

Living in the Moment: Empowered Caregiving in the United States for Family Members Living with Dementia

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Abstract

Adults living with dementia require increasingly higher levels of supervision as the disease progresses, often resulting in emotional stress for families. Eight female caregivers in the U.S. were recruited. Using feminist Critical Discourse Analysis, we engaged these caregivers in focus groups, exploring gender and empowerment related to caregiving responsibilities. Four major themes emerged:

- Female caregivers' perspectives on caregiving as a gender role,
- Female caregiver burden and emotional distress,
- Acceptance of the current situation and developing a new relationship, and
- Female caregivers' suggestions regarding care of family member living with dementia.

It is important to consider how to assist caregiver's empowerment and promote positive coping. In order to provide better services for female caregivers health professionals practicing in older adult settings should offer support groups and support acceptance and adaptation to the new relationship with the person living with dementia.

Keywords: Dementia; Caregiving; Gender Empowerment; Social Support

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Introduction

Dementia is a progressive neurodegenerative syndrome that causes irreversible decline in cognitive and intellectual function, with limitations in language, memory, executive function, orientation, and thinking processes [1]. In 2019, it is estimated that over 50 million people worldwide have dementia, with nearly 10 million new cases every year [2], and it is expected to increase 152 million by 2050 [3]. Alzheimer's disease (AD) is the most common type of dementia in older adults [1]. Lewy body dementia (LBD), the second most common cause of dementia, is an umbrella term that includes dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD) [4].

Individuals living with dementia experience significant physical limitations, including motor deficits and gait, all of which may lead to progressive loss of independence in activities of daily living (ADL) [5]. In addition, dementia affects behavioral and psychological symptoms of dementia (BPSD) such as agitation, physical/verbal aggression [6,7], paranoia/delusion, depression [6], and apathy [8]. Although cognitive impairment is a major clinical symptom of dementia, an extensive body of literature notes that BPSD are more significant factors associated with caregiver burden [9,10].

Older adults with dementia require increasingly higher levels of

supervision and personal care as the disease progresses. As dementia symptoms worsen, care required of family members can result in increased emotional stress and depression, health problems, and income and financial issues due to disruption in employment and paying for health care or other services [11-13]. Caregivers of dementia patients often provide physical assistance with basic ADL such as bathing, dressing, and taking medicine, as well as emotional support [8].

Female Family Caregivers

Among family caregivers of patients living with dementia, women disproportionately provide family caregiving; more than 66% of all family caregivers are women, with an average age of 69.4 years, and more than one-third are daughters of the person with dementia [14-16]. Although more male caregivers provide care or share in caregiving tasks than in the past, female caregivers still spend as much as 50% more time than males in providing assistance and care [17]. Female caregivers tend to handle the most difficult caregiving tasks, such as personal care including bathing or toileting, while male caregivers provide financial support, arrangements for care, and other less burdensome tasks [14]. Thus, the burden in female caregivers leads to feelings of social isolation and a lack of understanding and adequate social support from family or friends. This suggests that burden entails more than just time, effort, and energy, and includes



emotional and financial stressors [18]. Female caregivers may be more distraught by cognitive deterioration, in which the family member is not recognized by the person with dementia [4].

A number of studies have focused on the emotional, physical, and economic burdens experienced by family or unpaid caregivers of older adults with dementia [19-21]. In addition to caregiver emotional burdens, both male and female family caregivers are likely to suffer from disease and health complications as a result of caregiving stress; these conditions are often undiagnosed or undertreated and may increase the caregivers' susceptibility to disease and health complications [22]. Specifically, caregiving can produce negative effects on the caregiver's physical health, including sleep disturbance, lack of appetite, somatic complaints, and physiological changes, such as high levels of stress hormones [23], reduced immune function [24], coronary heart disease [25], impaired function of the endothelium, and increased incidence of hypertension [26]. The caregiving experience may also contribute to health behavior changes, such as lack of exercise, unhealthy dietary behaviors, smoking, and alcohol use [11].

The economic burden for female family caregiver is a growing concern. Health care costs, including long-term care for persons living with dementia, are substantial [28]. Approximately 16 million family members and other caregivers of persons living with dementia provide 18.2 billion hours of unpaid caregiving per year, representing a mean of 22 hours of care per caregiver per week [28]. The estimated economic value of family or unpaid caregiving was approximately \$230 billion in 2016 [28]. Approximately one in five family caregivers report financial strain due to diminished earnings and increased expenses as a result of providing care for family members living with dementia [28]. Spouse caregivers are more likely to suffer from physical burden and are less likely to receive assistance and social resources (e.g., caregiver support group, housekeeping services, social support, and networking) from others than are adult child caregivers of a parent living with dementia [28,29].

