lot in our aging research, how to make the aging world a

more accepting, like, I don't know, there's a lot of things in society that are not set up for people who are not mobile because of aging or whatever. (P1, Interview 1)

P1 was the only participant who mentioned the coordination of care for their parent with dementia with another person. P1's citations of care provision consistently coincided with statements of care navigation and coordination with their mother and sister. Most excerpts detailing their coordination were negative in nature, with P1 often citing anger or frustration attached to their proclaimed self-identification of caregiver. This is highlighted in an excerpt from P1 in which they expressed, "...I'm... 29 years old and I'm the one who's driving this when...really my mom married him [parent with dementia], so like really it should be on her" (P1, Interview 2).

P3 referred to themselves as a "caregiver" the second most out of all the participants. Personal identification of the identity of caregiver was often in reference to providing care for family. They consistently identified themselves as a mother in addition to a caregiver to their parent. P3 referred to their care responsibilities regarding their children as often as their care responsibilities regarding their parent with dementia. For example,

And so it's like, not only am I still taking on that role with her [parent with dementia], even in more depth now, like, and then I'm still a mom to my kids. And so it's like, I still, I think I just still mostly identify with that caregiving mother type role. (P3, Interview 4)

Demographically, P3 had been caring for their parent the longest when compared to the other participants. Their care responsibilities towards their parent with dementia began at age 14, meaning they began caregiving to their parent 22 years ago. Over the course of the five-month interview period, P3 referred themselves as a caregiver the most in the first two initial interviews. They did not explicitly refer to themselves as a caregiver in the later two interviews; however, in the last two interviews, they reflected on the longevity of their care responsibilities

and lamented their early involvement as a caregiver at a young age. This is highlighted in the following excerpt regarding P3's relationship with their parent with dementia: "I became the parent at about 14 years old and that unfortunately has never stopped and now I'm almost 36" (P3, Interview 1). Perhaps related to the longevity of the role, or other factors, P3's sentiments towards caregiving for their children and parent with dementia were generally positive in nature. P3 was the only participant who never denied personal identification with the term "caregiver" over the five-month period.

P3 often noted themselves as the parent figure in their relationship with their parent, despite being the child. For example,

The relationship with my parent, you know, it's always been backwards from as long as I can remember. You know, I was always the one that was more responsible and kind of took care of her...being only 36 trying to navigate for [another] adult, you know, all of the major decisions when you really aren't sure what they would want and, you know, handling all their finances, making sure their bills are paid on time on top of my own and my own family's has been quite a challenge. (P3, Interview 5)

Other participants shared similar sentiments regarding their relationship with their parent to P3. P2 reframed the term "caregiver" to "mom" or "momming" as they explained that it better fit their experience, as a person who provides care to their children as well as their parent with dementia. Over their five interviews, P2 was the most reluctant to refer to themselves as a "caregiver" out of all other participants. In fact, at the beginning of the study, they explicitly stated that "I don't think of myself as a caregiver if that's what you are going for" (P2, Interview 1). In their final interview, they acknowledged their proclivity to call "caregiving" as "mom" or "momming", and mentioned they would be open to using the term "caregiver" after participating in these interviews.

I was really resistant to being called [a] ‘caregiver’ when I talked to you, but I kept saying, I was like ‘mom’ and they’re the same freaking thing...I do ‘mom’ the hell out of everybody and I’m aware of that. I just don’t know why I am resistant to that label [caregiver] cuz honestly ‘momming’ people is not a good label. Being an open ‘caregiver’ is... (P2, Interview 5)

Anecdotally, P2 had the most estranged relationship with their parent prior to committing to caregiving responsibilities. Over the five-month interview process, P2 reported providing care to several other individuals outside of caring for their parent with dementia. P2 cited caring for their children as well as their niece during the interview process. They also referenced caregiving responsibilities outside of basic necessities, such as providing support to family members dealing with addiction and violent behavior. Despite being reluctant to refer to themselves as a “caregiver”, P2 did consistently refer to care responsibilities throughout the five interviews.

