

Health and Social Care Professionals' Experiences of Community-Based Dementia Care: A Qualitative Study of Needs, Barriers, and Ethical Challenges

Abstract

Background: As the number of people living with dementia (PwD) rises, community care is increasingly prioritized to support aging in place. However, dementia care at home presents complex challenges, including unmet medical needs, family caregiver burdens, and ethical concerns.

Aim: This study aimed to explore healthcare professionals' experiences and perceptions of community care for PwD, focusing on service delivery challenges, care needs, and ethical issues encountered in practice.

Methods: A qualitative descriptive design, following the Interpretive Phenomenological Approach, was used. Semi-structured interviews were conducted with 18 healthcare professionals providing community services, including doctors, nurses, and social workers. Data were analyzed thematically.

Results: Three main themes were identified: (1) Perceptions, differences, and gaps in service provision – professionals described varied understandings of dementia and highlighted inconsistencies in service coordination. Community care was often dependent on family initiative and limited by systemic barriers. (2) Dementia Patients' Needs and Challenges: Participants emphasized the physical and psychosocial needs of PwD, including hygiene, nutrition, and wound care. Many families lacked the knowledge or resources to provide adequate care. Financial strain, caregiver fatigue, and cases of neglect or abuse were common. (3) Ethical Issues in Community Care: Challenges included misuse of care pensions, unsafe living environments, and conflicts concerning autonomy and consent.

Conclusion: Community care for PwD is shaped by complex clinical, social, and ethical dynamics. Strengthening caregiver education, improving supervision, and establishing formal ethical support systems are essential.

Keywords: *Dementia, ethics, professionals, qualitative research*

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Introduction

Dementia is a progressive neurological condition that impairs memory, cognition, behavior, and independent functioning. As the global population ages, its prevalence continues to rise, affecting more than 55 million people worldwide and is projected to reach 139 million by 2050.¹ According to national statistics for 2024, the proportion of adults aged 65 years and older has steadily increased over the past decade, exceeding 10% of the total population, and is expected to grow further.² Parallel to these demographic shifts, the number of people living with dementia is increasing, placing greater pressure on families and health and social care systems.³

Globally, nearly 60% of individuals newly diagnosed with dementia live in low- and middle-income countries, and approximately 71% of future cases are expected to occur in these settings.⁴ In Türkiye, dementia represents a rapidly growing public health challenge: an estimated 800,000 people were living with dementia in 2019, and this number is projected to reach nearly 3 million by 2050, an increase of approximately 277%.³

In response to population ageing, home healthcare services in Türkiye have expanded through reforms promoting community-based care, including the Ministry of Health's Home Healthcare Services Regulation (2005) and the development of family physician-based models.⁵ Although these services provide essential medical and rehabilitative support, dementia care remains complex due to limited specialization and fragmented coordination between medical and social services.⁶⁻⁸ Dementia care in Türkiye is largely family-based, shaped by strong cultural expectations of familial responsibility and the limited availability of formal long-term care services. Because community-based services are accessible only to a limited number of people via municipal programs, state services, or private fee-based care, specialized services tailored to patients with dementia remain insufficient.⁶⁻⁸

Health and social care professionals providing community care to individuals with dementia face challenges that extend beyond clinical care. In this study, community care refers to health and social services provided to people with dementia in their homes and other non-institutional settings, including home healthcare services and municipality-based support programs. The intimate nature of community care creates complex situations, such as managing behavioral symptoms, ensuring safety in unsupervised environments, respecting autonomy amid cognitive decline, addressing consent issues, and balancing beneficence with limited resources.^{9,10} Profes-

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sionals and caregivers often struggle to respect patients' preferences while ensuring their safety and well-being.¹⁰ Disagreements between professionals and family caregivers may arise, particularly when patients are unable to express their wishes. Ethical conflicts frequently emerge around issues such as artificial feeding, involuntary treatments, and dignity at the end of life.^{9,11} Poor communication between professionals and families can further intensify these dilemmas, while limited resources, training, and organizational support may hinder ethical decision-making in care.^{9,11}

