International Journal of Geriatrics and Gerontology

Lehn DuPont J. Int J Geriatr Gerontol 9: 200.
www.doi.org/10.29011/2577-0748.100200
www.gavinpublishers.com

Research Article

GAVIN PUBLISHERS

Comprehensive Care for Patients with Dementia: A Qualitative Analysis

Jacqueline Lehn DuPont*

Rossier School of Education, University of Southern California, USA.

***Corresponding author:** Jacqueline Lehn DuPont EdD, Rossier School of Education, University of Southern, 3470 Trousdale Pkwy 90089, Los Angeles, CA. California USA.

Citation: Lehn DuPont J (2025) Comprehensive Care for Patients with Dementia: A Qualitative Analysis. Int J Geriatr Gerontol 9: 200. DOI: 10.29011/2577-0748.100200

Received Date: 28 January, 2025; **Accepted Date:** 03 February, 2025; **Published Date:** 06 February, 2025

Abstract

Background: Dementia is one of the major causes of disability and dependency among older adults globally. The complex, varying, and progressive clinical expressions of dementia require comprehensive, multipronged programs of care. Such programs are associated with improved quality of life for patients with dementia and their family caregivers. Yet fragments exist across aging specialty sectors that limit the widespread dissemination of multipronged dementia care programming. Furthermore, little is known about family caregivers' satisfaction with the care provided to their partners or family members living with dementia. This study aimed to explore family caregivers' perceptions of the delivery of critical components to comprehensive dementia care, including the thoroughness of diagnostic screening and referrals to geriatricians and family caregiver training programs. **Methods:** Semi-structured interview data were collected from 11 family caregivers of a partner, parent, or sibling living with dementia. The 11 participating family caregivers were responsible for a care recipient with dementia residing memory care facilities in Southern California. **Results:** Three themes were identified: 1) family caregivers' dissatisfaction with a lack of thorough diagnostic screening for dementia in the care recipients, 2) family caregivers' satisfaction with referrals to geriatricians and caregiver training programs, and 3) family caregivers' perceived impact of COVID-19 on limited medical resources for the care recipients. **Conclusions:** Comprehensive care programs are needed that promote timely diagnostic screening, referrals to geriatricians, and family caregiver training programs.

Keywords: Comprehensive dementia care; COVID-19; Dementia; Geriatricians; Family caregivers; Referrals; Family caregiver training programs

List of Abbreviations: IRB: Institutional Review Board; MMSE: Mini-Mental State Exam; PCP: Primary Care Physician; PI: Principal Investigator; RA: Research Assistant; USC: University of Southern California; WHO: World Health Organization

Background

More than 55 million people have dementia, which cost global economies an estimated 1.3 trillion US dollars in 2019, making dementia care a top priority worldwide [1]. Dementia is a progressive neurodegenerative disease encompassing cognitive and functional impairments and behavioral problems [2]. The varying and complex symptoms of dementia require expansive care management approaches [3]. In the United States, approximately 5.7 million Americans live with dementia (American Speech-Language-Hearing), and an expected 10,000 new cases are expected to emerge every year [4]. Primary care physicians (PCPs) often lack the time and specialized training to diagnose and treat patients with dementia thoroughly [5]. Family caregivers also report burnout in their roles as caregivers and a lack of self-efficacy in their abilities to care for family members with dementia [6,3].

Furthermore, integrated care is often fragmented due to inadequate numbers of aging specialists across sectors [7]. PCPs are often the first health care professionals seen by the care recipients and represent a key point of entry for referrals to specialists, including geriatricians and community agencies, including family caregiver training programs. Comprehensive programs of care are needed to effectively manage and treat patients living with dementia.

Delivering appropriate care is a challenge both in the US and internationally. A scoping review identified barriers to delivering comprehensive dementia care within several European countries

[8]. Some of these barriers include a lack of personalized care, limited knowledge, poor communication, and ineffective healthcare policies. These barriers include limited knowledge and confidence to care for people with dementia among healthcare staff, poor communication between care staff, and inconsistent medical record documentation. Multi-component interventions, including nurse practitioner and co-management, have improved the quality of care for dementia [9]. Nevertheless, approximately 40% of the needs of patients living with dementia go unmet even in the most successful multi-component intervention programs.