P4 referred to themselves as a “caregiver” the least. Demographically, P4 was the only participant who identified as a former caregiver to their parent with dementia. P4 noted that prior to caregiving for their parent with dementia they were caregiving for their other parent who had experienced a stroke with substantial deficits to their mobility and participation in activities of daily living. For a period of approximately one year and six months, P4 was caregiving for their mother who had suffered a substantial stroke and their father with dementia at the same time. When P4 mentioned care responsibilities, they always detailed care provision for both parents despite a period of six months in which P4 was only caregiving for one parent, their father with dementia. As P4 outlined their schedule during the period of time in which they were caring for both parents, saying “[I would] go to work and work 10 to 14 hours a day, come home [and] still be able to take care of them for 5-6 hours and...obviously you end up the next morning doing the same thing” (P4, Interview 1). Further, while P4 was the only participant not currently providing

care to another person during the five-month interview process, they stated that their involvement in their parents' care and subsequent deaths impacted the way they interact with individuals at their job as a law enforcement officer:

My realization you know as a caregiver...[I have] never taken care of someone before... it's very overwhelming and even going back to work [after parents' death] and going to like death investigations and whatnot and meeting with the children of the deceased, they too don't [or] didn't have any clue what they needed to do and so with my own experience [I'm] able to kind of provide them with kind of step by steps to help them out. I think that's helped them out as well but also helped me with my grieving process. (P4, Interview 1)

Reflection of Self in Caregiving Role: Reflecting on Caregiving Experiences Allowed for Personal Growth

Theme 2 described how self reflection over the five-month interview period contributed to personal growth and novel understanding of the impacts of the caregiving role. Similar to the previous section, this section is divided into the collective experiences across all participants and then the unique individual participant experiences.

Each participant reflected on their unique caregiving situation at least once throughout the five-month interview period. Self reflection looked different for each participant; however, collectively, participants voiced that their involvement in this study allowed them to engage in reflection regarding their role and its impact. For example, P2 cited the reason for entering this study was due to a recommendation from their university professor. They mentioned that their professor saw this study's recruitment poster and thought that the opportunity for P2 to talk to someone about their experience caregiving could be a way to help them cope with their role. In their final interview, P2 expressed that

...things really changed in the time...when I began talking to you in these interviews, and now, but also you know it helped me develop a better sense of who I am, not as my

mother's caregiver or as my niece's guardian, but this idea that I've always had in my head... (P2, Interview 5)

Other participant's shared similar sentiments. P1 commented that they

... never sat down and thought like how it, how I perceive myself differently and how others perceive me because of the situation... So for me, I think it's been helpful to kind of like sit down and take a minute to like talk about it and think about it. (P1, Interview 5)

P3 echoed the other participants, expressing

...this is kind of good for me too because it kind of allows me to be more intuitive with my feelings...I think we all go day to day so engulfed with our lives that, you know, to sit back and really think about this kind of stuff is harder than it seems. (P3, Interview 4)

Additionally, P3 initially refused compensation for the study, claiming that receiving

compensation for what they described in their fifth interview as "a big, long therapy session" seemed unjust given the benefits they reaped from their involvement.

P4 discussed how being involved in this study allowed them to reframe their experience taking care of their parent with a more positive regard. For example, compare these sentiments offered in the first interview and the final interview (*italics added for emphasis*):

After a month of kind of easing off in my mind and being away from my home where my parents passed, and where I was taking care of them just being who I was then, who I am now, who I will be. *And as their son, you know where was I? Was it good or bad? When I was... when they were alive how did I, you know take care of them, and then from that, what I've learned about myself and what my future is gonna be you know? How do I take care of myself the way that I [took] care of them?* (P4, Interview 2)

I know the first time, when we had this interview, [I] was more of, you know...putting myself down a little bit, in fact a lot...[I] didn't really give myself a whole lot of, I guess, I don't want to [say] credit, but just you know, didn't give too much positive thoughts to me, but now after about four or five, you know, of these talks just it, just made me think of OK who was I and what did I actually do and how did I actually impact, what did [I] impact positively towards my parents? How did [it] impact me, you know and looking through other people, [I] was kind of doing a comparison with what I did with my parents compared to what the other folks that I've seen from my job or from what I hear or from my acquaintances of what they've gone through, so it just made me like I think maybe

actually thinking about [it], I think the first couple interviews, [I] was [like was] there something more or better or something else I could have done to my parents when they were alive, and I think for after these talks, *again just having reflecting and thinking about it, I think I've done what I can, you know, for what I have the resources and everything I had at that point. There's nothing I could have done anything better.* (P4, Interview 5)

