

# Positive Aspects of Dementia Caregiving: Caregivers' Lived Experiences

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## Abstract

**Aims:** This study aims to qualitatively explore the positive experiences of caregivers for people with dementia (PwD).

**Methods:** A descriptive phenomenological design was employed with purposive sampling. This study was conducted in Indonesia by the Alzheimer's Indonesia organization. Participants were selected using purposive sampling methods. The study involved 11 caregivers, including paid caregivers and family members, including children, grandchildren, spouses, siblings, and other close relatives, who had provided care for at least one year. Data were collected through in-depth interviews conducted face-to-face or via Zoom in 2022. Colaizzi's method guided the data analysis to extract significant statements, formulate their meanings, and identify emerging themes. Rigor was ensured through data triangulation, peer checking, and participant validation.

**Results:** The study identified four main themes reflecting the positive experiences of caregivers of persons with dementia: (1) Personal Growth and Development, including increased patience, empathy, and caregiving competence; (2) improved relationships and connections, characterized by stronger emotional bonds and supportive family dynamics; (3) Search for Meaning and Role Satisfaction, where caregiving was seen as a purposeful, spiritually meaningful role; and (4) Positive Psychological Outcomes, such as reduced stress, greater emotional resilience, and enhanced well-being.

**Conclusion:** Despite the challenges, caregiving for individuals with dementia can lead to personal growth, stronger relationships, a sense of meaning, and emotional resilience. These positive experiences highlight the importance of supporting caregivers and recognizing their strengths.

*Keywords:* aging, caregiver, dementia, older adults, positive aspects.

## **Introduction**

Dementia is a significant and growing public health issue that affects millions of people worldwide (Laparidou et al., 2019). The World Health Organization (WHO) estimates that 55 million individuals currently live with dementia globally, a figure expected to rise to 78 million by 2030 and 139 million by 2050 (World Health Organization, 2021). Dementia impacts multiple dimensions of an individual's life, including cognitive abilities, emotional well-being, and social interactions (DiSantostefano, 2018; Li et al., 2017). Its progressive nature often results in increased dependency and the need for long-term care (Van Buuren et al., 2022). In many societies, particularly in low- and middle-income countries, family members often bear primary caregiving responsibilities, frequently without formal training or adequate resources (Ho et al., 2024).

Caregiving for persons with dementia is frequently viewed through the lens of burden and stress, overshadowing the potential positive aspects that caregivers may experience (Kunicki et al., 2021; Zhang et al., 2020). Caregivers often experience high levels of stress, anxiety, and depression owing to the intensive demands of dementia care (Orlova et al., 2024). This psychological strain is exacerbated by disease progression and the complexity of daily caregiving tasks (León-Campos et al., 2018). The stress-process model in caregivers captures the main challenges they face and highlights the types of support they need from healthcare services (Laparidou et al., 2019).

However, in recent years, there has been growing recognition that caregiving is not solely a negative experience (Hall et al., 2024). Despite these challenges, emerging research indicates that informal caregivers of PwD report meaningful and positive experiences throughout their caregiving journeys (Yuan et al., 2023). These positive aspects have been shown to moderate caregiver stress and enhance overall well-being (Walker et al., 2016). According to the transactional model of stress and coping, stress occurs when individuals perceive environmental demands as threats to their well-being that exceed their coping resources (Werntz et al., 2015; Yuan et al., 2023). Within this framework, positive caregiving experiences are valuable coping resources that can buffer the adverse effects of caregiving-related stress (León-Campos et al., 2018). Prior studies involving dementia caregivers have demonstrated a significant inverse relationship between positive caregiving experiences and caregiver burden.

Despite this evolving perspective, much of the current evidence stems from Western contexts, potentially overlooking the influence of cultural, spiritual, and familial values that shape caregiving in other regions (Yuan et al., 2023). In collectivist cultures, caregiving is often closely linked to familial responsibility, religious devotion, and cultural norms, which significantly influence the challenges and perceived benefits of caregiving (Kline & Killoren, 2022; Zhan, 2004). Thus, this study addresses this gap by exploring positive caregiving experiences within the Indonesian cultural context. This study aimed to qualitatively explore the positive experiences of caregivers of PwD, drawing on diverse caregiving roles, including those of adult children, spouses, and formal caregivers. Through in-depth interviews, this research seeks to understand how caregiving fosters emotional growth, strengthens interpersonal connections, nurtures meaning and role satisfaction, and contributes to psychological well-being of the caregivers.