Effective dementia care takes a multipronged approach to fully meet the needs of care recipients and their family carers. Person-centered care (PCC) is a prominent international model of dementia care practiced in several European Countries, the US, Australia, Canada, and Singapore. PCC prioritizes the needs of the patient. Some of the key tenets of PCC include prioritizing patient well-being, seeking to improve the healthcare providers-patient relationship, and tailoring treatments to the needs and worldviews of the patient [2]. However, systemic challenges exist in the delivery of PCC, including heterogeneity in the delivery of PC and the lack of a standardized definition of this program [2]. The University of California Los Angeles (UCLA) Alzheimer's and Dementia Care (ADC) program, implemented in July 2012, is an award-winning model for effective, comprehensive managed care programs. This intervention operates with co-management with a dementia care manager (DCM) and a nurse practitioner who collaborate with primary care physicians and community programs to offer a multipronged program of dementia care. This program involves holistic evaluations, coordinated care between primary care physicians and geriatric specialists, and referrals to caregiver training [2]. Evidence shows that this comprehensive program correlates with improved patient and family caregivers' outcomes [3]. This program highlights the value of comprehensive care management programs in treating dementia.

Thorough dementia care meets the needs of patients and their family caregivers [9]. This form of care includes the provision of a thorough and timely diagnostic screening for dementia and coordinated referrals to a geriatrician and family caregiver services [9]. A timely and accurate diagnosis can help with symptom management, slow disease progression, and reduce the number of emergency department visits [10,11]. Dementia diagnoses that are promptly made also allow more time for older adults to make advanced directive (e.g., end-of-life) decisions and foster longer independent living [9]. Furthermore, an accurate diagnosis is made with thorough blood and urine tests, brain scans, behavioral assessments, and evaluations that rule out other conditions that mimic symptoms of dementia [10, 12]. Despite the strong evidence suggesting the importance of timely and accurate diagnostic screening, approximately 50% of patients with dementia never even receive a diagnosis [10].

Multipronged dementia care requires coordinated electronic, phone, or in-person referrals to geriatricians [13,2]. Geriatricians are primary care physicians with additional training in treating older patients [14]. Referrals to geriatricians help reduce the responsibility of care managed mainly by family caregivers [15]. Furthermore, coordinated care between primary care physicians and geriatric specialists relates to reduced behavioral problems and depressive symptoms in patients with dementia and improved quality of life for patients and their family caregivers [2].

Another component of comprehensive dementia care includes family caregiver support and training programs (Rueben et al., 2019). Family caregivers of individuals with dementia are crucial to care recipients' quality of life [16]. These caregivers are often called invisible second patients because they often show elevated burnout, depression, social isolation, and physical health problems [17]. Family caregiver training workshops, which often focus on teaching carers skills in coping, knowledge, and communication, are crucial for reducing caregiver burden and depression and improving the quality of care for patients with dementia [17]. Family caregiver training offered by the Alzheimer's Society has been shown to significantly improve the quality of life of family caregivers and their care recipients in several countries, including the US, Asia, Russia, Finland, and Italy [18]. The effectiveness of another program called the SAVVY Caregiver Training Program was tested in three states across the US, including Minnesota, Colorado, and Alaska. The findings showed that family caregivers reported increased skill, knowledge, and confidence after completing a 12-hour SAVVY course [19]. A study in the UK that was focused on a caregiver training program called Carers Create showed that carers who attended this program reported improvements in the quality of their relationships with their care recipients and relief from the daily pressures of caregiving [20]. In addition, a longitudinal study showed that caregivers who received an at-home-based caregiver training intervention showed improved health-related quality of life 18 months after participating [21]. Evidence suggests that family caregiver training programs are crucial for improving the quality of life of family caregivers and their care recipients.

Despite evidence about the benefits of thorough dementia care programs, there has been limited dissemination into general clinical practice due to resource limitations and systemic change [3, 22]. Furthermore, it is unclear how comprehensive care for patients with dementia was during the COVID-19 pandemic when medical care and resources were limited [23]. The current study uses qualitative, semi-structured interviews with family caregivers to gain an in-depth understanding of the comprehensiveness of care for patients with dementia. The overarching research question was how do family caregivers perceive the comprehensiveness of care, including the thoroughness of diagnostic screenings and referrals to geriatricians and family caregiver training programs?

Methods

Research Team and Reflexivity

Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines have been used to report this qualitative research study [24]. In line with the COREQ tenet of the research team and reflexivity, the researcher's characteristics, including her background and positionality, including her role as a graduate student and a career as an assisted living administrator, were deeply reflected on and discussed during data collection and analysis [25]. The researcher's reflections helped to clarify bias concerning the family caregivers' perceptions of a lack of thorough diagnostic screening for patients with dementia while also taking care to present results counter to these perceptions. In addition, the researcher reflected on her responsibility as the sole author of this study and ensured that her data collection strategy and analysis were rigorously peer-reviewed by her research supervisor, a Professor of Clinical Education. A volunteer research assistant carried out the data collection, so the researcher never directly interviewed the participants. The researcher did not personally know or interact with any of the participants. Carefully considering foundational questions regarding time and the setting for the data collection phase of the research, possibly intruding into the lives of family caregivers and patients, have also been essential points of discussion.