However, most existing evidence originates from high-income Western countries. Far less is known about how multidisciplinary healthcare professionals experience dementia care in community-based settings within middle-income or non-Western contexts, where family responsibility is central and formal support structures remain limited. In Türkiye, studies have reported difficulties in managing behavioral symptoms, communication barriers, and emotional strain in dementia care; however, ethical challenges in community-based care remain underexplored.^{12,13} Research involving physicians indicates that their role in home health care is often limited to consultation, with minimal direct involvement in patient management.¹⁴ Additionally, studies examining home healthcare services for people with Alzheimer's disease highlight gaps in coordination between professional teams and families, which adversely affect caregivers' well-being and the effectiveness of services.¹⁵

The absence of clear ethical guidance in community-based dementia care further intensifies these challenges.¹⁶ In Türkiye, where dementia care is commonly perceived as a family responsibility, healthcare professionals frequently mediate between patients' needs and family expectations within under-resourced systems.^{13,17} Understanding these culturally and systemically rooted dilemmas is essential for developing training, policies, and support systems that promote ethical, high-quality dementia care.

Therefore, this study aims to explore healthcare professionals' perceptions of dementia care, the practical and systemic challenges encountered during home-based service delivery, and the ethical dilemmas arising in everyday community-based practice. These dimensions are interconnected, as professionals' experiences are shaped by organizational constraints, family involvement, and ethical decision-making. By examining service delivery challenges, care needs, and ethical dilemmas in community settings, this study addresses a critical gap in the literature and provides contextually grounded insights from a middle-income, family-centered care system.

Study Questions

1. What are healthcare professionals' experiences and perceptions of community-based care for people living with dementia?
2. What challenges and gaps do healthcare professionals encounter in service delivery and coordination, and what dementia-related care needs are most difficult to meet in home/community settings?
3. What ethical issues and dilemmas arise in community-based dementia care, and how do healthcare professionals manage these issues in practice?

Materials and Methods

Study Design

This study employed a qualitative descriptive design informed by the Interpretive Phenomenological Approach (IPA).¹⁸ It explored healthcare professionals' experiences and perceptions of community-based dementia care across disciplines, including doctors, nurses, and social workers. Focus group interviews were used to capture shared perspectives on professional roles, service challenges, and ethical concerns in community care. The study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines to ensure methodological rigor.¹⁹ It was conducted within the framework of COST Action CA21137 [EDEM] as an initial phase of a cross-national analysis.

Participants and Setting

Participants were healthcare professionals recruited via purposive sampling from community care units of state hospitals, nursing homes, and municipal community care services. Data saturation was assessed during ongoing data collection and analysis, and was considered achieved when successive focus groups generated no new themes and repetitive patterns were observed by the third focus group. Most focus groups were conducted face-to-face in meeting rooms at participants' workplaces to ensure confidentiality and minimize disruption to routine duties, while one was conducted online via a secure videoconferencing platform.

Eligibility required at least six months' experience in community-based dementia care, including services provided through Alzheimer's Associations, and availability to participate in a focus group. Professionals without direct experience in community-based dementia care, those with less than six months of relevant experience, or those unable to attend a full focus group session were excluded.

Data Collection Tool

Data were collected through semi-structured interviews. An interview guide was developed covering topics such as perceived challenges, needs, ethical issues, and strategies in dementia care.²⁰

Data Collection

Semi-structured focus group interviews were conducted between March and July 2024 to explore healthcare professionals' perspectives on community-based dementia care. Three focus groups (each with 5–8 participants) were held (two face-to-face and one online), each lasting 90–120 minutes. Interviews were conducted in Turkish, the native language of both participants and researchers. The use of both formats accommodated participants' clinical workload, geographical dispersion, and scheduling constraints. All sessions were audio-recorded with participants' consent and transcribed verbatim.