Throughout the interview process, P4 consistently questioned their experience as a caregiver as related to the care expectations their parents had for them. Of interest, P4 was the only participant who identified as a person of color and who immigrated to the United States. P4 noted that their parents had care expectations that differed from Western care ideals. When explaining their relationship with their parent with dementia, P4 noted that there was a hierarchy and expectation for children to provide care to their parents. They stated:

...so my relationship with him was pretty close but he wasn't as, you know, ... [he was] more of a like a friend...like [in a] hierarchy, you know, father and then the children... then we immigrated here to the US [and] it was the same [relationship]. (P4, Interview 1)

P1 also often discussed how other aspects of their identity influenced their caregiving abilities. P1 once noted that their caregiver identity was “increas[ing] a little bit” however their identity as a student “kind of just blend[s]” into their caregiving role as an intrinsic part of how they view themselves (P1, Interview 2). They noted their involvement in their PhD program as being an aspect of their identity that they think about the most often. Similarly, they noted that the identity of “student” is how they believe other individuals perceive them. P1 never mentioned caregiving as a part of their identity that is perceived by others about them. When asked about their identity as a student, P1 stated, “of the identities I hold, I think probably being a student has the greatest effect on how other people perceive me” (P1, Interview 3). P1 voiced similar sentiments throughout the five-month interview process. P1 often framed these two identities as a student and caregiver as being correlated with one another. For example, P1 would

mention an increase in their caregiver identity during moments in the five-month interview period in which they had less school responsibilities, and vice versa. P1 began their interviews in July, a period in which their school responsibilities were lessened. As noted in the previous section, P1 self-identified as a caregiver the most in their earlier interviews. P1 noted in an earlier interview, that they feel like:

...being a student itself [is] kind of at a point where, like. I don't have class every single day to kind of keep me on track...so, I think some of that has, just is downwards a little bit more, just chang[ed] and then caregiving is increased. (P1, Interview 2)

This is contrasted by their feelings in latter interviews, where they state:

...I definitely think the caregiving identity is like in the back of my head and I'm feeling guilty about not feeling those roles, as I should, but definitely the student this time around has taken the forefront of what I perceive my identity to be. (P1, Interview 4)

They go on to further describe how these two identities are correlated, noting that:

Caregiver [is] kind of an afterthought of things sometimes [in] these last few weeks, so I definitely think that like that's kind of been pushed aside a little bit because I've been busy and also because like he [parent with dementia] seems okay...so I think it's been pushed aside a little bit I don't think I've identified quite as much or thought about it quite as much as I had previously if that makes sense. (P1, Interview 4)

P2, also a university student, experienced the intersection of their student identity and caregiver identity differently from P1. They cited that their caregiving identity was “competing” with their student identity in their early interviews (P1, Interview 2). Over the course of the five-month interview period, P2 moved their parent to a longer-term care facility. In their fourth interview, P2 had newly moved their parent in to the long-term care facility. When speaking about this decision, they became tearful, saying:

I was a single mom, so you know, you gotta do what you gotta do. And then I had my niece, and then I had my mom, and a lot of that is backing off now. So there could be something for me before I'm 60, and you know...I could do something that, I wanted to teach when I was, you know, in elementary school, so I mean I had other things I wanted

to do along the way. I mean I think the thing I really love to do is not possible at my age, but you know I could work towards that, even if I don't get to it, I'm thinking about it and that's a big deal. (P2, Interview 4)

In their final two interviews, P2 spoke more about other aspects of their identity such as being a mother, a student, and a spouse, noting that they “get to be a couple with my husband, again” (P2, Interview 4).

CHAPTER IV

DISCUSSION

The results of this study provide insight into the growing body of literature on how a care partner's identity is shaped and offers a few hypotheses regarding change or evolution over time, particularly as related to the reflection process, that should be explored further. Specific questions arose from the analysis that illuminate the need for integration of caregiver identity research and facilitation practices into future professional practice in order to improve access to better support for caregivers.