Study Design

This study used an interpretive phenomenological approach to analyze the qualitative interview data from 11 family caregivers [26-28]. A phenomenology research design was used to collect in-depth data on participants' people's lived experiences and perceptions to develop a deeper understanding of the phenomena [29,30]. Although no formula exists to calculate the ideal sample size for a qualitative study [31], the phenomenological approach typically accepts samples from a single case to 20 [35]. The current study followed the recommended approach for phenomenological research, which is to collect data until saturation is reached. Data saturation occurs when responses become repetitive [26]. Once no new data was revealed in the family caregivers' responses, data collection was stopped.

Setting

The semi-structured interviews were carried out online via Zoom. The data collection tool was a 32-question semi-structured interview protocol with open-ended questions. The participants were 11 family caregivers of patients with dementia who resided at memory care facilities in Southern California. The researcher reflected that family caregivers will have varying experiences with staff and accommodations that may influence their experiences and perceptions when coming from multiple facilities. To be eligible to participate, family caregivers were required to be older than 18 years of age and the family caregiver of a partner, adult child, or sibling of a patient with dementia. Participants were recruited via purposeful sampling. Purposeful sampling is the preferred recruitment strategy in qualitative research [33]. Table 1 presents the inclusion criteria for this study. All participants gave written informed consent following the rules and guidelines of the University of California (USC) Institutional Review Board (IRB).

Family caregivers are eligible to participate if they meet the following criteria:
1. primary family caregiver (alive or deceased) of a person who has or had mild to severe cognitive impairment or dementia
2. older than 18 years of age
3. able to participate in an online Zoom interview

Table 1: Family Caregiver Inclusion Criteria

Data Collection

Interview topics were based on existing literature concerning comprehensive care programs for patients with dementia (Table 2) [16,3]. A semi-structured schedule of topics guided the interviews with each participant, but this structure was not strictly adhered to, whereby certain lines to questioning developed during data collection. Interviews lasted 1 hour, on average (27 minutes to 1 hour and 48 minutes). The audios were transcribed and were 25 pages, on average (7 to 40 pages). The interview responses were anonymized before analysis, and pseudonyms were given to each participant in replace of their real name. Summaries of the transcripts were sent to each participant for their approval.

Family Caregivers	
1.	brief description of the patient with dementia
2.	experiences with quality of diagnostic screening for the patient
3.	experiences with referrals to geriatricians
4.	experiences with referrals to family caregiver training programs
5.	experiences with medical care for patients during COVID-19

Table 2: Topics for the Semi-Structured Interview

Data Analysis

Coding was conducted by two researchers, including the researcher and a research assistant. A deductive-inductive hybrid approach was used for coding and theme development [40]. Guided by deductive reasoning, a codebook was created with specific a-priori themes, including the quality of patient diagnosis and satisfaction with referrals to geriatricians and family caregiver training programs. New data-driven themes and sub-themes were inductively generated and incorporated into the codebook during data analysis. The research team worked collaboratively to refine themes and compare findings. Quotations were selected from across the sample to illustrate the data underlying the themes and sub-themes.

Results

Eleven family caregivers of people with dementia agreed to participate in the study. (Tables 3 and 4) present the demographic characteristics of the patients and family caregivers, respectively. Thematic analysis of the interviews with the family caregivers identified three main themes: 1) family caregivers' dissatisfaction with a lack of thorough diagnostic screening for dementia in the care recipients, 2) family caregivers' satisfaction with referrals to geriatricians and caregiver training programs, and 3) family caregivers' perceived impact of COVID-19 on limited medical resources for the care recipients (Figure 1).

Patient Pseudonym	Diagnosis	Relationship with Informant	Gender	Living or Deceased	Age
Lisa	Alzheimer's Disease	Mom	Female	Living	96
Janet	Alzheimer's Disease	Mom	Female	Living	77
Alexa	Alzheimer's Disease	Mom	Female	Living	78
Fran	Alzheimer's Disease	Mom	Female	Deceased	78 when passed
Linda	Alzheimer's Disease	Mom	Female	Living	77
Bella	Dementia	Mom	Female	Deceased	102 when passed
Camelia	Dementia	Wife	Female	Living	80
Cynthia	Dementia	Mom	Female	Living	105
Fred	Dementia	Great Uncle	Male	Living	95
Nancy	Posterior Cortical Dementia	Sister-in-Law	Female	Deceased	50
Helen	Vascular Dementia	Mom	Female	Deceased	82

Table 3: Demographic Characteristics of Patients.