While research on caregivers of dementia patients has focused on negative outcomes associated with caregiving, including the caregiver's physical or psychological burden or economic loss, or psychological distress such as depression and anxiety [11,19,20,22, and 30], there is limited knowledge about the female caregiver's perceptions on positive aspects of caregiving experience [31]. Lloyd J, et al. (2016) [32], conducted a systematic review of 14 qualitative studies, which explored positive aspects of caring in dementia. Some of the studies reflected the importance of personal growth as a human being, positive attitudes as a caregiver, and the prior relationship with the family member living with dementia as important in order to effectively cope and improve quality of life.

Feminist Critical Discourse Analysis

Feminist critical discourse analysis (CDA) is a political perspective on gender concerned with demystifying the interrelation of gender, power, and ideology in discourse [33]. According to CDA premises, gender is a social relation that enters into and partially constitutes all other social relations and activities [34]. Feminist CDA aims to advance a "rich and nuanced understanding of the complex working of power and ideology in discourse in sustaining (hierarchically) gendered social arrangement" [33]. The purpose is to alter significantly the existing conditions that are gender oppressive and to promote social justice. The economic burden of caregivers of family members with dementia includes significant social and material constraints. Female family caregivers often have double-shift work between the office and home that contributes to economic burden, social isolation, and emotional distress [1].

Feminist CDA is aimed at addressing social systems that contribute to oppressive practices, such as undervalued caregiving responsibilities, through conversation analysis [34]. CDA invites critical awareness of relations between women in and among groups of women with the intention of understanding how they can empower one another to oppose gendered social structures. This qualitative study applied feminist CDA. The researchers examined the social and material constraints of the participants to determine whether they experienced gender oppression or empowerment as they cared for a family member living with dementia.

Research Questions

This article describes and discusses a qualitative study of how female caregivers perceived gender roles in caring for a family member living with dementia including AD and DLB. The specific research questions were:

- How do female caregivers feel responsible for caregiving as a gender-specific role? and
- How do female caregivers perceive a connection between gendered roles as caregiver and caregiver burden?

The interactional conversations among female caregivers were explored through focus groups and encompassed a feminist critical discourse analysis (CDA) to explore gender related to caregiving responsibilities [33].

Materials and Methods

Design

After completion of the 12-week intervention describe below [35], the three focus groups were conducted using a semi-structured interview guide with the primary female caregivers of the dementia research participants. The aim was to explore the caregivers' perspectives on caring for the participants with dementia and to explore each caregiver's relationship with the person with dementia based on feminist CDA [33]. The use of focus groups creates multiple lines of communication that help to create a nonthreatening environment for dialogue in the company of other women who have had the same experience [36]. The caregivers had developed a relationship with one another as they waited for their family member while they participated in the intervention. This familiarity with one another prior to the focus group strengthened the focus group discussion as they were comfortable with one another. The secondary gain of mutual aid and support was evident in the participants.

Sampling

This study with caregivers was a follow-up to the intervention study that examined the effects of non-pharmacological interventions in older adults living with dementia. In the intervention study, family members living with dementia participated in a 12-week non-pharmacological intervention (chair yoga [CY], participatory music intervention [MI], or chair-based exercise [CBE]) to determine the effects of CY, compared to the effects of the attention control interventions, on physical function, BPSD, quality of life, and sleep. In the quantitative study [35], 31 dementia patients attended CY, MI, or CBE in twice-weekly 45-minute sessions for 12 weeks (24 sessions); 27 completed the interventions and final data collection. Family caregivers did not participate in the interventions with the dementia participants. In order to participate in the follow-up focus group session, the caregiver had to

- Be the caregiver of a family member who had completed one



of the three interventions (CY, MI, CBE),

- Be the female primary caregiver of the family member (parent, sibling, or husband) living with dementia who was living in the community,
- Have enough caregiving experience to address the questions related to her role as a primary caregiver,
- Be able to speak and understand English, and
- Be willing to be digitally recorded.

Of the 27 caregivers who were invited to participate in the focus group, nine agreed but one did not participate due to a medical issue. The 18 caregivers who declined to participate provided several reasons:

- Medical appointment for the family member living with dementia when the focus group was held ($n = 8$),
- Currently employed ($n = 6$), and
- Other personal matters ($n = 4$).

The data collection plan was to conduct three focus groups (CY, MI, CBE) with three family members in each. In the CBE group, one of the participants cancelled due to a personal medical issue and one had a transportation issue (this person was later interviewed at her home). This left only one from the CBE group to be interviewed at the scheduled site and time. Thus, eight caregivers participated in either a focus group ($n = 6$) or individual interviews ($n = 2$). Although this is a small sample size, this is consistent with qualitative studies [37]. The first author conducted both focus groups and individual interviews and has been conducting feminist qualitative interviews and data analysis for over a decade.

Procedures

The study procedures were approved by the participating university's Institutional Review Board. The female caregivers of the intervention participants were contacted by a research assistant at the completion of the intervention study and were invited to share their perspectives in a focus group. Those who verbally agreed were scheduled for the focus group session or an interview using the semi-structured interview guide. The interview guide was developed based on a review of the literature and consultation with a clinical researcher in dementia. The specific topics addressed in the interview guide were:

- How do caregivers feel responsible for caregiving as a gender-specific role? and,
- How do caregivers perceive a connection between gendered roles as caregiver and caregiver burden? and,

- How do female caregivers cope with burden and stress from caregiving?