Data Analysis

Data were analyzed using an IPA-informed thematic analysis. Phenomenological concepts derived from IPA, such as attention to lived experience and interpretative meaning-making, informed the analytic stance, while the primary analytic goal was to identify recurring patterns and shared meanings across participants rather than to generate idiographic cases.²¹ Audio recordings were transcribed verbatim in Turkish and analyzed in the original language to preserve meaning and contextual nuance. The analysis followed an iterative and inductive process. Transcripts were read repeatedly for familiarization, and initial notes capturing descriptive, linguistic, and conceptual observations were recorded in the margins. Codes were generated inductively, compared across transcripts, and then clustered into broader categories and themes. Themes were examined within and across focus groups and organized into superordinate themes and subthemes representing shared and divergent experiences. Illustrative quotations were selected to demonstrate how interpretations were grounded in the data. To enhance analytic rigor, preliminary codes and themes were discussed in analytic meetings within the research team. When differing interpretations emerged, researchers returned to the original transcripts and refined the themes through iterative discussion until consensus was reached. Reflexive memoing and peer debriefing were used to support transparency and credibility in the analytic process.

Rigor and Trustworthiness

To ensure rigor and trustworthiness, Lincoln and Guba's criteria²¹ for credibility, dependability, confirmability, and transferability were applied. Credibility was supported through peer debriefing, reflexive memo writing, and an audit trail; member checking was not feasible due to participants' clinical workload. Transferability was addressed by providing detailed contextual descriptions of the setting and participants, enabling readers to assess applicability. Dependability was achieved by systematically documenting each research stage, including recruitment, data collection, and analysis, with coding decisions and theme development recorded in reflexive memos. Confirmability was strengthened through researcher reflexivity and by grounding interpretations in participants' narratives rather than in researchers' assumptions. Together, these measures ensured a transparent and methodologically robust analytic process.

Ethical Considerations

This study was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki. Ethical approval was obtained from the Ethics Committee of Koç University [Approval Number: 2024.022.IRB3.005, Date: 25.01.2024]. All participants provided written informed consent, and confidentiality was ensured through pseudonymization.

Results

Eighteen healthcare professionals participated in the study, including five physicians, eight nurses, and five social workers. Participants ranged in age from 27 to

Table 1. Participant characteristics

Participant #	Gender	Age	Marital status	Education	Work experience (years)	Place of work	Type of service
Participant #1	W	28	Single	Medicine	4	State Home Care Unit	Public
Participant #2	M	51	Married	Medicine	26	Municipality Home Care	Public
Participant #3	W	51	Married	Medicine	26	Municipality Home Care	Public
Participant #4	M	40	Married	Medicine	14	Municipality Home Care	Public
Participant #5	M	59	Married	Medicine	32	Municipality Home Care	Public
Participant #6	W	45	Single	Nursing Vocational School	22	Municipality Home Care	Public
Participant #7	W	35	Married	Nursing High School	20	Municipality Home Care	Public
Participant #8	W	45	Married	Nursing - MSc	23	Municipality Home Care	Public
Participant #9	W	28	Married	Nursing - BSc	6	Municipality Home Care	Public
Participant #10	W	28	Single	Nursing - MSc	6	Municipality Home Care	Public
Participant #11	W	37	Single	Nursing - MSc	15	Municipality Home Care	Public
Participant #12	M	28	Single	Nursing - BSc	6	State Home Care	Public
Participant #13	M	27	Single	Nursing - BSc	5	State Home Care	Public
Participant #14	W	28	Married	Social Work - MSc	6	Nursing Home	Public
Participant #15	W	28	Married	Social Work - MSc	6	Municipality Social Service	Public
Participant #16	M	35	Married	Social Work - BSc	12	Nursing Home	Private
Participant #17	W	28	Married	Social Work - MSc	6	Municipality Social Service	Public
Participant #18	M	32	Married	Social Work - MSc	9	Municipality Social Service	Public