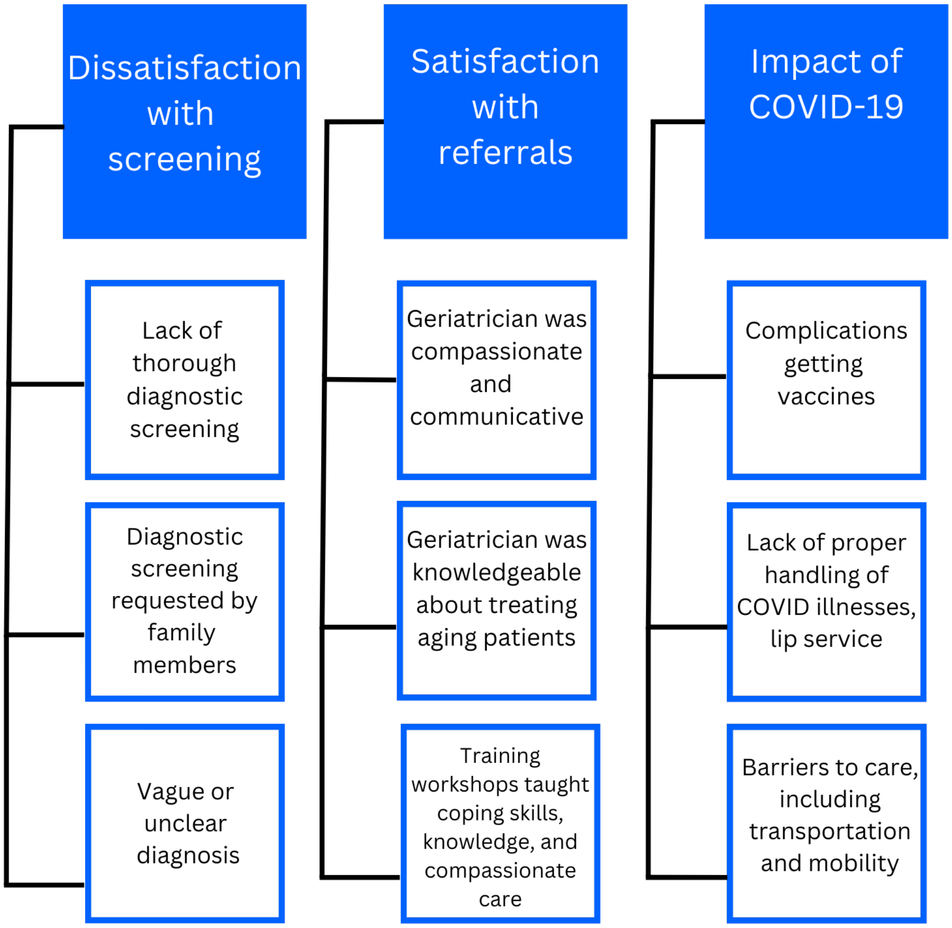
Family Caregiver Pseudonym	Gender	Age	Highest Level of Education	Occupation
Chris	Male	60	Master's Degree	Business/consulting
Eloise	Female	53	Master's Degree	Homecare director
Cleo	Female	54	High School Degree	Account executive in telecommunications
Mike	Male	55	Master's Degree	CEO Non-profit
Michelle	Female	79	Bachelor's Degree	Fundraiser at a University Alzheimer's Research
Jon	Male	82	Bachelor's Degree	Teacher
Rachel	Female	56	Master's Degree	Community outreach

Samantha	Female	64	Bachelor's Degree	Consultant
Jennifer	Female	56	Master's Degree	Outreach/Philanthropist
Angela	Female	52	Bachelor's Degree	Sales Director IT
Xavier	Male	52	Bachelor's Degree	Computer Software Sales

Table 4: Demographic Characteristics of Family Caregivers

Figure 1

Themes and Sub-Themes from the Qualitative Data



Note. This figure represents the themes and sub-themes that were identified from the family caregivers' qualitative interview data. The three main themes are depicted in solid blue squares and include: 1) family caregivers' dissatisfaction with a lack of thorough diagnostic screening for dementia in the care recipients, 2) family caregivers' satisfaction with referrals to geriatricians and caregiver training programs, and 3) family caregivers' perceived impact of COVID-19 on limited medical resources for the care recipients. The sub-themes depicted in blue outlined squares, support the three main themes. The black lines indicate the connections between each sub-theme to the higher-order main themes.