Prior to each focus group session, the research assistant explained the process and assured that participation was voluntary. Each caregiver reviewed and signed an informed consent form and was provided a copy of the interview guide. Each caregiver also completed a demographic questionnaire prior to the focus group session or interview. Each interview lasted approximately 1.5 hours and was digitally recorded (with participant's permission) and transcribed by a professional transcription company. Each participant caregiver was given a \$30 gift card in appreciation of time and effort expended.

Data Analysis

The data were coded using constant comparative analysis to determine the female caregivers' perspectives on caregiving and how those perspectives had influenced caregiver burden, emotional distress, quality of life, and the relationship with the family member living with dementia. Constant comparison is the qualitative data-analytic process whereby each interpretation and finding are compared with existing findings as it emerges from the data analysis [38]. The analysis was designed to identify patterns and themes using a thematic analysis approach [39]. In addition, feminist CDA was used to analyze the impact of female caregiving. This method involved several stages of identifying, analyzing, and reporting patterns and themes within the data. QSR International's NVivo 12, a qualitative software, was used to run word frequencies, develop themes, and code data [40]. In order to identify a major theme, it was required that there be consensus among participants. Two researchers independently identified major themes and discussion of different codes until consensus was reached. After themes were identified and a coherent pattern was developed, extracts that were representative examples of the themes were included in the report of results. Yardley L (2000) [41], four broad principles for assessing the credibility of qualitative research were applied: sensitivity to context, commitment and rigor, transparency and coherency, and impact and importance.

Results

Sample Characteristics

Table 1 presents information about the participants and the duration of their caregiving for family members living with dementia. Eight female caregivers took part in one of four interview sessions. Table 2 presents demographic characteristics of the family caregivers. The age of the caregivers ranged from 54 to 81 years. Six were non-Hispanic Whites. Except for one participant whose family member had been

Table 1: Duration of caregiving and description of care recipients.

Caregiver ^a	Caregiver Age ^b	Caregiver Recipient's Characteristics	Type of dementia	MMSE score	Hours of Caregiving per week
Abigail	66	Has cared for her 92-year-old mother (participant in MI) for 1.5 years	Alzheimer's disease ^c	1	119
Betty	60	Has cared for her 62-year-old brother (participant in MI) for 1 year	Alzheimer's disease	13	20
Carolyn	73	Has cared for her 91-year-old mother (participant in MI) for 10 years	Alzheimer's disease	10	35
Dottie	81	Has cared for her 84-year-old husband (participant in CBE) for 5 years	Alzheimer's disease	19	95
Evelyn	74	Has Cared for her 76-year-old sister (participant in CY) for 6 months	Alzheimer's disease	18	16
Frieda	54	Has cared for her 91-year-old mother and 88-year-old aunt (participants in CY) for 2 years and 2.5 months respectively.	Alzheimer's disease (mother); Dementia with Lewy bodies (Aunt)	17	84
Gail	78	Has cared for her 81-year-old husband (participant in CY) for 3 years	Alzheimer's disease	15	85
Helen	65	Has cared for her 93-year-old mother (participant in CBE) for 3 years	Alzheimer's disease	15	100

Where: ^aPseudonym. ^bMean age = 69 years (SD = 9.2 years), range 54-81 years. MMSE = Mini Mental State Examination.



Table 2: Demographic characteristics of the caregivers (N = 8).

		n	%
Gender	Female	8	100
Race	Non-Hispanic White	6	75
	African American	1	12.5
	Hispanic/Latino	1	12.5
Marital status	Single/never married	4	50
	Married	3	37.5
	Divorced	1	12.5
Relationship to the family member with dementia ^a	Offspring	4	50
	Spouse	2	25
	Sibling	2	25
Primary caregiver	No	2	25
	Yes	6	75
Living with family members with dementia	Yes	5	62.5
	No	3	37.5
Sharing caregiving responsibilities with the sibling(s)			
if the caregivers have sibling(s)	Yes	4	80
	No	1	20
Sharing caregiving responsibilities with the child(ren)			
if the caregivers have child(ren)	Yes	1	50
	No	1	50
Hours per week of caregiving when living with family members with dementia			
Mean = 70.29 (SD = 38.65), Range = 16-119			
Hours per week of caregiving for caregivers who did not live with those with dementia			
Mean = 27.5 (SD = 10.6), Range = 20-35			

Where: ^aOne caregiver provides care for two family members with dementia (mother and aunt), so the total of family members with dementia is nine.

diagnosed with dementia with Lewy bodies, all participants' family members had been diagnosed with moderate to severe Alzheimer's disease as demonstrated by a Mean Mini-Mental State Examination score of 13.5. In terms of relationship to the family member living with dementia, four were daughters, two were spouses or partners, and two were siblings. Of the family members living with dementia, three were male, including brother or husband. Six participants were taking care of their family member as the primary family caregiver and one was the primary caregiver for both her mother and her aunt living with dementia. Five participants lived with their family member with dementia and spent a significant amount of time caring for the family member, ranging from 16 to 119 hours per week. The caregivers who did not live with the family member with dementia spent 20 to 35 hours per week in caregiving. Four caregivers shared caregiving responsibilities with one or more siblings.