Table 2. Summary of findings

Theme	Subtheme	Key descriptive findings	Illustrative examples (profession)
Theme 1: Perception and Gaps in Service Provision	Perceptions of People with Dementia and Management of Care	People with dementia (PwD) are perceived as highly dependent; care is focused on safety, hygiene, and supervision; families experience long-term burden and exhaustion	<i>"They are like a baby; they need protection."</i> (Doctor)
	Service Delivery and Financial Barriers	Community care relies heavily on families; limited supplies are provided; families often purchase medical materials themselves; coordination occurs informally	<i>"The nurse goes first and sends photos of the wound."</i> (Doctor)
Theme 2: Needs and Care Challenges	Needs of People with Dementia	Basic care needs include hygiene, nutrition, mobility, and wound care; social support (cleaning, cooking) is also required	<i>"Our workers even go to clean and cook for her."</i> (Nurse)
	Care Challenges	Untrained family caregivers and paid foreign workers, language barriers, reuse of medical equipment, and delayed care due to poverty	<i>"They reuse catheters because they cannot buy new ones."</i> (Nurse)
	Involvement of Relatives in Care	Family caregivers should learn care tasks; training improves outcomes; emotional and financial support are needed	<i>"We taught them how to dress the wound, and it improved."</i> (Nurse)
Theme 3: Ethical Issues in Community Care	Failure to Fulfill Care Responsibility	Misuse of care pension; neglect and abuse; resistance to institutional care for financial reasons	<i>"They receive money but don't care for him."</i> (Social worker)
	Human Dignity in the Home Environment	PwD are kept in unsuitable rooms, unhygienic conditions, and isolation by family	<i>"They put him in a dark, dirty room."</i> (Doctor)
	Problems Caused by Cognitive Impairment	Difficulties with consent; conflicting wishes between patient and relatives; risk of false accusations	<i>"We decide instead of the patient."</i> (Doctor)
	Solution Finding for Ethical Problems	Team discussions, personal ethics, legal referral by social workers, and lack of formal ethics committees	<i>"We discuss it as a team."</i> (Nurse)

59 years, and six were single (Table 1). The analysis generated three overarching themes reflecting professionals' experiences of community-based dementia care: (1) perceptions of people with dementia and gaps in service provision; (2) the needs of people with dementia, care challenges, and family involvement; and (3) ethical issues and dilemmas in community care. These themes illustrate how healthcare professionals navigate clinical, social, and ethical complexities while providing care in home and community settings. A descriptive overview of findings across themes and professional groups is presented in Table 2, while the narrative below focuses on the interpretive analysis of participants' experiences.

Theme 1: Perceptions for People with Dementia and Gaps in Service Provision for People with Dementia

This theme explores healthcare professionals' understanding and interpretation of dementia, and how these perceptions shape the delivery of community-based care.

Sub-theme 1a: Perceptions Regarding People with Dementia and Management of Care

The participants view dementia as a progressive condition requiring intensive supervision and safety measures, frequently comparing patients' vulnerability to that

of children, and they perceive people with dementia as needing significant caregiver support and safety precautions. “.... They are like a baby; they need protection in terms of security, and their doors are locked.... All of them need to be monitored. They cannot do it alone.” (Doctor)

The participants highlight the progressive nature of dementia care and the shifting responsibilities of families over time. The complexity of managing behavioral symptoms and safety concerns, such as preventing falls, ensuring medication adherence, and handling incontinence, further challenges family members as the disease progresses. “Since patients with dementia cannot communicate their complaints, relatives and caregivers face a difficult situation. Relatives can become anxious and stressed while trying to solve the problems of their suffering patients. This makes caring for people with dementia more difficult for both relatives and healthcare professionals.” (Nurse)

This continuous pressure frequently results in caregiver burnout. Participants observed that some families reach a point of total exhaustion at which their inquiries about prognosis mask a deeper desire for the patient’s suffering to end. “Relatives of the patients also experience burnout. They take care of them for an extended period, and they become fatigued. The relatives ask us whether this disease will get better. What they really want to ask is when he will die. They appear to be waiting for death.” (Doctor).

Sub-theme 1b: Service Delivery and Financial Barriers

Healthcare professionals play a crucial role in coordinating and delivering community care services for people with dementia, particularly those who are bedridden. Pressure ulcers and catheter use are common concerns for bedridden patients with advanced dementia and comorbidities. Multidisciplinary collaboration is facilitated through WhatsApp groups, allowing nurses to quickly refer patients to physiotherapists, psychologists, or other specialists. Home visits are more than just medical check-ups; they provide psychosocial support, especially for patients who live alone and may have limited social interactions.

Nurses are often the first to visit patients, assess their condition, and take photographs of wounds, which are then shared with physicians to guide treatment decisions. As one doctor explained: “Every patient is visited as a team, but we doctors cannot keep up, so first the nurse goes and assesses the patient.” If she takes photos of the wound and shares them with us, then the treatment process can begin.”