Family Caregivers' Dissatisfaction with a Lack of Thorough Diagnostic Screening for Dementia in the Care Recipients

Ten out of 11 participants indicated dissatisfaction with the diagnostic screening or diagnosis. All family caregivers stated that diagnoses were based on the results from MMSE evaluations [34] and lacked follow-up assessments, including blood and urine tests, behavioral assessments, and brain scans. Furthermore, the family caregivers indicated they had to request screening for their care recipient. In other words, the family caregivers perceived that primary care physicians lacked initiative in recommending diagnostic screening for the patient. As one participant stated, "it wasn't until I brought up ideas like the Mini Mental Exam that the doctor acknowledged that. He said, 'Oh yeah, I've done that before, we could do that'" (Chris, Family Caregiver). This statement suggests that the family caregiver brought up the idea of implementing the Mini Mental Exam to the physician order for test to be carried out. Another participant expressed that her mother's physician believed that her symptoms of cognitive impairment were normal for her age. As stated by the participant, "he [the physician] was like, 'well, for her age'… but she was only in her late 60s. You know, the frustration came like when he seemed to suggest, 'what do you want from her, she's fine.' I find that even today I really believe it is very hard to get a decent diagnosis" (Michelle, Family Caregiver). The participant's quote suggests her perception that her mom's physician delayed diagnosis because of the idea that cognitive delays are a part of the aging process.

Participants indicated problems with vague or unclear diagnoses resulting from a lack of thorough screening. "The diagnosis was all over the place. First, they said she may have Vascular Dementia, or maybe its Lewy Bodies, or maybe AZ" (Cleo, Family Caregiver). This comment suggests that the physician was unclear about the dementia condition that had been diagnosed. Likewise, another participant stated that her mom's neurologist "did the brain scan and basically walked into the room and said, you have vascular dementia and started talking about Alzheimer's Disease" (Eloise, Family Caregiver). The participants' comments suggest dissatisfaction with the diagnostic screening or diagnosis.

Satisfaction with Referrals to Geriatricians and Caregiver Training Programs

The family caregiver participants indicated that referrals to a geriatrician or caregiver training program improved their experiences with the care of the patient with dementia. The participants felt that geriatricians were knowledgeable, compassionate and took the time to speak with and answer the patients' questions. As commented by one participant, "my mom's physician was a geriatrician and a lot of his patients were aging, so he was very knowledgeable and amazing with my mom. He kneeled down in front of her and looked directly at her when he talked to her and asked her questions. He showed compassion toward my mom. It was a big improvement from my mon's previous GP" (Michelle, Family Caregiver). Another participant indicated that the geriatrician calmed down her mother. According to the participant, "he came and talked to her. Because she was having the crying episodes, she was thinking about things that weren't there and we were getting to the point that we felt it was appropriate for her to begin having some meds that might calm her down a bit" (Angela, Family Caregiver). Another participant indicated satisfaction with his mom's gerontologist because of his age-specific training. The participant stated, "he just sees older adults. He's a specialist in gerontology. So that makes a big difference because that's all he sees" (Chris, Family Caregiver).

The family caregivers indicated that concerning caregiver training workshops, either no referrals were made, or when referrals were made, it was because of access to memory care resources, through health insurance companies, or the assisted living facility. In addition, the participants indicated the benefit of SAVVY family caregivers of patients with dementia in Southern California. "We took the SAVVY caregiver curriculum. It is pivotal I recommend it to everyone whose parents are going through Alzheimer's. The SAVY caregiver course is exceptional" (Xavier, Family Caregiver). The family caregivers indicated the benefit of the training workshops for gaining coping skills, communicating effectively with physicians about the patient, and learning compassionate care for the patient. "I went to support groups and other training sessions. They helped me to understand what I could and couldn't change. They helped me understand how to communicate with the doctor and with my mom. They helped me understand what was going on" (Jennifer, Family Caregiver). The participants indicated satisfaction with referrals to geriatricians and caregiver training.

Family Caregivers' Perceived Impact of COVID-19 on Limited Medical Resources for the Care Recipients

Family caregivers' perceived impact of COVID-19 on limited medical resources for care recipients The family caregivers indicated concerns about restrictions in medical care and resources for their care recipients due to the COVID-19 pandemic. For example, participants described trouble with getting the COVID-19 vaccines for patients. "There have been complications with trying to get the vaccine" (Eloise, Family Caregiver). Another participant commented, "I don't think they, and obviously I'm very attuned to it because of my mom being in an assisted living facility and that's where the outbreak started. That's where a great percentage of the deaths, the illnesses, and the deaths of men. So, I'm very, it's an acute issue with me. And I still don't think it's ever been, it's ever been handled properly" (Samantha, Family Caregiver). Yet another participant indicated that lip service is paid to prioritizing aging patients, "I mean, the first thing that comes to mind is lip service. Yeah. We want to protect older adults" (Chris, Family Caregiver). Finally, a participant suggested transportation and mobility barriers to getting medical care for her mother were exacerbated by the challenges of the pandemic. According to the participant, "so when you already have trouble with transportation, you already have behavioral issues perhaps or mobility impairments or your wife is 86 and you're 89 and you're a slip hazard, trip hazard. All those are barriers to care. So, I think COVID simply compounded that times 500" (Mike, Family Caregiver).