Identity Over Time

The Caregiver Identity Theory (Montgomery & Koloski, 2013) offers a predictable pattern of caregiver identity change over time in relation to care responsibilities. In this study, caregiver's identity appeared to be characterized through experiences with both the care recipient and through other care commitments and appeared to change as those commitments changed. In line with previous literature, some participants saw other identities become less relevant with increasing intensity and quantity of primary care responsibilities (Eifert et al., 2015). For example, recall that P1 referenced their caregiver identity the most. Of all of the participants, they were that one that all care responsibilities related to their parent fell upon them as their parent's health declined, highlighting an increase in quantity of care responsibilities. P1's consistent identification as a caregiver was seemingly intensified by the lack of involvement from their other family members as evidenced by their negative quotes regarding interactions with their other family members on their parent's coordination of care. As a result, P1 reaffirmed their caregiver identity as their responsibilities increased and their feelings towards their parent's

care intensified. P1 also noted shifts in their identity between “caregiver” and “student” as their parent required more or less intensive care. This suggests that one important factor influencing the caregiver identity may be the intensity of primary caregiving responsibilities.

It is likely that there is more subtlety in the relationship between caregiver identity and caregiver intensity. For example, one question that arises from the current study is whether recognition or awareness of one’s caregiver identity come as a product of involvement in care relationships more generally, including but not limited to the target care recipient. Caregiving interactions were framed within the context of a non-voluntary care relationship; therefore, an extension of their already established relational role (O’Connor, 2007). Providing care to another family member may be viewed as contributing to the overall positive self-identification as a caregiver. For example, participants in the current study who identified as parents cited more care responsibilities to other individuals (e.g., children, other family members) that contributed to their connection with their caregiver identity.

Specific to adult children caregivers, the current data also raise the question of whether role reversal is inevitable in complex parent-child care relationships. In this study, role reversal appeared in both P2 and P3’s interviews. Both of these participants in particular had complex parent-child relationships. For example, P2 grew up and cared for their mother with bipolar and narcissistic personality disorder throughout their life. Notably, P2’s was reluctant to classify themselves as a “caregiver” and was more readily accepting of the term “mom”. The term “mom” was a pre-established identity for this participant and carries the similar nuances as the term “caregiver”. However, the use of “mom” instead of “caregiver” reframes the relationship and positions the caregiver as the maternal figure in the parent-child relationship. Similarly, as

P3 started caregiving for their mother at a young age (14 years old) due to their mother's illicit drug abuse, and had maintained that role of "caregiver" for 22 years. P2 and P3's data were consistent with reciprocity of care trends in children who view their parents as unfit for their parental role (Silverstein et al, 2002). This could be because children forced to maintain such caregiving relationships over a long period of time (e.g., over a decade) or in void of reciprocity, may experience more caregiver identity salience. It could be that P3 never denied their identity as a caregiver because their identity was more salient and less variable to increases in care responsibility or intensity. Similarly, P2 rejected the term "caregiver" because "mom" had become more of a salient identity despite having alike connotations. In the future, caregiver identity research may look more specifically into complex parent-child relationships such as the one's defined above and whether these prior relationships result in unique caregiver identities, such as the adopted material identity observed here. Future identity salience research in this caregiver population is warranted in order to provide greater insight in the experiences of those with complex-parent child relationships.

These parent-child relationships may also be informed and impacted by cultural background and beliefs, socioeconomic position, and other environmental variables. Despite the small sample size of the current study, it was clear that each participant had unique circumstances that impacted their relationship with their parents such as disability, mental health disorder, substance abuse, and immigration status. For example, P4 and their parents immigrated from Korea to the United States. Based on what P4 revealed in their interviews, they shared differing perspectives of care expectations from other participants. Such differences may potentially be due to their cultural background, as supported by previous literature (e.g., Mikolaj

et al., 2022). Future research is indicated with a larger more diverse set of participants in order to further examine hypotheses regarding the impact of culture on the parent-child relationship.