Social workers primarily provide referral-based support, guiding families to diagnostic clinics, disability benefits, and Alzheimer’s associations for psychoeducational support and financial aid. As one social worker explained, “As social workers, we cannot go to every home and communicate one-to-one with the family with Alzheimer’s disease, but if there is a relative with Alzheimer’s disease or suspicion of Alzheimer’s disease in the family, we direct the elderly and the applicants accordingly to the service they need.”

Despite existing state and municipal support, significant service gaps remain. Professional feedback indicates that public provision of medical consumables, such as diapers, catheters, and wound dressings, is frequently insufficient. Consequently, family caregivers must cover these essential costs out-of-pocket, as the state’s financial assistance fails to meet the daily demands of advanced dementia care.

Theme 2: Needs and Care Challenges

The complexities of the disease necessitate comprehensive care that spans physical, emotional, and social domains. This theme explores the multifaceted needs of individuals with dementia, the challenges associated with their care, and the critical role of family involvement in ensuring quality of life.

Sub-theme 2a: Needs of People with Dementia

People living with dementia require extensive and continuous support, as they often lose the ability to meet even their most basic needs. As dementia progresses, patients become increasingly dependent on others, often requiring help with every aspect of daily living. Doctors emphasize that many patients are immobile and vulnerable to additional illnesses such as pneumonia and cystitis. They highlight the critical need for full-time caregivers, holding that “These patients forget many things.” They cannot do it alone.” (Doctor)

In addition, dementia patients and their families require practical social support, including assistance with household tasks such as cleaning, cooking, and shopping. One healthcare worker described going beyond clinical care to meet patients’ daily needs within their services.

“Although her child lives across the street, our workers still go to her house to clean and cook for her, to meet her needs.” (Nurse)

While doctors and nurses are clearly aware of the comprehensive needs of patients with dementia, social workers may overlook basic care needs unless they have prior experience with or specific training in dementia care. This gap becomes evident in their limited involvement with families, as one social worker explained: “I mean, at least when we go to the house for social inspection, we cannot go for social inspection very often.” Suppose they approach us with an application or a denunciation. After conducting a social investigation, we go to supervise families once or twice a year at most, but that’s it.” (Social workers)

Sub-theme 2b: Care Challenges

A common issue is reliance on untrained or inadequately prepared caregivers in home care.

“The relatives say they are taking care of the wound, but they are not. It is important to ensure that they continue treatment to reduce the burden of care.” (Doctor)

Paid caregivers often fill community care gaps due to labor shortages and the demand for personalized, affordable care. Although institutional care is costlier than family care, families often share expenses to avoid institutionalization. However, many caregivers are informally employed and unlicensed, creating precarious, uncertain conditions: “There are foreign caregivers in most homes. I ask the patient’s relatives who they are, they say they are relatives, but these people have no knowledge of patient care.” (Doctor)

Financial limitations also exacerbate care deficiencies. In low-income households, caregivers may reuse medical equipment or delay treatments because of cost, which can lead to serious complications.

“They use the tracheostomy catheter repeatedly because they cannot obtain it; consequently, infection develops.” (Nurse) “They don’t do the dressing because they don’t have money to buy wound dressing or they can’t do it because of their workload in a crowded family.” (Nurse)

Doctors share these concerns that inadequate care at home may lead to deaths.

“When these patients receive inadequate care, they may die from sepsis or other infections. One patient I visited at home had an odor of urine and a discharging wound. Care was inadequate. We attempted to care for him, but he died 5 days later.” (Doctor)

Another critical factor affecting the quality of community care is the limited availability of social workers to monitor care regularly. Follow-up visits are rare and often occur only in response to complaints: “Let’s say they come to us with an application or a denunciation.” After conducting a social investigation, we go to supervise families once or twice a year at most, but that’s it.” (Social worker) This lack of regular supervision of the care provided at home makes it difficult to identify and intervene in cases of neglect or mistreatment, further complicating the care of patients with dementia.

Sub-theme 2c: Involvement of Relatives in Care

Family involvement is a cornerstone of effective dementia care, and participants widely agree that it can be enhanced through education, support, and empowerment. Teaching family members how to perform basic caregiving tasks not only lightens the burden on professionals but also contributes to improved patient outcomes.