Major Themes

Empowerment was implicit in all four major themes as demonstrated by the participants' determination. Four major themes and four subthemes were identified in the data:

- Female caregivers' perspectives on caregiving as a gender role (subtheme: female caregivers' dedication to and devotion for the family member living with dementia);
- Female caregiver burden and emotional distress;
- Acceptance of the current situation and developing a new relationship (subtheme: living in the moment);
- Female caregivers' suggestions regarding care of family members living with dementia (subthemes: importance of home environment to the family member living with dementia, importance of support among caregivers).

Figure 1 is a diagram of the back-and-forth of three of the major themes:

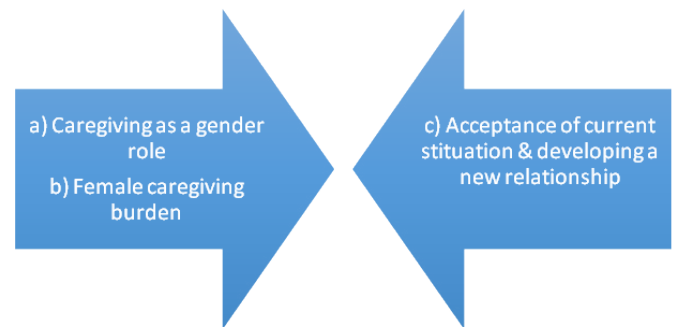


Figure 1: Conceptual diagram of 3 major themes.

- Caregiving as a gender role,
- Burden and how it may be mitigated by,
- Acceptance of the situation and developing a new relationship with the family member living with dementia.

The female caregiver experiences both a gendered role and caregiver burden, which is counteracted with the acceptance of the situation and developing a new relationship. This is a continuous and daily, lived experience for the participants. The participants made an active decision to live in the moment and embrace the new relationship with the family member living with dementia rather than being frustrated with the emotional toll of caring for the family member with dementia. This process created a positive outlook and empowerment for the participants. Using a feminist CDA, the figure represents the relationship between genders as a social relationship that partially constitutes all other activities in caring for a family member living with dementia. The women discussed their experiences in discourse that exemplified support and empowerment in a task that is undervalued, economically burdensome, isolating, and emotionally demanding. The following verbatim extensive quotes demonstrate the conversation between the caregivers.

Major Theme 1: Female Caregivers' Perspectives on Caregiving as a Gender Role

The caregivers discussed the role of gender in caregiving responsibilities. They agreed that females generally feel more obligated than other family members to serve as caregivers to family members living with dementia. The caregivers of participants in the CY group shared the following comments about their nurturing qualities:

Evelyn: Oh, honey, she don't have anybody but me. The rest of the family won't step up unless I push a button. I don't have time for that. I just do what she needs done, and I and God deal with it.

Frieda: I'm the same way. You know your husband the best, she knows her sister the best, and I know my aunt and my mom the best.

Carolyn, a 73-year-old woman who cares for her mother, who was in the MI group, said, "We do what we have to do. As women, we do what we have to do or what we need to do."

Similarly, Helen, whose mother had participated in CBE, discussed gender roles as a component of caregiving and discussed the relationship with her mother by describing herself as a "little helper" for her mother and in taking care of two younger sisters:



I was the caretaker for the two younger sisters, and I think their lives were much more carefree. She was centered on being a good mother, but I was mother's little helper.

Subtheme: Female caregivers' dedication to and devotion for the family member living with dementia: All participants described the care and love that they provided to their family member living with dementia. A wife expressed her determination to continue to care for her husband living with dementia who had participated in CBE.

Dottie: He gets dressed. He's smart enough that if he thinks his underwear is clean, he hides the clean one. And to see it, you know, dissipating, I said, "I'm not going to let it go all the way down." There's no way. I mean, it's a battle. It's a battle. As long as he stays the same, and I consider him very close to being the same, then I will not give up.

Two caregivers whose family members were in CY agreed:

Frieda: it was something that we committed to. I think that's the real point of my reflection-I should just speak for me. But I also recognize the six or seven other caregivers that, we were committed to our (family) members. And then they were committed to us.

Evelyn: Well, she's my sister. You don't have a choice, you know.

The caregivers whose family members were in MI concurred:

Carolyn: You know, she looked after me, so I have to look after her. But I'm just glad she's home. I come from a family of nine, and I'm the oldest, and I kind of think my siblings expected me to do it. So, what am I supposed to do? Not look after-you can't not look after your parents. That has been embedded in me. They're your parents; they looked after you. So, we, as Blacks-I don't know how many-we just kind of look after our families. That's what you're supposed to do, you know.

Betty: That's your brother. Go get him. That's it.