## **Methods**

### **Study Design**

A descriptive phenomenological study was conducted using in-depth interviews for data collection. This study followed the methodological framework for descriptive phenomenological research proposed by Abraham & Padmavathi (2024).

### **Population and Sample**

The participants were caregivers who provided care to individuals with dementia. These caregivers were paid caregivers and family members, including children, grandchildren, spouses, siblings, and other close relatives, such as nieces, nephews, daughters-in-law, or parents-in-law, who provided direct care and support for individuals with dementia. This study included 11 caregivers. No eligible participants refused to participate, and there were no dropouts during the study period. The number of participants was determined based on data saturation, which was reached when no new information or themes emerged in the interviews. After the eleventh interview, the researcher observed repetition in participants' responses, indicating that the data had reached saturation.

Participants were selected using purposive sampling, a non-probability sampling technique commonly used in qualitative research. This approach allowed the researcher to intentionally recruit individuals who met specific criteria relevant to the study objectives. Participants were identified through the Alzheimer's Indonesia organization, which provides support and networking for families of individuals with dementia. The inclusion criteria for participants were: (i) family members and paid caregivers who are currently providing care for a person with dementia, (ii) aged 18 years or older, (iii) having provided care for at least one year, (iv) able to communicate fluently in Indonesian, and (v) directly involved in caregiving activities.

### **Instrument**

In qualitative research, the primary instrument is the researcher. The in-depth interview guide used in this study consisted of six open-ended questions developed based on the research objectives and a review of the relevant literature on the positive aspects of caregiving and dementia care. To ensure clarity and appropriateness, the interview guide was reviewed by two experts in qualitative research and gerontology nursing. A pilot interview with one caregiver was also conducted to test the clarity and flow of the questions, and minor adjustments were made before the main data collection began. The interview guide included the following questions: (1) Can you describe your experience caring for a person with dementia? (2) Could you share how you feel about the caregiving process? (3) Have you experienced any positive aspects of your life while caring for a person with dementia? (4) Please describe something that you find meaningful or that gives you a positive impression of your caregiving experience. (5) Could you describe your daily activities while caring for a person with dementia? (6) What type of care or support services do you think you need while caring for a person with dementia?

### **Data Collection**

The selection of data collection techniques was based on the research objectives to facilitate the gathering of relevant information. This study was conducted naturally, utilizing primary data sources through in-depth interviews with the participants. The interviews were conducted by the researcher (EPA), a female bachelor's nursing student with training and experience in qualitative interviewing, face-to-face while adhering to health protocols (mask-wearing, physical distancing, and hand hygiene). If face-to-face interviews were not feasible, interviews were conducted online via Zoom meetings in 2022. No individuals other than the participant and the researcher

were present during the interviews to ensure privacy and comfort throughout the data-collection process. Each interview lasted approximately 45–60 minutes and was guided by six open-ended questions developed based on the research objectives and the relevant literature. The data collection tools included an interview guide, voice recorder, writing instruments, and field notes for recording non-verbal cues.

### **Data Analysis**

This study employed Colaizzi's method for data analysis because of its advantages over other phenomenological approaches, particularly its emphasis on validating findings with participants and allowing revisions based on their feedback (Creswell, 2018). The analysis began with the researcher understanding the phenomenon and Positive Aspects of Caregiving (PAC) through a literature review and rapport building with participants. Data were collected through in-depth interviews, and the narratives were transcribed verbatim by the researchers (EPA and TPA). The researcher then thoroughly read the transcripts multiple times to better understand the participants' experiences. No specific software was used for data management or analysis; all transcripts and field notes were manually organized and analyzed using Microsoft Word and Excel to assist in coding, categorizing, and developing themes, based on Colaizzi's phenomenological approach. Significant statements relevant to the research objectives were identified and extracted, and then organized into a data analysis table. Each significant statement was interpreted to uncover its underlying meaning, staying true to the participant's perspective while bracketing the researcher's own assumptions. These formulated meanings were then grouped into themes based on similarities in context and meaning. The themes and subthemes were synthesized into a rich, concise description that captured the essence of the participants' experiences. The researchers acknowledged their perspectives and experiences in caregiving and nursing, which could potentially influence the interpretation of participants' narratives. To minimize bias, reflexive journaling was maintained throughout the study to document the assumptions and reflections during the data collection and analysis. The research team also engaged in continuous discussions to ensure that the interpretations remained grounded in the participants' lived experiences rather than the researchers' preconceptions. The findings were validated to ensure credibility by presenting them to the participants for confirmation, with opportunities for correction or clarification. Additional validation was conducted by qualitative research experts. The final step involved refining the analysis based on feedback to enhance the accuracy and trustworthiness of the study results.