“Initially, the patient’s relatives were unable to manage the wounds and bleeding. Over time, we taught them to provide wound care and assume that responsibility, and we subsequently observed improvement in the patient’s wounds.” (Nurse)

Doctors emphasize hands-on instruction, demonstrating specific tasks and providing ongoing education for patients and their families. Similarly, social workers stress that patients should remain at home as long as possible to promote involvement and shared decision-making: “The best option for family involvement is actually for patients to stay at home as long as they can.” In this way, they can make relevant decisions more comfortably at home.” (Social workers).

However, family involvement requires more than technical training. Families must receive emotional and financial support for such training to be meaningful and sustainable. Raising awareness and building caregiving capacity are essential to fostering conscious, competent participation in the care process.

Theme 3: Ethical Issues in Community Care

This theme explores the meanings attributed to ethical behavior, the ethical dilemmas that arise in community care settings, and the coping strategies professionals employ when navigating these difficult scenarios.

Sub-theme 3a: Failure to Fulfill the Care Responsibility

Sub-theme 3a (1): Misuse of Care Pension and Neglect

A significant ethical issue in community care is relatives' misuse of the care pension intended to support the patient. Nurses and social workers reported that financial aid is often redirected, leaving neglect unnoticed until situations become dire.

"The people who care for the patient receive a care pension, but they do not use that money for him. They do not meet his needs." (Nurse)

"There are also families who keep him in a room and receive financial support. In fact, they do not provide him with any care." (Social Workers)

Nurses frequently find family members failing to fulfill their responsibilities and witness signs of neglect or abuse. These incidents create ethical dilemmas, balancing family autonomy against the duty to safeguard vulnerable patients. Professional codes require action in cases of suspected abuse, despite potential conflicts. As one nurse recounted: *"On one of my visits, the patient's relative was beating the patient with dementia. I was threatened if I complain to the police."* Often, professionals cannot prove an act of neglect or abuse unless someone outside the family, such as a neighbor or another relative, files a formal complaint.

"A patient being mistreated can sometimes say this. The patient sometimes reports that they are hungry. His relative says he fed him. The patient has experienced weight loss. In this case, we can do nothing; we cannot detect it." (Doctor)

In such ethical dilemmas, professionals find themselves torn. They recognize the need for institutional care but face resistance from families who view the patient as a source of income.

"He actually needs institutional care, but his relatives do not want to leave him because they see community care as a source of income. We cannot take him if the relatives refuse." (Nurse)

Sub-theme 3a(2): Human Dignity in Home Environment

Another ethical concern involves patients living in inhumane or degrading conditions. Driven by shame or fatigue, some caregivers hide patients in unsuitable environments or provide inadequate care.

"Relatives confine people with dementia to the worst part of the house – a dark, dirty, stuffy place where no one can see them." (Doctor)

"When we go home, the family caregiver takes the PwD upstairs; when we leave, the caregiver can bring him into the empty room downstairs." (Social Worker)

Nurses shared similar observations regarding the impact of poor environments on health outcomes:

"We cannot enter the home because there are many cats; the patient has a wound, and the environment is unclean." (Nurse) *"The patient lives in a house filled with garbage. A urine odor is present. The inability to change living conditions makes our job difficult."* (Nurse)

Healthcare workers face ethical challenges balancing their duty to provide care with personal safety. Professionals may refuse to provide risky treatments, such as IV antibiotics, in homes where patients are alone or where they (the patients) fear violence or legal accusations.

"We do not administer medications, such as antibiotics, at home, because serious side effects, including anaphylactic reactions, can occur." (Nurse)

Because many patients are unable to provide informed consent or to communicate effectively, professionals avoid being alone with them to reduce the risk of misunderstandings or legal risks. The presence of a third party ensures transparency and protects both parties.

"The patient must be accompanied. If no one accompanies the patient, we cannot enter the home or provide the medication." (Nurse)

"We terminated services for the patient because he was mobile and lived alone. We need someone to accompany us." (Doctor)

While justified as a safeguard, this requirement disproportionately disadvantages socially isolated individuals, raising concerns about neglect and the violation of the right to health. This reflects systemic inequities, as those with the fewest resources face the greatest barriers to essential care.