Notably, not all participant's data supported the predicted trajectory in caregiver identity as proposed by the Caregiver Identity Theory. As previously stated, the Caregiver Identity Theory proposed that once an individual is no longer in a caregiving role, they lose their caregiver identity. Notably, P4 continued to see themselves as a caregiver the end of their official caregiving role. P4 reported currently utilizing their caregiver identity retrospectively to provide counsel to those entering caregiving roles. While the sample size was small, former caregivers appear to continue to see themselves as holding a caregiver identity. Future research should be intentional to include both current and former caregivers despite their differences in current experience as excluding former caregivers in future identity research may neglect an important caregiver-identifying population.

Systems of Support

The reflection process engaged in through the multiple interview paradigm used in this study may have been a therapeutic process for participants. Every participant noted benefits from engaging in the interview process given their role as current or former caregiver. The most cited benefit across participants was being given the space to reflect on their role and the impact of the role on their health. Previous literature supports that individuals who identify as informal caregivers to their family members do not often seek out support services due to feelings of embarrassment or incompetence (Macleod et al., 2017). Interestingly, the current study's methods were not advertised as a support service, nor did the researcher consult participants or advise them in any way during the interview period. In fact, the benefits described by the

participants were not part of the initial objective of the study nor part of the interview guide. However, the participants' sentiments were indicative of the aim to better understand the experience of the "invisible second patient" and how to better facilitate support. Caregiver support services may be effective even in small doses across multiple months – even when not approached as "supportive care". It may also be that the true barrier to caregivers seeking services lies in the accessibility and focus of such resources.

There is a potential that engaging in this interview process was the first time the participants had thought about their caregiving experiences. It is possible that through engaging in reflection, participants may have come to the notion that they identify with the caregiver experience thus instilling a sense of belonging to the caregiver identity (Eifert et al., 2015). The "invisible second patient" narrative cites one of the barriers to participation in support services is lack of community and sense of belonging in that community (Biegel & Johnsen, 2004; Engel, 2022). Perhaps if a caregiver does not identify with the caregiving role, they will be less likely to access support services. A potential reason participants reaped benefits from participation in this study may be due to their eventual positive identification of the caregiver identity, an identity that they particularly realized through the reflection process. This warrants future research on reflection of self-identity as a therapeutic process in caregiving populations.

Implications for Practice

A few suggestions warrant consideration when working with informal care partners to their family members with dementia. These implications for practice are informed by the hypotheses that arose from the current study as well as the present body of literature.

Firstly, clinicians should recognize each caregiver's experience is going to be different, and therefore they will require different supports. For example, previous research has shown that caregivers belonging to caregiver identity subgroups, such as care partners of color or care partners with foreign-born parents, have increased care responsibilities and intensity of care provision as well as increased caregiver burden when compared to their white, non-immigrant counterparts (Cohen et al, 2019; Moon et al, 2020). Disparities among identity subgroups, namely individuals who subscribe to diverse cultural beliefs on care expectations, can be addressed by centering individuals from diverse cultural backgrounds in caregiver support research. As clinicians, it is one's duty to provide culturally responsive and appropriate training and counseling to care partners in order to best support both care partners and care recipients. Further, support services such as care partner counseling should change throughout the disease trajectory to account for the progressive nature of the disease. It may be beneficial for clinicians to offer regular support sessions to care partners that are conversational and facilitate care partner reflection. The current study proposes that self reflection may be a successful way of instilling awareness of one's caregiving role and subsequent recognition of caregiver identity, a hypothesis that warrants further investigation. As aforementioned, supports should be centered on culturally appropriate or sensitive strategies such as attending to language preferences and cultural values and beliefs (Dilworth-Anderson et al., 2020). Another avenue for consideration is implementing care partner support groups for disproportionately affected care partner populations. El Portal Latinx Alzheimer's Project is an example of a community-based collective developed with the goal to coordinate ethnic-sensitive services for care partners and recipients at risk for high instances of caregiver burden and burn out (Aranda et al., 2003).