### **Rigor**

To achieve rigor, we employed several strategies, including accurate documentation of participant responses, recording and professional transcription of all interviews verbatim, and employing multiple data sources, including transcripts and interviewer's memos. Additionally, we held regular peer-checking meetings to discuss our interpretations and ensure a consensus on a logically sound interpretation.

### **Ethical Statement**

This study was approved by the Faculty of Nursing, Universitas Airlangga Committee Ethics (2650-KEPK). All participants were given an Information Sheet and time to consider consent before being contacted for interviews. Verbal informed consent was obtained and audio-recorded before the interviews began.

**Results**

Demographic Characteristic

The demographic characteristics of the participants are presented as frequencies and displayed accordingly (Table 1). The participants represented diverse backgrounds and roles in caregiving, including biological children, spouses, and paid caregivers of PwD, providing a comprehensive perspective on caregiving experiences. Demographic data indicate that the majority of the participants were female (81.8%), held a bachelor’s degree (72.7%), and were predominantly married (54.5%). In terms of their relationship with PwD, the largest proportion was biological children (63.6%), with others including paid caregivers, nieces, wives, and grandchildren.

**Table 1.** Demographic Characteristic of Participants (n=11)

ID	Age	Gender	Education	Marital Status	Occupation	Duration of Caregiving	Relationship with PwD
P1	24	Female	Bachelor’s Degree	Single	Social Worker	6 years	Paid Caregiver
P2	30	Male	Bachelor’s Degree	Single	Entrepreneur	3 years	Son
P3	61	Female	Bachelor’s Degree	Married	Entrepreneur	2 years	Niece
P4	29	Female	Diploma	Single	Unemployed	5 years	Daughter
P5	60	Female	Bachelor’s Degree	Married	Housewife	4 years	Wife
P6	57	Female	Bachelor’s Degree	Single	Entrepreneur	3 years	Daughter
P7	49	Female	Diploma	Married	Housewife	2 years	Daughter
P8	53	Female	Diploma	Single	Freelance Copywriter	5 years	Daughter
P9	45	Female	Bachelor’s Degree	Married	Housewife	1.5 years	Daughter
P10	35	Female	Bachelor’s Degree	Married	Private Employee	1 year 5 months	Daughter
P11	29	Male	Bachelor’s Degree	Single	Entrepreneur	8 years	Grandchild

**Themes**

Four main themes emerged from this study: personal growth and development, improved relationships and connections, search for meaning and role satisfaction, and positive psychological outcomes.

Theme 1: Personal Growth and Development

This theme identifies caregivers’ instances of self-discovery, emotional maturity, and the development of caregiving skills.

*Subtheme 1.1: Emotional Maturity and Self-Discovery.*

Caregivers indicated developing patience and empathy as a result of reflecting on aging and the vulnerabilities of individuals with dementia.

*“I’ve become more patient in caregiving.” (P4)*

*“We’ll also grow old like them, so we can learn to be patient.” (P8)*

This process of reflection also enhanced emotional growth and empathy towards elderly people.

### *Subtheme 1.2: Skill and Competence Development*

The participants also reported learning practical caregiving skills and developing adaptive coping strategies.

*“Learning more about how to properly care for older adults with dementia properly.” (P1)*

*“Talking to myself... it can’t be changed or cured, and I try to take care for my father.” (P10)*

These experiences reflect enhanced self-efficacy and acceptance in managing the challenges of dementia care in the Philippines.

## Theme 2: Improved Relationship and Connection

Caregiving was perceived as a relational journey that deepens emotional bonds and strengthens family and community ties.

### *Subtheme 2.1: Strengthening Bonds.*

Daily routines, such as bathing or feeding, were transformed into moments of shared affection and closeness.