Discussion

The study explored the perceptions of family caregivers of patients with dementia about the comprehensiveness of dementia care. The family caregivers collectively indicated dissatisfaction with a lack of thorough diagnostic screening for dementia in the care recipients, satisfaction with referrals to geriatricians and caregiver training programs, and a perceived impact of COVID-19 on limited medical resources for their care recipients.

The family caregivers' dissatisfaction with a lack of thorough diagnostic screening for dementia corresponds with previous research, which showed that approximately 50% of patients with dementia are never formally diagnosed [10]. The family caregivers indicated that the primary care physicians themselves did not initiate screening for dementia. Instead, the family caregivers often had to prompt the physicians to screen for dementia in the care recipients. One caregiver commented that her mother's general practitioner seemed to suggest memory loss was natural for a woman in her late 60s. The family caregivers in this study emphasized that screenings consisted of only the MMSE and lacked evaluations to rule out other conditions, which has been confirmed by prior research [35]. The use of the MMSE is concerning, given that numerous studies have shown that it lacks adequate sensitivity [36]. Furthermore, the family caregivers indicated problems with vague or confusing diagnoses resulting from a lack of thorough screenings. In our study, the family caregivers perceived that diagnoses could be more accurate with thorough evaluations.

The family caregivers' satisfaction with referrals to geriatricians corresponds with previous research showing that a sample of geriatricians supported comprehensive care for patients with dementia, including timely and accurate diagnoses, treatments, and advanced care planning [37]. In this study, family caregivers stated that geriatricians provided more knowledgeable and compassionate care. Furthermore, the participants indicated that the geriatricians spoke directly to the patients with dementia and took the time to answer questions from the patients and family caregivers, which has been supported by prior research focused on geriatrician's delivery of respectful and compassionate care to people with dementia [38]. Every family caregiver indicated that the physician they originally sought to diagnose the care recipient had been their PCP for several years. Consistent with previous research [2], there may have been an overreliance on these physicians to screen for and treat the care recipients for dementia thoroughly. The data revealed that the physicians did not refer the patients to an older-age psychiatrist or integrated team of specialists [39,40]. However, the family caregivers were highly satisfied when referred to a geriatrician or family caregiver training program. Therefore, a key conclusion from this study is the value of referrals to enhance the comprehensiveness of care [41].

Family caregivers also indicated satisfaction with referrals to caregiver training programs. More training programs can be modeled after a nonprofit program already in Orange County and many other counties called the Savvy Caregiver program [19]. This program offers 8-week-long training sessions for family caregivers of individuals with dementia [19]. This training program teaches family caregivers basic knowledge about dementia, skills to determine fluctuating abilities in individuals with dementia, and attitudes needed to manage the challenges of caring for these individuals. The family caregivers' satisfaction with caregiver training is confirmed in studies of the effectiveness of carer training programs [42-44]. These studies often show that family caregivers express reduced burden, improved knowledge and confidence, closer relationships with their care recipients, and improved quality of life [16, 18-20].

This study took place during COVID-19. Family caregivers expressed concerns about limited medical resources and cared for patients with dementia during the pandemic. These concerns are confirmed by research focused on under-resourced medical services during COVID-19 [23]. More coordinated efforts across sectors are needed to ensure that aging patients receive the care they need in general and in times of crisis like the COVID-19 pandemic.

A strength of this study is that it explored family caregivers' perceptions about the general comprehensiveness of dementia care. The perceptions of the family caregivers included common themes. The small number of participants is a limitation because the findings may not generalize to the larger population of family caregivers. Furthermore, the data was based on family caregivers' perceptions of dementia care, which could be subject to bias. Furthermore, the researcher needed to reflect on her positionality, including her role as a graduate student and career as an assisted living administrator. This intensive reflection clarifies bias for the family experiences with dementia diagnosis and treatment for their care recipients [45].

Future research using a mixed method design would strengthen the creditability of the data using the triangulation of two different kinds of data collection [33]. Future research could also benefit from a multi-report approach that includes responses from family caregivers and physicians who treat patients with dementia. Furthermore, PCPs represent a valuable entry point for referrals to integrated care across sectors. More research is needed to understand the efficacy of educational interventions with PCPs on how to make referrals to integrated care plans with various specialists, including geriatricians, older age psychiatrists, and occupational therapists.