"Agitated patients may attempt to remove NG catheters, PEG tubes, or other devices. If the patient's relatives do not help us, we close the patient's file. We try our best, but there is nothing we can do when we are attacked." (Doctor)

Sub-theme 3b: Problems Caused by the Patient's Cognitive Impairment

Cognitive decline complicates the ethical landscape of community care, particularly regarding consent and decision-making. Dementia-related impairments limit a patient's ability to understand procedures or to express stable preferences, thereby shifting authority to family members or healthcare professionals. *"We cannot get consent from PwD. We have to make decisions on behalf of the patient... or on behalf of his/her relatives."* (Doctor)

Conflicts frequently arise when patients and families express opposing wishes, placing healthcare professionals in challenging positions. *"The patient does not want a catheter, but his relatives tell us to put one in... I told them to agree among themselves and I left."* (Doctor)

Such situations illustrate the ambiguity regarding whose wishes should prevail when patients resist care that others deem necessary for safety or hygiene. Social workers highlighted the difficulty of assessing a patient's reliability. *"Just because the person has cognitive impairment, what the person says may be ignored... but he may be telling the truth. A dilemma exists regarding this."* (Social Worker)

Nurses also described being vulnerable to accusations following interventions, especially when patients misunderstood the clinical process. *"You perform an interventional procedure and they are happy, but after you leave, they call the office and complain that the nurse mistreated me."* (Nurse)

These accounts demonstrate that cognitive impairment not only affects consent capacity but also exposes professionals to legal and moral risks. This reinforces the need for clear documentation and shared decision-making in community settings.

Sub-theme 3c: Solution Finding for Ethical Problems

In the absence of formal ethics committees, most ethical decisions are made collaboratively within care teams. Healthcare workers rely on team discussions, professional values, and personal conscience rather than standardized institutional guidance. Participants reported using collective reasoning and informal consultations as primary tools for resolving dilemmas.

Nurses emphasized that in-home care depends heavily on individual integrity: *"You are at home, there is no one supervising you, you do what you do according to your own values and you leave."* (Nurse) Team-based discussions are commonly used to evaluate complex cases and to distribute responsibility for difficult decisions. Social workers utilize social investigation reports and may involve judicial authorities in serious cases of ethical violations. This reflects an escalation pathway where informal professional judgment is supplemented by legal mechanisms when safety or dignity is threatened. *"We use social investigation reports when there is an ethical problem. If unresolved, we forward the final decision to the judicial authorities."* (Social Worker)

All groups expressed a strong desire for accessible ethical training, particularly on-line programs tailored to community care. Participants highlighted a clear need for formal ethics committees, clearer practice guidelines, and ethics education specifically designed for community-based dementia care.

Discussion

This study explored healthcare professionals' experiences of community-based dementia care, distinguishing findings that align with international literature from those that offer context-specific insights. Participants described dementia as a progressive and debilitating condition requiring intensive care, particularly in advanced stages. These perceptions are consistent with previous research indicating that dementia disrupts cognition, physical functioning, and social integration.²²

Beyond confirming these patterns, participants, particularly nurses and physicians, highlighted the emotional toll on families, describing caregiver burnout and distress, which sometimes led to a silent wish for the patient's suffering to end. This moral ambivalence reflects the cumulative psychological strain of prolonged caregiving without adequate formal support. Such exhaustion underscores the need for accessible respite care services. A broader review similarly reports that respite services can help prevent negative outcomes such as caregiver burnout and declining well-being.²³ However, participants' accounts suggest that access to these services remains limited and inconsistently organized within community care settings.

Although multidisciplinary service models exist, participants reported inconsistencies in service delivery, including gaps between professional roles and disruptions in continuity of care. While home visits by nurses and physicians were valued for their responsiveness and coordination, resource limitations, understaffing, and bureaucratic barriers often hindered continuity of care. The absence of an integrated system linking municipal and state services further complicated service delivery. These findings align with the literature, which identifies fragmentation and underfunding as major weaknesses in community-based dementia care.^{24,25}

Participants also emphasized the complex and holistic needs of people with dementia, identifying hygiene, nutrition, mobility, wound care, and emotional support as essential aspects of care. As dependency increases with disease progression, caregiver preparedness and professional support become increasingly important. Medical and social care needs were viewed as closely intertwined, with household assistance, financial aid, and psychosocial support considered as essential as clinical interventions. These findings support international calls for integrated care models that extend beyond a purely biomedical perspective.