Abigail: When it's all over, you can put your head on the pillow and sleep and have, you know, no regrets.

Helen, whose mother had participated in CBE, said: "My dad and I were exceptionally close. As he said, I was the only one that looked like him and acted like him. And he made me promise to look after mom. And my word is my bond. I will never break that promise."

Major Theme 2: Female Caregiver Burden and Emotional Distress

The caregivers discussed the emotional distress, sadness, and physical burden often associated with caregiving responsibilities. A wife expressed anger about taking care of her husband:

Dottie: It's just like I wish I had the time to do more things with him. As far as symptoms go, it's not easy. I get very stressed out at times. I get extremely stressed out at times. I also carry anger that it even happened. But I know why it happened. In his case, he always worked with engines. In my case it's high [stress], because I've got so much that I have to do myself, and I don't get that break unless he goes to the [adult center].

Another spousal caregiver shared with the other participants in the CY group who care for their sister and mother and niece:

Gail (who still lives in her house of 53 years with her husband): It's just a variety of things, you know. He wants to go home all the time. We lived in our house 53 years. And he'll say his address, and he wants to go home. And I can't talk about it. It's very painful.

Frieda: The reminiscing is really tough though, which we're talking

about here, is the reminiscing symptoms of the dementia is very tricky, because it's upsetting, first of all-which I've totally gotten over that. I don't fall apart anymore. Sometimes I feel like I'm becoming a stone, but not really. It's just you have to compartmentalize.

Evelyn: You have to have a protected-right. You have to have a protected state of mind.

Frieda expressed a difference from Gail as a spousal caregiver: I'm not married to it. So, I separate business from pleasure. I'm not married to it. It's different.

Gail agreed as a spousal caregiver: It's different. I would assume it's different.

Frieda: It's different when you're sister; it's different when you're a niece.

One participant cared for her mother every day. She described emotional and physical exhaustion and isolation from social activities.

Helen: But I even used to go out for a few hours and meet some friends for dinner. Of course, she called me quite a bit, but I would do that. I can't even go into the bathroom sometimes. You know, I have to remind her I'm here. You know? I can't talk-I don't get on the phone with friends until after she's in bed, by which time I'm exhausted. She needs that reassurance that she-she talks a good game. My biggest challenge is lack of time for myself. And I face the difficulties when you're one of four, and only one of you has volunteered to give up everything. I stopped working, I sold all of my-gave away all of my possessions, you know, and now living in one room in my mother's house, you know? It's challenging. You know, I now understand how my mother felt after my dad had his stroke, because everybody called and asked, "How is Dad?" But nobody ever asked "How is Mom?" Now, everybody's asking how's Mom doing, but nobody is asking how I'm doing and what I need, other than friends who have been through this. I was emotionally drained. I was exhausted. I fought with her. I've always gotten six to eight hours of sleep at night." I said, "Now, I'm lucky if I get three or four. And it's not good sleep."

Major Theme 3: Acceptance of the Current Situation and Developing a New Relationship

The caregivers shared that one positive coping strategy was to accept a new relationship with the family member living with dementia. A specific approach was to be present and embrace the new relationship by treasuring those moments.

Helen: I think my brother and two sisters are in serious denial. I don't know if they have the capacity to love the person that she is now. And that's something when you're dealing with dementia, you have to forget who your mother or your parent was, because that's not the person they are. It's a new relationship. They're a totally different person. And my mother even says it sometimes. She'll say to me, "I was never this way before." And I'll jokingly say to her, "I used to be able to throw my legs over my shoulders, I can't do it anymore," just to try to get her away from what was. Like in the evenings when I'm helping her, she's standing in front of the toilet, and I'm helping her to pull up the pull-ups. She'll say to me, "Isn't this funny? I used to do this for you." And it breaks my heart. It breaks my heart, you know that she's been put in that position. But I try to say to her-she'll say, "Why did God do this to me?" I said, "Ma, he could have given you cancer." "You have to deal with what's now."

Helen continued regarding the new relationship and its challenges,

I might be a throwback to a long time ago, or from a different culture altogether. But it has affected my relationship with my mother.



It has brought up some distasteful memories from my childhood. It has sometimes made me hate her. It has sometimes made me pissed off at my siblings. But I keep reminding myself, I'm not angry at her, I'm angry at what the disease is doing to her. It's different. It is a big, big difference. This would not be her choice. This behavior would not be her.

Subtheme: Living in the Moment: The following examples demonstrate the power of noticing and appreciating the simple pleasures in daily life such as dressing for the day, watching game shows at the end of the day, carefree dancing, and driving practice. A daughter of a participant in the CY intervention shared her perspective of coping:

Frieda: We don't focus on the shortcomings. We focus on where we're at, at all times. It keeps me in the moment. I have to stay in the present. This morning with my mother, we have a huge agenda today. And I wrote it down last night while I was visiting. And I said, "Just look at what you have to do now." And that was at 8:30. "All I've got to do is get dressed." The caregivers of participants in the CY intervention shared stories about living in the moment. Evelyn began the conversation about her sibling:

I took Celeste to the Y one day. We had this guest guy that had been on "Dancing with the Stars," and he was going to show us some different dances. So I say, "I think you'd like to go to that." So we went, and the man could hardly talk. "This reminds me when I was in high school. We did this." She did it. She just wouldn't shut up. But he learned to project louder than her, and then she grabbed me. "Look. Look, look." And I'm in the middle of a dance move thinking I'm doing good, and she grabs me. But she enjoyed that. She enjoyed it. But she didn't remember it long. But she was in the moment.