In addition to providing caregivers with appropriate support, clinicians should be trained to facilitate conversations regarding identity. As noted above, the current study preliminarily supports the perceived benefits of engaging in a reflective interview process as well as offers insight into how such a reflection process focused on identity can lead to increased positive identification as a caregiver. However, learning to facilitate reflection of identity could benefit not only the caregiver, but also the clinician. Clinicians should be trained to look at their own identities with the aim to recognize how the identities they hold come across to clients and caregivers in their practice. Identity introspection is an important component of identity reflection as it allows for clinicians to recognize their biases and potential areas for education and growth (Yager &Kelsay, 2021). Reflection as a clinician is just as crucial as it is for the caregiver. Overall, the reflection process may actually benefit all parties, not just the caregiver and the clinician, but also the client or care recipient.

Of relevance to the discussion of practical implications as well as central to the qualitative methodology process is recognition of the role and experience of the researcher in the current study. As noted previously, the primary investigator had previous experience facilitating conversations related to identity in professional/leadership development settings. However, the experience of facilitating reflection of identity as a researcher was very different from facilitating such conversations in the professional setting. Conversations were more emotional and vulnerable at times in this setting. Despite these differences, the leadership facilitation curriculum employed by the research appeared useful with caregivers and may warrant further research regarding its use as a clinical tool. Speaking perhaps to the discussion above regarding clinician reflection, as a researcher, using leadership facilitation to elicit identity conversations, I

found this experience rewarding as a researcher and clinician. The vulnerability and trust between researcher and participant developed across five months was far from what I thought was possible given the design of the study. With that, it was an honor to have monthly conversations with these individuals, hear their unique stories, and share in their caregiving journey. The power of such a relationship, built over such a brief window of time, is important to consider for further research and clinical practice.

Limitations of the Study and Future Directions

One may question the validity and reliability of this study's research design as qualitative phenomenological research is often criticized for lacking scientific rigor (Noble & Smith, 2015). To combat this criticism and increase this study's credibility, the PI employed procedures to safeguard against personal bias, provided clear justification for the methods adopted and supported analytical finds with verbatim quotes from the participants. Certainly, this study still presents with its limitations. Although the bracketing procedure was employed to reduced researcher's personal bias in data interpretation, one cannot fully eliminate bias from influencing one's perception (Anderson, 2010). It is possible idiosyncrasies influenced the interpretation. Additionally, the PI was the only researcher who interpreted the data, thus elevating the potential risk for biased interpretation. This is seemingly an unavoidable limitation of this research design.

In future research, the interview period may warrant extension. The five-month interview period effectively captured changes in caregiver identity, however these changes were likely tied to the reflection process engaged in by the participants rather than changes in external circumstances/their environment. Extending the interview period and employing more of a longitudinal design may allow for more change as the care recipient's disease progresses and

allow for better delineation of the change in identity tied specifically to the dementia process.

Lengthening the interview period from five-months to one year may yield different results.

The participant sample size was small due to time constraints for recruitment and participant inclusion. The semi-longitudinal nature of this study made it imperative that recruitment and participant inclusion in the study occurred in time for participants to complete all five interviews before the researcher's spring graduation deadline to allow for sufficient time for the researcher to analyze the data. This placed constraints on the amount of time allotted for recruitment of participants. Future research should strive to extend the recruitment process to possibly include more individuals in the study. Most of the recruitment for this study was done through online caregiver support services, which may have only targeted a subset of the caregiving population. Support services for caregivers are often underutilized. In fact, few participants "self-referred" themselves into the study; 3/4 participants were actually given the information to participate from a colleague or other acquaintance. While reformation of support services is indicated by the current study, future recruitment strategies should also prioritize making recruitment material more "user-friendly" such having recruitment material in different languages. Additionally, future caregiving research should incorporate cultural beliefs, values and norms among diverse care partners and recipients from a nationally representative sample that better captures a comprehensive understanding of care partner groups at risk as well as inter- and intragroup risk factors (Dilworth-Anderson et al., 2020). It is the duty of the health care professionals to recognize the elevated risk of caregiver burden their clients from diverse cultural background, so they can better connect them to support resources.

Conclusion

The current study aimed to facilitate reflection of self-identity in first-time parents with dementia in order to inform hypotheses related to the trajectory of this lived experience and the factors influencing the invisible second patient perspective. Based on the participants' descriptions of their experiences, we identified a number of areas for future work, including identity salience in complex parent-child relationships, former caregiver identity over time, the impact of culture on the parent-child relationship, and the self-reflection process as a therapeutic tool. Together with the previous literature, this work supports a continued need for care partner services that facilitate reflection and are culturally responsive. Through future research and clinical efforts, there is the opportunity to engage a wider audience of care partners in reflection on their caregiving role, ultimately aiming to improve the health and wellbeing of both the care partners and their recipients.