Conclusion and Implications for Practice

Family caregivers indicate the need for improved comprehensiveness of care for patients with dementia, especially regarding the thoroughness of diagnostic screening and family caregiver training referrals. Care for dementia patients improves with primary care physician referrals to geriatricians. Geriatricians provide quality and compassionate care and take the time to community directly with people with dementia. Furthermore, family physicians are an essential point of entry for specialist referrals. Educating them on how to implement integrated care plans for various aging specialists, including geriatricians, psychiatrists, and occupational therapists, is crucial. This study provides a starting point for understanding family caregivers' perceptions of the comprehensiveness of dementia care.

Availability of data and materials

All data generalized/analyzed are available upon request with corresponding author.

Declarations

Ethics approval and consent to participate

All participants gave their written informed consent and consent to participate in accordance with relevant guidelines and regulations. All experimental protocols were approved by the University of Southern California (USC) Institutional Review Board (IRB).

Consent for publication

The participants gave their consent to participate in the study. The names of the participants have been anonymized. Informed consent was obtained from all participants for the publication of data in an online open-access article.

Availability of data and materials

All data and materials are available upon request. You should contact the corresponding author, Dr. Jacqueline Lehn DuPont to request data from this study at jlehn@usc.edu.

Author's contributions

JD analyzed and interpreted the family qualitative data regarding the comprehensiveness of care for patients with dementia and wrote the manuscript.

Acknowledgement

The author acknowledges Dr. Horwitz for her contribution as a voluntary RA for this study.

Conflict of interest: I have no conflict of interest to disclose.

References

1. Kuehn BM (2021) WHO: need for global dementia care planning is urgent. JAMA, 326:1471-1471.
2. Reuben DB, Tan ZS, Romero T, Wenger NS, Keeler E, et al. (2019) Patient and caregiver benefit from a comprehensive dementia care program: 1‐year results from the UCLA Alzheimer's and Dementia Care Program. Journal of the American Geriatrics Society, 67: 2267-2273.
3. Reuben DB, Evertson LC, Jackson‐Stoeckle R, Epstein‐Lubow G, Spragens LH, et al. (2022) Dissemination of a successful dementia care program: Lessons to facilitate spread of innovations. Journal of the American Geriatrics Society, 70: 2686-2694.
4. World Health Organization (2022) Dementia.
5. Reuben DB, Evertson LC, Wenger NS, Serrano K, Chodosh J, et al. (2013) The University of California at Los Angeles Alzheimer's and Dementia Care Program for comprehensive, coordinated, patient‐centered care: preliminary data. Journal of the American Geriatrics Society, 61:2214-2218.
6. Cations M, Radisic G, Crotty M, Laver KE (2018) What does the general public understand about prevention and treatment of dementia? A systematic review of population-based surveys. PloS one, 13: e0196085.
7. Moore A, Frank C, Chambers LW (2018) Role of the family physician in dementia care. Canadian Family Physician, 64:717-719.
8. Martin A, O'Connor S, Jackson C (2020) A scoping review of gaps and priorities in dementia care in Europe. Dementia, 19: 2135-2151.
9. Jennings LA, Tan Z, Wenger NS, Cook EA, Han W, et al. (2016). Quality of care provided by a comprehensive dementia care comanagement program. Journal of the American Geriatrics Society, 64: 1724-1730.
10. Panegyres PK, Berry R, Burchell J (2016) Early dementia screening. Diagnostics, 6:6.
11. Weldingh NM, Mellingsæter MR, Hegna BW, Benth JS, Einvik G, et al. (2022) Impact of a dementia-friendly program on detection and management of patients with cognitive impairment and delirium in acute-care hospital units: a controlled clinical trial design. BMC geriatrics, 22:266.
12. Health Quality Ontario. (2014) The appropriate use of neuroimaging in the diagnostic work-up of dementia: An evidence-based analysis. Ontario Health Technology Assessment Series, 14:1-64.
13. Pace CA, Gergen-Barnett K, Veidis A, D'Afflitti J, Worcester J, et al. (2018) Warm handoffs and attendance at initial integrated behavioral health appointments. The Annals of Family Medicine, 16: 346-348.
14. John Hopkins Medicine (2023) Specialists in aging: Do you need a geriatrician?
15. Lee L, Hillier LM, Stolee P, Heckman G, Gagnon M, et al. (2010) Enhancing dementia care: a primary care–based memory clinic. Journal of the American Geriatrics Society, 58: 2197-2204.
16. Kobayashi M, Honda M (2021) The effect of a multimodal comprehensive care methodology for family caregivers of people with dementia. BMC geriatrics, 21:1-8.
17. Brodaty H, Donkin M (2009) Family caregivers of people with dementia. Dialogues in Clinical Neuroscience. 11:217–228.
18. Corbett A, Stevens J, Aarsland D, Day S, Moniz‐Cook E, et al. (2012) Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. International Journal of Geriatric Psychiatry, 27: 628-636.
19. Hepburn KW, Lewis M, Sherman CW, Tornatore J (2003) The savvy caregiver program: Developing and testing a transportable dementia family caregiver training program. The Gerontologist, 43:908-915.
20. Skingley A, Billam D, Clarke D, Hodges R, Jobson I, et al. (2021) Carers Create: Carer perspectives of a creative programme for people with dementia and their carers on the relationship within the (carer and cared-for) dyad. Dementia, 20:1319-1335.
21. Kuo LM, Huang HL, Liang J, Kwok YT, Hsu WC, et al. (2017) Trajectories of health-related quality of life among family caregivers of individuals with dementia: A home-based caregiver-training program matters. Geriatric Nursing, 38:124-132.
22. Tolson D, Rolland Y, Andrieu S, Aquino JP, Beard J, et al. (2011) International Association of Gerontology and Geriatrics: A global agenda for clinical research and quality of care in nursing homes. Journal of the American Medical Directors Association, 12:184-189.