Frieda shared, although it is emotionally difficult, it is a choice to be present: It's painful. But not really, because you've got to find the joy. It's spiritual in nature.

Gail shared with her group a tradition she had with her husband with all of their children and grandchildren when they received their driver's learning permit of practicing in a nearby cemetery: You are talking about being present. My daughter came over yesterday, and our granddaughter, and they were all excited. She just got her learner's permit to drive. So she was showing grandpa and us, you know. And so we went-this is tradition. My daughter says, we live where there's a cemetery back, and there's not usually anybody there, hardly. It's a road that goes around, and that. And that's where I taught, and my husband taught the kids to drive all the time, in the cemetery. And so she took us to the cemetery, and we rode around. We went there because there's nobody there. She would have (hit another vehicle) if there were a car there. Then she backs out, and I said, "Oh, I think we got the one behind us, too." (Laughter) Then he couldn't remember her name later. He says, "Who was that tall girl?"

Evelyn reassured Gail her husband remembered this family tradition in the moment: But he did remember the person. Not her name, he remembered:

Frieda: But he also went in the car. Driving around. Because again, I think a psyche can kick in. You're fortunate, because you are doing things that are from his past. We have to conjure up this laughter. My mom and I throw a party whenever I can. I just throw parties. And I've thrown a lot of hard-stress, good parties. I mean, big ones. And I had an eclipse party for my mom and my aunt and I, just the three of us. And as soon as the sun started to go dark, I turned on a bunch of different kinds of music out in the yard, and Elvis came on, and I was dancing with my mom to Elvis out in the yard, like a banshee. And I don't care who sees us, I don't care how loud it is, we are dancing during this eclipse. We're trying to keep these moments.

Major Theme 4: Female Caregivers' Suggestions Regarding Care of Family Members Living with Dementia

The experienced caregivers shared insightful approaches about caring for a family member living with dementia. A participant whose husband had participated in CBE is an educator who had worked with children with autism. She had a unique perspective, compared to that of the other caregivers, regarding care of a family member living with dementia. Rather than providing assistance with everything, she helped her husband to do things by himself so he would not lose the basic skills.

Dottie: I keep him involved. I talk to him no differently. I don't do everything for him. We sit at the counter to eat, and I have him set it, the placemats, do everything. I find that asking him to *focus* on what he's looking for, not to try to picture it, by say, "Oh, I'm looking for the salt and pepper shaker"-focus on the salt and pepper shaker, and he goes right to it. You have to know the person, too. And the more you don't let him do normal things, the more he's going to forget, also. Because every skill that they lose, they're losing brain cells. I tell him. I say, "Listen, you've got to do this, because if you don't do it-I says, "You're going to lose it." I use the word *focus*, not *remember*.

Some of the caregivers of participants in CY had wanted to be involved in the exercises that were done in class in order to reinforce them at home.

Frieda: I want to know what my women are doing here [intervention], so we can carry- "do you recall" for my mom. I don't ask my aunt, "do you remember?" But I say to my mom, "Do you recall what the movement was," like for anything, like Mind and Mobility, I watch. Then when we're at home, I mimic it so that we can keep going.

Another suggestion by Frieda and Evelyn was to remain calm when working with a family member living with dementia.

Frieda: Calmness, or redirecting. Go back to your book.

Evelyn: And I have to learn calmness, my daughters tell me. See, I forget that she's sick. And we used to have our little sister arguments, and then we laugh and go on about our business.

Frieda: It's so important to have camaraderie and continuity.

Carolyn from the MI group agreed that compassion is paramount. "She's a different person. It's not her. It's not the mommy that I remember, so I try to have as much compassion for her."

Subtheme: Importance of Home Environment to the Family Member Living with Dementia: Three caregivers, representing each intervention (MI, CBE, CY), shared the belief that the home environment is crucial.

Carolyn (MI): People feel freer in their own environment, their own, you know, place.

Helen (CBE): And I think she deserves the same dignity. So maybe I'm the only one that learned the lesson that the others did not. I also have always believed, based on my professional career, and working in the field of aging a long time ago-people do better in their own homes than they do in an institution. Institutionalizing people is nothing more than warehousing them. And I told you my latest analogy. It's like putting a dog down. Putting a dog in a shelter, and letting them put it down. Because that's what eventually is going to happen. And I don't think that's the way you pay your respects.