APPENDIX A

INFORMED CONSENT DOCUMENT

Consent for Research Participation

Title: The Impact of Caregiving on Caregiver's Identity in Dementia
Researcher(s): Savannah Campbell, University of Oregon, Principal Investigator
Samantha Shune, University of Oregon, Faculty Advisor
Researcher Contact Info: 541-347-7494
savanahc@uoregon.edu
sshune@uoregon.edu

You are being asked to participate in a research study. The box below highlights key information about this research for you to consider when making a decision whether or not to participate. Carefully consider this information and the more detailed information provided below the box. Please ask questions about any of the information you do not understand before you decide whether to participate.

Key Information for You to Consider
<ul style="list-style-type: none">• Voluntary Consent. You are being asked to volunteer for a research study. It is up to you whether you choose to participate or not. There will be no penalty or loss of benefits to which you are otherwise entitled if you choose not to participate or discontinue participation.• Purpose. The purpose of this research is to explore how caring responsibilities impact caregiver's identity in first time caregivers for their parents with dementia.• Duration. It is expected that your participation will last 1-hour a month for 5-6 months.• Procedures and Activities. You will be asked to attend a monthly, recorded interview conducted via the online meeting platform, Zoom, which may elicit discussions about topics pertaining to personal identity, caregiving roles and experiences related to caring for a parent with dementia.• Risks. Some of the foreseeable risks or discomforts of your participation include possible stress, emotional distress, inconvenience, and possible loss of privacy.• Benefits. By participating in our study, you will be helping researchers and clinicians better understand how we can assist in providing support to first time caregivers in the community.• Alternatives. Participation is voluntary and the only alternative is to not participate.

Who is conducting this research?

The researchers Savannah Campbell, and Dr. Samantha Shune from the University of Oregon are asking for your consent to this research.

Why is this research being done?

The purpose of the research is to explore how caring responsibilities impact caregiver's identity in first time caregivers for their parents with dementia. You are being asked to participate because you identify as a first-time informal (not compensated for caregiving services) caregiver,

and you are currently or have in the past cared for a family member with a diagnosis of dementia. About 10-20 people will take part in this research.

How long will I be in this research?

We expect that your participation will last 1-hour a month for 5-6 months. During each monthly meeting, you will engage with the researcher for an approximately 1-hour interview in which you will be asked a series of questions to guide the interview topics.

What happens if I agree to participate in this research?

If you agree to be included in this research, your participation will include a monthly, recorded interview conducted via the online meeting platform, Zoom, which may elicit discussions about topics pertaining to personal identity, caregiving roles and experiences related to caring for a parent with dementia. If you choose to participate, you may skip any interview questions that you wish not to answer, and you may stop the interview at any time.

What happens to the information collected for this research?

Information from the interviews collected for this research will be used for the researcher's master thesis and dissertation. We may publish/present the results of this research. However, we will keep your name and other identifying information confidential.

How will my privacy and data confidentiality be protected?

We will take measures to protect your privacy. Despite taking steps to protect your privacy, we can never fully guarantee your privacy will be protected. All interviews will be conducted on a secure online meeting platform (Zoom), and the researcher will be in a secure location while conducting interviews. Due to the nature of the research, we cannot guarantee that your space is secure and confidential but will provide guidance on how to find a secure space if one is not readily available to you.

We will take measures to protect the security of all your personal information, but we can never fully guarantee confidentiality of all study information. Measures we will take include: your personal information will be accessible only to the researcher and research team member; the video data will be converted from Zoom into a transcript which will be de-identified and stored in a password protected electronic server. All records will be maintained for 10 years for data analysis and publication purposes.

Individuals and organization that conduct or monitor this research may be permitted access to and inspect the research records. This may include access to your private information and include any other records. These individuals and organizations include: The Institutional Review Board (IRB) that reviewed this research.