*“I’ve learned how to care, treat, and accompany my mother properly.” (P8)*

*“The most important thing in caring for a someone with dementia is to love our parents.” (P10)*

Such interactions facilitate a shared understanding and emotional intimacy between caregivers and recipients.

### *Subtheme 2.2: Family and Social Support.*

Siblings and caregiver support relieved the burden and retained motivation.

*“There are three of us siblings, so we can look after each other... when I am burnt out, my sister assists me.” (P6)*

*“Families can teach each other, exchange advice on how to care for people with dementia effectively and appropriately.” (P10)*

This describes the community-and culturally embedded nature of caregiving in extended family structures.

## Theme 3: Search for Meaning and Satisfaction in the Role

Caregivers viewed their work as a moral and spiritual duty performed in good faith.

### *Subtheme 3.1: Sense of Purpose and Responsibility*

Caregivers view their roles as a moral and spiritual duty that must be embraced with sincerity.

*“Like it or not, I have to accept my father’s condition.” (P4)*

*“We learn to accept ourselves and see it as a test from God — we’re chosen to care for this person with dementia.” (P10)*

This mindset transformed caregiving into an unconditional life calling grounded in belief and acceptance.

### *Subtheme 3.2: Competence in Role and Achievement*

The participants were pleased and proud to have overcome caregiving challenges and promoted the health of their kin.

*“I feel satisfied, I really do. In my neighbourhood, there are individuals who abandon their old parents, but thank God that is not our case...” (P3)*

*“Being able to talk, make her laugh brings her happiness... that is happiness for me and for her.” (P5)*

These words express a sense of gratification and emotional fulfillment resulting from good care and strong family bonds.

#### Theme 4: Positive Psychological Outcomes

Caregiving fostered emotional resilience and spiritual growth, enabling caregivers to adapt positively to sustained adversity

##### *Subtheme 4.1: Increased Well-being and Coping*

Participants reported being quieter, more patient, and emotionally solid as they gained the ability to deal with stress and to regulate their feelings.

“I feel peaceful taking care of my parents. I don't know why, but there's peace within that I couldn't describe.” (P11)

“Yes, I've been practicing my patience more.” (P9)

This indicates that caregiving enhances coping skills and promotes psychological adaptation through self-acceptance and contemplation.

##### Subtheme 4.2: Spiritual Satisfaction

Religion was a pervasive theme in sustaining hope and optimism, with caregivers framing their activities as part of God's plan.

“God willing... Allah will bring happiness in this world and the hereafter that is His promise.” (P11)

“Allah is pleased when we try first, plan it out, and then He will show us the way.” (P5)

Such faith fostered gratitude and peace of mind, illustrating how spirituality was a resilient coping asset along the caregiving journey.

### **Comprehensive Analysis**

Across the four themes, caregiving was experienced as a dynamic process that entangled emotional, relational, and spiritual dimensions. Participants wrestled with and grew through the recognition that their ability to sustain care was significantly shaped by acceptance, family interdependence, and religious meaning-making.

Although caregiving was recognized to be psychologically and physically demanding, participants preserved balance using adaptive coping habits such as acceptance, reframing, and shared family responsibility. Instead of eliminating stress, they transformed it into a meaningful experience based on love, duty, and spirituality.

These findings suggest that emotional and physical equilibrium among caregivers was not attained through personal endurance but rather through a system of spiritual endurance instilled in society. Thus, the caregiving experience possessed a form of collective coping in which empathy and stress coexisted within religious and family structures.

### **Discussion**

The findings of this study reveal that caregiving for PwD can lead to positive experiences, personal transformation, and emotional enrichment despite the inherent challenges. Four major themes emerged from the data: personal growth and development, improved relationships and connections, search for meaning and role satisfaction, and positive psychological outcomes. These themes highlight the multidimensional benefits of caregiving, especially in cultural contexts like Indonesia, that emphasize familial duty, emotional bonds, and spiritual beliefs. Sociodemographic characteristics appeared to shape positive caregiving experiences. Younger and more educated caregivers emphasized learning, self-reflection, and personal growth, while older caregivers, mostly spouses or long-term homemakers, highlighted faith, acceptance, and spiritual strength. Female caregivers commonly describe caregiving as a moral and familial duty, reflecting the cultural expectations in Indonesia. These variations suggest that background factors, such as age, gender, and education, influence the experience of positive aspects of caregiving.