Evelyn (CY): When she moved back to her home. She had been living with me for five months, and she was totally uncomfortable, because it was not hers. It was not her familiar. And they have to be around their own familiar to be completely comfortable.

Subtheme: Importance of Support among Caregivers: The caregivers whose family members were in the CY intervention had developed an emotional bond over the 12-week period, as demonstrated in this dialogue.

Frieda: We were really together, for once, on the same page, instead of us being individuals.

Evelyn: We would lift each other up, and knowing that we were all going through the same thing. But we felt better, knowing we weren't alone.

Frieda: I think the challenging time was actually-I think being around each other for the caregiver, during the chair yoga, was priceless. Because the timing for our family-I was starting to really lose it. Because it was coming on so fast [the dementia symptoms].

Evelyn: We need a break sometimes.

Frieda: It was coming on so fast, the symptoms. And then you realize that they level out, in different levels. They level out in different areas. But having a place to go as a caregiver, where everybody is participating in one room, and then the caregivers are rallying the next room-you don't feel alone.

Evelyn: No, you got that support there.

Frieda: And it was the atmosphere, too. When we pulled up in the parking lot, we were together, right?

Evelyn: Yes. And then we'd speak, and everybody recognized everybody.

Frieda: Yeah, it's, like, saying "hello," and "let's go in together," and holding the door. And my mom would go to the restroom, your husband would go to the restroom.

The caregivers whose family member living with dementia were in the MI intervention reported that their neighbors were supportive. They shared meals and had a social night every Friday evening. Carolyn from the MI group shared that she was receiving some familial support.

My daughter comes; she's in and out. And I feel relieved, because somebody else is doing something besides me, and that kind of gives me a chance to have a part of a life. And I'm just enjoying what I do.

Discussion

Based on the findings, it is important to consider how to assist caregiver's empowerment and promote positive coping. The caregivers who participated in this study perceived their gender as central to the role of being a caregiver and described the emotional and physical burden that this entailed. The discourse among caregivers focused on acceptance of the disease and the importance of support in enduring social and material constraints (interpersonal, isolation, and second-shift responsibilities) of dementia caregiving. One of the major reasons that female family caregivers provide care to family members living with dementia is the caregiver's perceived obligation as a gender-specific role (e.g., spouse, partner, daughter, sister, and niece). Similar studies demonstrated female caregivers, compared to male caregivers, perceive more social expectation as a caregiver to place their family member's care above their own, and they experience more family barriers to self-care

[42,43]. Likewise, participants in the current study stated that it was their role and duty as women to care for the family member living with dementia. Though our study's purpose did not address male perceptions of caregiving, participants identified that gender role was a factor in their caregiving and described that they were dedicated and devoted to the family member living with dementia (Subtheme: Caregivers' dedication to and devotion for the family member living with dementia).

Unlike previous studies of D'Onofrio G, et al. (2015) [19], Fonareva I, et al. (2014) [22], Galvin JE, et al. (2017) [20], and Goren A, et al. (2016) [11], that highlighted caregiver burden and negative outcomes in female caregivers, the current study identified that the female caregivers' empowerment and personal growth may contribute to positive coping. The findings suggest incorporating an empowerment approach to managing caregiver stress and burnout may provide positive family caregiving for older adults with AD or DLB. Empowerment is a process of increasing personal, interpersonal, or political power so that individuals can take action to improve their life situations [44]. Caregivers who are empowered might be buffered from negative consequences of caregiving for themselves and for those for whom they care. Small group work is the ideal modality for empowering interventions because it is an effective means for integrating techniques such as mutual aid, developing skills and collective problem-solving [44]. Further research could examine the impact of empowerment approaches and positive coping for female caregivers.

In a recent conceptual article, Seaman AT (2018) [45], discussed caregiving as a creative meaningful intervention. He described how relational labor in caregiving is involved in making and maintaining a family-not only the physical and emotional labor to help the person living with dementia but also the continuous work and support to maintain connections that constitute family. This was evident in the current study finding of emotional connections under the subtheme "*Living in the moment*". Likewise, in a cross-sectional Iranian study [31], examining positive aspects of caregiving measured by caregiver gains, satisfaction, meaningful life, and enhanced family relationship, there was a negative association between positive aspects of caregiving and caregiver burden. Eriksson H, et al. (2013) [46], concluded that women consider their caregiving role and responsibility as the most important one in their everyday lives. Caring for themselves was less important to them. The concern becomes who cares for the caregiver and whether this is a gendered social structure, as demonstrated in Major Theme 1: Caregivers' perspectives on caregiving as a gender role.

Similar to Lloyd J, et al. (2016) [32], many of the participants expressed that it was important to accept the dementia and to develop a new relationship with the family member living with dementia. A study of family caregivers of persons living with dementia reported high levels of stress, depression, and decreased health due to the emotional, psychological, and existential challenges as caregivers witnessed disease progression in the family member [47]. Those researchers suggested that burden is decreased as the caregiver seeks new ways to attune to, connect, and reconnect with the family member living with dementia. In the current study, this was expressed as an important strategy, as shown in Major Theme 3: Acceptance of the current situation and developing a new relationship.