23. Smith EE, Couillard P, Fisk JD, Ismail Z, Montero-Odasso M, et al. (2020) Pandemic dementia scarce resource allocation. Canadian Geriatrics Journal, 23: 216-218.
24. Tong A, Sainsbury P, Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care, 19: 349-357.
25. Burkholder GJ, Cox KA, Crawford LM, Hitchcock JH (2020) Research design and methods: An applied guide for the scholar-practitioner. Sage.
26. Creswell JH, Creswell JD (2018) Research design: Qualitative, quantitative, and mixed methods approaches (5th ed.). Sage.
27. Patton MQ (2002) Qualitative research and evaluation methods (3rd ed.). Sage.
28. Pietkiewicz I, Smith JA (2014) A practical guide to using interpretative phenomenological analysis in qualitative research psychology. Psychological journal, 20: 7-14.
29. Ibrahim N, Ng F, Selim A, Ghallab E, Ali A, et al. (2022) Posttraumatic growth and recovery among a sample of Egyptian mental health service users: a phenomenological study. BMC Psychiatry, 22: 255.
30. Tuffour I (2017) A critical overview of interpretative phenomenological analysis: A contemporary qualitative research approach. Journal of Healthcare Communications, 2:52.
31. Patton MQ (2003). Qualitative evaluation checklist. Evaluation checklists project, 21:1-13.
32. Subedi KR (2021) Determining the Sample in Qualitative Research. Online Submission, Scholar's Journal, 4:1-13.
33. Merriam SB, Tisdell EJ (2016) Qualitative research: A guide to design and implementation (4th ed.). John Wiley & Sons.
34. Tombaugh TN, McIntyre NJ (1992) The mini‐mental state examination: a comprehensive review. Journal of the American Geriatrics Society, 40: 922-935.
35. Dementia Australia (2022) Tests used in diagnosing dementia.
36. MacAulay RK, Wagner MT, Szeles D, Milano NJ (2017) Improving sensitivity to detect mild cognitive impairment: cognitive load dual-task gait speed assessment. Journal of the International Neuropsychological Society, 23: 493-501.
37. Mansfield E, Bryant J, Nair BR, Zucca A, Pulle RC, et al. (2022) Optimising diagnosis and post-diagnostic support for people living with dementia: geriatricians' views. BMC geriatrics, 22: 143.
38. Tolson D, Fleming A, Hanson E, de Abreu W, Crespo ML, et al. (2016) Achieving prudent dementia care (Palliare): an international policy and practice imperative. International Journal of Integrated Care, 16: 18.
39. Boise L, Camicioli R, Morgan DL, Rose JH, Congleton L (1999) Diagnosing dementia: perspectives of primary care physicians. The Gerontologist, 39: 457-464.
40. Bingham AJ, Witkowsky P (2022) Deductive and inductive approaches to qualitative data analysis. In C. Vanover, P. Mihas, & J. Saldaña (Eds.), Analyzing and interpreting qualitative data: After the interview (pp. 133-146). SAGE Publications.
41. UCLA Health (2023) UCLA Alzheimer's and Dementia Care program.
42. Callahan CM, Unroe KT (2020) How do we make comprehensive dementia care a benefit? Journal of the American Geriatrics Society, 68: 2486-2488.
43. Chodosh J, Colaiaco BA, Connor KI, Cope DW, Liu H, et al. (2015) "Dementia care management in an underserved community: the comparative effectiveness of two different approaches." Journal of Aging and Health, 27: 864-893.
44. Peterson K, Hahn H, Lee AJ, Madison CA, Atri A (2016) In the Information Age, do dementia caregivers get the information they need? Semi-structured interviews to determine informal caregivers' education needs, barriers, and preferences. BMC Geriatrics, 16:164.
45. Stringfellow A (2017) Caregiving 101: What is durable power of attorney?