### Personal Growth and Development

Personal growth and development illustrate how caregiving can lead to emotional maturity, increased empathy, and the development of practical-care skills. Many participants shared that their experience taught them patience and helped them better manage stress through self-reflection and acceptance. This aligns with previous research indicating that caregivers often report personal growth as a significant positive outcome of their caregiving experience. This includes becoming more patient, resilient, and self-aware, and gaining a deeper understanding of life and relationships (Leipold et al., 2006; Netto et al., 2009; Sanders, 2005; Yen, 2018). Caregivers also develop a sense of mastery and spiritual growth, contributing to their overall well-being (Netto et al., 2009; Sanders, 2005). The demands of caregiving can increase cognitive complexity and maturity. This growth is often associated with the duration of caregiving and the challenges faced, such as lack of social acknowledgment and the need for help with daily activities (Leipold et al., 2008). The findings indicate that nurses and community health workers can actively contribute to caregivers' personal development by offering educational sessions, reflective support groups, and stress management training that affirms caregivers' efforts and enhances their coping abilities.

### Improved Relationship and Connection

Improved relationships and connections highlight how caregiving can strengthen the emotional bonds between caregivers and care recipients. Daily routines, such as feeding and bathing, became meaningful opportunities for affection and togetherness among participants. Previous research has shown that caregivers' responsiveness and sensitivity to cues during feeding can significantly enhance the interaction, making it a moment of connection and care (Beel-Bates et al., 2012). Similarly, affective touch, such as stroking or giving half-embraces, displays affection and intimacy, which helps calm residents and fosters a positive relationship (Mononen, 2019). Caregivers often modify their interactions and the care environment to minimize stress and address the needs of both care partners, including simplifying communication and using written cues (Polenick et al., 2020). Additionally, support from family members and caregiver communities played a crucial role in sustaining the emotional well-being of caregivers, allowing them to share responsibilities and gain strength from solidarity (Lindeza et al., 2024). These insights suggest that nurses and community health workers can enhance caregiver-care recipient relationships by offering communication training, emotional support programs, and family centered interventions that promote shared caregiving responsibilities and the development of empathy.

### Search for Meaning and Satisfaction in the Role

The search for meaning and role satisfaction emphasizes how caregiving is perceived as a purposeful and spiritually meaningful responsibility. Participants described feelings of acceptance and duty when caring for PwD. Some viewed caregiving as a divine test, while others found pride and fulfillment in their ability to provide quality care. These results align with previous research showing that most caregivers experience increased life responsibilities (Ghezaljah et al., 2020). This sense of meaning contributed to a more substantial commitment to the caregiving role of the participants. These qualitative insights align with quantitative findings, in which participants demonstrated moderate levels of sense of coherence, resilience, and emotional regulation, along with a high degree of satisfaction with care. Notably, Sense of Coherence emerged as the strongest predictor of satisfaction with care, explaining up to 67% of the variance in a previous quantitative study, particularly through its components of Significance and Comprehensibility (Sarabia-Cobo &

Sarriá, 2021). This reinforces the notion that a caregiver's ability to find meaning and understand their role is crucial in sustaining caregiving satisfaction.

#### Positive Psychological Outcomes

Positive psychological outcomes reflect the emotional and spiritual benefits that caregivers experience. The participants reported feeling calmer, more grateful, and more emotionally resilient over time. Many found strength in their faith and expressed optimism about their caregiving journey, believing that their efforts were valuable not only in a worldly sense but also spiritually significant. These psychological resources are significantly associated with better caregiver outcomes, including improved quality of life, life satisfaction, and overall well-being (Lamont et al., 2019). Resilience is a critical factor that enables caregivers to recover from, resist, or adapt to the physical and psychological demands of caregiving (Petriwskyj et al., 2016). Another study showed that psychological outcomes in family caregivers of PwD, such as self-efficacy, spirituality, resilience, rewards, gain, and meaning, align with positive psychology theory (Stansfeld et al., 2017). Spirituality was also a positive psychological outcome in this study. Higher spiritual well-being helps caregivers handle physical symptoms, psychological distress, and other caregiving challenges (Balboni et al., 2022; Ferrell et al., 2013). This study revealed that caregivers achieved equilibrium between psychological and physical discomfort by employing adaptive coping methods, including religious introspection, self-acceptance and collaborative caregiving within the family. Instead of eradicating stress completely, they converted it into a significant and spiritually enriching experience. The findings indicate that nurses and community health professionals can maintain this balance by offering mindfulness training, stress reduction programs, and culturally attuned counselling that bolster caregivers' resilience and spiritual fortitude.