Implications for Clinical Practice

How can health care professionals such as clinical social workers support caregivers in this process? To reduce physical, emotional, and psychological strain, family caregivers warrant special attention. Caregiver support groups have been effective in coping with the loss of



a relationship and forming a new relationship with the family member living with dementia. Social group work provides the opportunity for mutual aid. Mutual aid creates the settings in which people can support one another with their similar concerns. Mutual aid enables group members “to recognize and empathize with others, to listen to others and express one’s self, and see the commonalities with other group members empowers participants to interact more effectively” in their challenging caregiving role [48]. Caregivers could identify with each other’s obstacles and feel understood and validated, resulting in greater sharing of subjective reactions to caregiving and more effective problem solving and coping strategies [49]. In the current study, it was noted that the spousal caregivers, Dottie and Gail, expressed profound grief in observing their spouses’ decline. Gail received emotional support from her focus group members when she expressed that it was painful that her husband did not remember their home. Consistent with previous findings of Damianakis T, et al. (2018) [49], and Whitlatch CJ, et al. (2018) [50], these interactions between caregivers in the focus groups in the current study highlighted the importance of mutual aid, supportive connections, and shared lived experiences.

Focusing on caregivers and addressing the emotional strain of caring will aid in providing the necessary support for family caregivers and may improve health and quality of life for caregivers. The participants in the current study agreed that emotional support was important for their health and well-being. Helen shared that no one was caring for her, the caregiver, other than friends who had experienced caring for a family member living with dementia. She shared her complex emotional reactions, such as anger, related to caring for her mother, but reported that she copes by blaming the dementia and not her mother: “This would not be her choice. This behavior would not be her.” She was quick to alter her emotions to gender-specific emotions of what is acceptable in society. This was shared during an individual interview. Would she have received an empathic and supportive response from another female caregiver in a focus group? In order to increase the wellbeing of caregivers those working with families impacted by dementia should encourage gender-based support groups for female caregivers caring for a family member living with dementia [51]. Likewise, participants in the current study expressed appreciation for support received from others who understand the experience of caring for a family member living with dementia (*Subtheme: Importance of support among caregivers*).

A feminist CDA includes knowledge from other sources that are not typical privileged knowledge sources, such as female caregivers of family members living with dementia. It is important to consider how care is valued, distributed, and understood. Care practices are understood as a means of affirming one’s morality by acknowledging and sustaining personhood through social relations. When a family caregiver cares for a family member living with dementia, there is a continuously changing relationship and the caregiver must learn to accommodate the effect of cognitive changes on daily life. In addition, the caregiver must refigure an imagined future and formulate how to continue family rituals and relational endeavors. Rather than being overlooked, the female caregiver should be embraced for the positive aspects of caregiving and longevity of the family. A recent qualitative study examined gendered identity and agency in dementia and found women were more relational [52]. The current system is predominantly an unchanging gendered social structure that encompasses social and material strains, which are often oppressive to female caregivers as more individualistic and rational versus relational.

Limitations

Limitations of this study are acknowledged. Findings from the small sample are not generalizable. However, participants reported that they found the discourse about caregiving to be meaningful. The two individual interviews may have produced different results from the results of the focus groups. Some caregivers declined to participate in a focus group because of work responsibilities. Those who participated were not asked about current employment. Characteristics of participants and nonparticipants may have been different. The caregivers in this sample were highly motivated and involved with their family members living with dementia. The participants in this study experienced a highly challenging caregiver role, as they were caring for moderate to severe family members living with dementia but persevered. Future studies could examine if the empowerment approach is gender specific or if it is an individual characteristic. It would be interesting to explore if male caregivers exhibit similar positive perspectives in caregiving. These motivating factors may contribute to gender empowerment in caregiving.

Conclusion

This exploratory study builds on current knowledge of caregiver burden by considering a feminist CDA of gender and empowering caregiving. Based on the findings, support groups may be helpful for caregivers to reduce emotional distress and health burdens. The Alzheimer’s disease International offer virtual support groups for dementia caregivers which may be utilized during the current pandemic and for those with transportation or financial constraints. Social workers and other health professionals practicing in older adult settings should offer support groups. Papell CP (2015) [53], has shared about social group work as “dynamic interactive processes created by those members in the life of the group. It is in the processes of group life that humans struggle for their essential humanity and health.” In our focus groups, the family caregivers encouraged each other to practice living in the moment and learning to accept and adapt to the new relationship with the family member living with dementia [54-57]. Because women are primarily the caregivers of family members living with dementia, it is important to increase gender awareness in informal caregiving and highlight the difficulties of living up to the gendered standards that female caregivers face [58,59]. If female caregivers are currently at higher risk of emotional, physical and economic harm as long-term caregivers for family members living with dementia, then development of an empowerment approach which highlights the positive outcomes of caregiving may benefit the caregiver and the institutions that provide support and services.

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Conflict of Interest

The Authors declare that there is no conflict of interest.

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