We protect your information from disclosure to others to the extent required by law. The research team includes individuals who are mandatory reporters. If the research team has reasonable cause to suspect abuse or neglect of a child or adult, a report may be required under Oregon State Law. In such a case,

the research team may be obligated to breach confidentiality and may be required to disclose personal information.

What are the risks if I participate in this research?

There may be risks of stress, emotional distress, inconvenience and possible loss of privacy and confidentiality associated with participating in a research study.

What are my responsibilities if I choose to participate in this research?

If you take part in this research, you will be responsible for: attending monthly meetings with the researcher, therefore access to a computer/smartphone is essential. You are responsible for finding a device on which to attend said meetings.

What if I want to stop participating in this research?

Taking part in this research study is your decision. Your participation in this study is voluntary. You do not have to take part in this study, but if you do, you can stop at any time. You have the right to choose not to participate in any study activity or completely withdraw from continued participation at any point in this study without penalty or loss of benefits to which you are otherwise entitled. Your decision whether or not to participate will not affect your relationship with the researchers or the University of Oregon.

What if I am injured because of participating in this research?

If you are injured or get sick because of being in this research, call the researchers immediately.

If you experience harm because of the project, you can ask the State of Oregon to pay you. If you have been harmed, there are two University representatives you need to contact. Here are their addresses and phone numbers:

General Counsel/ Office of the President
1226 University of Oregon
Eugene, OR 97403-1226
(541) 346-3082

Research Compliance Services
5237 University of Oregon
Eugene, OR 97403-5237
(541) 346-2510
ResearchCompliance@uoregon.edu

A law called the Oregon Tort Claims Act may limit the amount of money you can receive from the State of Oregon if you are harmed.

Will I be paid for participating in this research?

For taking part in this research, you may be paid up to a total of \$150.00 gift card.

Your compensation will be broken down as follows:

- For each meeting you attend, you may be paid \$30.00 hourly.
- Payment will be prorated in circumstance of incomplete participation

Who can answer my questions about this research?

If you have questions, concerns, or have experienced a research related injury, contact the research team at:

Dr. Samantha Shune (faculty advisor)
541-347-7494
sshune@uoregon.edu

An Institutional Review Board (“IRB”) is overseeing this research. An IRB is a group of people who perform independent review of research studies to ensure the rights and welfare of participants are protected. UO Research Compliance Services is the office that supports the IRB. If you have questions about your rights or wish to speak with someone other than the research team, you may contact:

Research Compliance Services
5237 University of Oregon
Eugene, OR 97403-5237
(541) 346-2510
ResearchCompliance@uoregon.edu

STATEMENT OF CONSENT

I have had the opportunity to read and consider the information in this form. I have asked any questions necessary to make a decision about my participation. I understand that I can ask additional questions throughout my participation.

I understand that by signing below, I volunteer to participate in this research. I understand that I am not waiving any legal rights. I have been provided with a copy of this consent form. I understand that if my ability to consent or assent for myself changes, either I or my legal representative may be asked to re-consent prior to my continued participation in this study. As described above, you will be audio/video recorded while performing the activities described above. Recordings will be used for data analysis only.

Initial the space below if you consent to the use of audio/video as described.

_____ I agree to the use of audio/video recording

I consent to participate in this study.

Name of Adult Participant

Signature of Adult Participant

Date

Researcher Signature (to be completed at time of informed consent)

I have explained the research to the participant and answered all of his/her questions. I believe that he/she understands the information described in this consent form and freely consents to participate.

Name of Research Team Member

Signature of Research Team Member

Date

APPENDIX B

SCRIPT FOR TELEPHONE SCREENER

Telephone Script

Hello, this is Savannah Campbell from the University of Oregon. I am calling because you indicated you would be interested in participating in my study, "The Impact of Caregiving on Caregivers Identity in Dementia".

Are you still interested in participating in this study?

I am going to ask you a few questions about yourself and your relationship with your parents to determine if you would be a good fit for this study:

- Are you at least 18 years of age?
- Do you currently care for a parent or parent(s) with a formal (medical) diagnosis of dementia?
- Are you currently compensated for caring for your parent or parent(s) with dementia?
- Have you ever held informal caregiving roles in the past?
- Do you have access to a computer, phone, or tablet capable of video conferencing?

Thank you for your time today

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