#### Limitations

While this study provides rich insights into the positive experiences of dementia caregivers, certain contextual boundaries must be considered. The relatively small sample size, appropriate for a phenomenological approach, offers depth rather than breadth, and future research with larger or more diverse populations could further enrich this understanding. Additionally, the study was conducted in a single cultural context, Indonesia, adding valuable cultural nuance but may not reflect the full spectrum of experiences across different caregiving cultures globally. Furthermore, potential bias must be recognized, as caregivers may have highlighted the favorable aspects of their experiences because of dominant cultural and religious norms that prioritize thankfulness, patience, and filial loyalty. The tendency for social desirability may have affected the manner in which the participants recounted their caring experiences.

#### Contribution to Global Nursing Practice

This study contributes meaningfully to global nursing practice by exploring caregivers' experiences within the Indonesian cultural context, thereby adding valuable diversity to the existing literature, which has largely centered on Western perspectives. The findings highlight how caregiving can foster emotional growth, deepen relationships, and strengthen spiritual resilience, insights that are valuable for designing holistic and culturally responsive nursing interventions. For global nursing professionals, this study reinforces the importance of recognizing and nurturing caregivers' strengths as part of person- and family centered care models. These insights may inform culturally sensitive caregiver support interventions in other collectivist societies, emphasizing the need for approaches that honor familial values, interdependence, and spirituality as key resources in caregiving practice.

### **Conclusion**

In conclusion, this study examined the favorable experiences of caregivers of individuals with dementia within the Indonesian cultural framework. The findings indicate that caregiving, despite its challenges, promotes personal development, enhances familial bonds, cultivates a profound sense of purpose, and yields favorable psychological effects, including resilience and spiritual wellness. These results indicate that caregiving is not only a challenging obligation but also a transformational experience influenced by the cultural values of faith, familial connection, and filial loyalty. The variety of caregivers' socio-demographic backgrounds also affected the perception and shaping of these positive experiences. Future studies should encompass larger and more diverse samples to investigate the impact of cultural, gender, and generational characteristics on positive caregiving experiences across various situations. Quantitative or mixed-method approaches could further validate and assess these favorable attributes more thoroughly.

### **Author contribution**

RI conceptualized the study, supervised the research process, and contributed to manuscript writing and critical revision. EPA and TPA conducted the data collection, transcription, and initial thematic analysis. LCD and VA assisted with the literature review, data validation, and manuscript formatting. JH contributed to methodological design, data interpretation, and final editing of the manuscript.

### **Conflict of interest**

The authors declare no conflicts of interest.

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### **Reference**

- Abraham, D. M., & Padmavathi, P. (2024). A methodological framework for descriptive phenomenological research. *Western Journal of Nursing Research*, 47(2), 125–134. <https://doi.org/10.1177/01939459241308071>
- Balboni, T. A., VanderWeele, T. J., Doan-Soares, S. D., Long, K. N. G., Ferrell, B. R., Fitchett, G., Koenig, H. G., Bain, P. A., Puchalski, C., Steihauser, K. E., Sulmasy, D. P., & Koh, H. K. (2022). Spirituality in serious illness and health. *JAMA*, 328(2), 184. <https://doi.org/10.1001/jama.2022.11086>
- Beel-Bates, C., Stephenson, P. L., Nochera, C. L., & French Rogers, J. (2012). Caregiver-resident interaction with barnard's feeding scale. *Research in Gerontological Nursing*, 5(4), 284–293. <https://doi.org/10.3928/19404921-20120906-03>
- Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (5th ed.). Sage Publications. ISBN 978-1-4129-6556-9
- DiSantostefano, J. (2018). Dementia diagnosis coding. *Journal for Nurse Practitioners*, 14(3), 148–152. <https://doi.org/10.1016/j.nurpra.2017.09.019>
- Ferrell, B., Otis-Green, S., & Economou, D. (2013). Spirituality in cancer care at the end of life. *The Cancer Journal*, 19(5), 431–437. <https://doi.org/10.1097/PPO.0b013e3182a5baa5>
- Ghezaljah, T. N., Raffi, F., & Ladani, F. K. (2020). The caregiver burden of Alzheimer's patients: an evolutionary concept analysis. *Revista Latinoamericana de Hipertensión*, 15(1). <https://doi.org/10.5281/zenodo.4074208>

- Hall, S., Rohatinsky, N., Holtslander, L., & Peacock, S. (2024). Positive aspects of caregiving from the saskatchewan caregiver experience study. *Activities, Adaptation and Aging*. <https://doi.org/10.1080/01924788.2024.2319459>
- Ho, H. T., Jia, R., Habibi, N., Stern, C., Carter, G., Santin, O., Stone, J., Valenzuela, C., & Aromataris, E. (2024). Experiences of informal caregivers of people with dementia in low- and middle-income countries: A systematic review protocol. *JBI Evidence Synthesis*, 22(7), 1362–1370. <https://doi.org/10.11124/JBIES-23-00470>
- Kline, G. C., & Killoren, S. E. (2022). Adolescent sibling caregiving and responsibility: Retrospective reports among Mexican-origin young adults. *Family Relations*, 71(3), 953–967. <https://doi.org/10.1111/fare.12646>
- Kunicki, Z. J., Gaudiano, B. A., Miller, I. W., Tremont, G., Salloway, S., Darling, E., Broughton, M. K., Kraines, M. A., Hoopes, R., & Epstein-Lubow, G. (2021). Differences in burden severity in adult-child family caregivers and spousal caregivers of persons with dementia. *Journal of Gerontological Social Work*, 64(5), 518–532. <https://doi.org/10.1080/01634372.2021.1912242>
- Lamont, R. A., Quinn, C., Nelis, S. M., Martyr, A., Rusted, J. M., Hindle, J. V., Longdon, B., & Clare, L. (2019). Self-esteem, self-efficacy, and optimism as psychological resources among caregivers of people with dementia: Findings from the IDEAL study. *International Psychogeriatrics*, 31(9), 1259–1266. <https://doi.org/10.1017/S1041610219001236>
- Lapidou, D., Middlemass, J., Karran, T., & Siriwardena, A. N. (2019). Caregivers' interactions with health care services – mediator of stress or added strain? Experiences and perceptions of informal caregivers of people with dementia: A qualitative study. *Dementia*, 18(7–8), 2526–2542. <https://doi.org/10.1177/1471301217751226>
- Leipold, B., Schacke, C., & Zank, S. (2006). Prädiktoren von persönlichkeitswachstum bei pflegenden angehörigen demenziell erkrankter. *Zeitschrift Für Gerontologie Und Geriatrie*, 39(3), 227–232. <https://doi.org/10.1007/s00391-006-0375-5>
- Leipold, B., Schacke, C., & Zank, S. (2008). Personal growth and cognitive complexity in caregivers of patients with dementia. *European Journal of Ageing*, 5(3), 203–214. <https://doi.org/10.1007/s10433-008-0090-8>
- León-Campos, M. O., Slachevsky Chonchol, A., & Miranda-Castillo, C. (2018). Coping, social support and depression in informal caregivers and its relationship with unmet needs of people with dementia. *Ansiedad y Estrés*, 24(2–3), 73–80. <https://doi.org/10.1016/j.anyes.2018.04.001>
- Li, H.-L., Zhang, Y.-B., Chen, S., Cai, B., Liu, Z.-J., Niu, Y.-F., & Yu, H. (2017). Dementia and psychiatric disorders. In *Inherited Neurological Disorders: Diagnosis and Case Study* (pp. 125–147). Springer Singapore. [https://doi.org/10.1007/978-981-10-4196-9\\_7](https://doi.org/10.1007/978-981-10-4196-9_7)
- Lindeza, P., Rodrigues, M., Costa, J., Guerreiro, M., & Rosa, M. M. (2024). Impact of dementia on informal care: A systematic review of family caregivers' perceptions. *BMJ Supportive & Palliative Care*, 14(e1), e38–e49. <https://doi.org/10.1136/bmjspcare-2020-002242>
- Mononen, K. (2019). Embodied care: Affective touch as a facilitating resource for interaction between caregivers and residents in a care home for older adults. *Linguistics Vanguard*, 5(s2). <https://doi.org/10.1515/lingvan-2018-0036>

- Netto, N. R., Jenny, G. Y. N., & Philip, Y. L. K. (2009). Growing and gaining through caring for a loved one with dementia. *Dementia*, 8(2), 245–261. <https://doi.org/10.1177/1471301209103269>
- Orlova, O. V, Boiko, D. I., Bodnar, L. A., & Zhyvotovska, L. V. (2024). Cognitive dysfunction and disturbed daily activities of people with dementia impact the psychological stress in family caregivers depending on their anxiety and depression severity. *Health Psychology Open*, 11, 1-13. <https://doi.org/10.1177/20551029241305549>
- Petriwskyj, A., Parker, D., O'Dwyer, S., Moyle, W., & Nucifora, N. (2016). Interventions to build resilience in family caregivers of people living with dementia. *JBI Database of Systematic Reviews and Implementation Reports*, 14(6), 238–273. <https://doi.org/10.11124/JBISRIR-2016-002555>
- Polenick, C. A., Struble, L. M., Stanislawski, B., Turnwald, M., Broderick, B., Gitlin, L. N., & Kales, H. C. (2020). “I’ve learned to just go with the flow”: Family caregivers’ strategies for managing behavioral and psychological symptoms of dementia. *Dementia*, 19(3), 590–605. <https://doi.org/10.1177/1471301218780768>
- Sanders, S. (2005). Is the Glass Half Empty or Half Full? *Social Work in Health Care*, 40(3), 57–73. [https://doi.org/10.1300/J010v40n03\\_04](https://doi.org/10.1300/J010v40n03_04)
- Sarabia-Cobo, C., & Sarriá, E. (2021). Satisfaction with caregiving among informal caregivers of elderly people with dementia based on the salutogenic model of health. *Applied Nursing Research*, 62, 151507. <https://doi.org/10.1016/j.apnr.2021.151507>
- Stansfeld, J., Stoner, C. R., Wenborn, J., Vernooij-Dassen, M., Moniz-Cook, E., & Orrell, M. (2017). Positive psychology outcome measures for family caregivers of people living with dementia: a systematic review. *International Psychogeriatrics*, 29(8), 1281–1296. <https://doi.org/10.1017/S1041610217000655>
- Van Buuren, L., Van Delden, L., & Mohammadi, M. (2022). Dementia architecture: Designing typological floorplans using the “research through design” approach. In *Design for People Living with Dementia* (pp. 91–107). Taylor and Francis. <https://doi.org/10.4324/9781003095460-8>
- Walker, R. V, Powers, S. M., & Bisconti, T. L. (2016). Positive Aspects of the Caregiving Experience: Finding Hope in the Midst of the Storm. *Women and Therapy*, 39(3–4), 354–370. <https://doi.org/10.1080/02703149.2016.1116868>
- Werntz, A. J., Dodson, C. S., Schiller, A. J., Middlebrooks, C. D., & Phipps, E. (2015). Mental health in rural caregivers of persons with dementia. *SAGE Open*, 5(4). <https://doi.org/10.1177/2158244015621776>
- World Health Organization. (2021). *Dementia*. WHO.
- Yen, C.-M. (2018). Models of transformative learning among family caregivers of people with dementia: Positive experience approaches. *Journal of Research in Education Sciences*, 63(2), 187-202. [https://doi.org/10.6209/JORIES.201806\\_63\(2\).0008](https://doi.org/10.6209/JORIES.201806_63(2).0008)
- Yuan, Q., Zhang, Y., Samari, E., Jeyagurunathan, A., Goveas, R., Ng, L. L., & Subramaniam, M. (2023). Positive aspects of caregiving among informal caregivers of persons with dementia in the Asian context: A qualitative study. *BMC Geriatrics*, 23(1), 1–11. <https://doi.org/10.1186/s12877-023-03767-8>
- Zhan, H. J. (2004). Through gendered lens: explaining chinese caregivers’ task performance and care reward. *Journal of Women and Aging*, 16(1–2), 123–142. [https://doi.org/10.1300/J074v16n01\\_09](https://doi.org/10.1300/J074v16n01_09)

Zhang, F., Cheng, S.-T., & Gonçalves-Pereira, M. (2020). Factors contributing to protection and vulnerability in dementia caregivers. In *Genetics, Neurology, Behavior, and Diet in Dementia: The Neuroscience of Dementia, Volume 2* (pp. 709–722). Elsevier. <https://doi.org/10.1016/B978-0-12-815868-5.00045-1>