Care challenges were particularly evident in families with limited resources or health literacy. Participants reported that some caregivers lacked training, and that foreign home-care workers were sometimes employed despite language barriers and minimal preparation for healthcare tasks. These conditions occasionally resulted in neglect, inappropriate reuse of medical equipment, and poor wound management, sometimes leading to serious outcomes such as infections or sepsis. These observations echo earlier findings that informal dementia caregiving remains undervalued and under-resourced.²⁶ Risks may be amplified in home settings where formal supervision mechanisms are limited. Importantly, the findings challenge the assumption that family involvement is inherently protective. Although education improved caregiving capacity in some cases, participants also described neglectful or abusive practices within families. These findings suggest that financial support alone is insufficient and that family caregiving requires structured supervision and professional guidance to ensure safe and dignified care.²⁷

Ethical challenges in dementia care are widely documented, particularly regarding patient autonomy, decline in decision-making capacity, stigma, and the impact of caregiving on families.²⁸ Caring for people with dementia requires balancing respect for autonomy with the realities of progressive cognitive decline, while maintaining ethical principles such as beneficence, justice, and nonmaleficence. Recent international reviews also highlight a Global North–South divide in dementia care ethics, with countries in the Global South often relying heavily on family-based care due to limited institutional support and weaker legal frameworks.²⁹ This structural context helps explain the ethical uncertainty experienced by professionals in community settings when navigating autonomy, surrogate decision-making, and dignity.

Participants frequently described ethical dilemmas related to misuse of care pensions, neglect of patients, and difficulties in reporting or proving abuse. Without formal complaints or inspections, professionals often felt powerless. Similar concerns have been documented in studies examining elder abuse in domestic settings.³⁰ Poor living conditions or deliberate isolation sometimes compromised patients' dignity, creating tensions between maintaining family-based care and safeguarding that dignity. Healthcare professionals also faced physical and legal risks when entering unsafe home environments, occasionally leading them to withdraw from providing care. Such decisions shifted ethical responsibility from institutions to individual professionals. This situation reflects moral distress – knowing the ethically appropriate action but being constrained from acting – a phenomenon widely reported among healthcare providers.^{31,32} Cognitive impairments further complicated the process of obtaining informed consent and increased professionals' vulnerability to misinterpretation or to accusations. International qualitative studies similarly identify ethical dilemmas in home-based end-stage dementia care, particularly in

decisions between comfort-focused and life-prolonging treatments. Differences between professional and family perspectives are often ethically legitimate, but they may generate conflict in contexts characterized by limited resources and communication challenges.¹¹ Recent qualitative research from community care settings also documents moral distress among home-care nurses, particularly when working alone and confronting conflicts between professional values and organizational or financial constraints. These findings suggest that moral distress is primarily linked to structural limitations rather than individual shortcomings.³¹

Evidence from other resource-limited contexts further illustrates these structural challenges. A phenomenological study in Albania found that caregivers experienced significant moral tension when balancing autonomy, safety, and dignity in the absence of adequate support, highlighting systemic injustice rather than individual failure.²⁷ Similar tensions have been reported in North Macedonia, where healthcare professionals experienced ethical conflict when attempting to reduce family burden without adequate state-supported services.³³ In most cases, professionals addressed ethical dilemmas informally through personal judgment, peer consultation, or experience, rather than through structured ethical support.³⁴ While this approach allows flexibility, reliance on individual reasoning may create inconsistencies and emotional strain. Establishing multidisciplinary ethics committees and regular ethics discussions within community care services could support more consistent decision-making and reduce moral distress.

Limitations

Several limitations should be considered. While framed within Interpretative Phenomenological Analysis (IPA), the use of focus groups may have limited idiographic depth due to group dynamics. The heterogeneous sample provided broad perspectives but potentially reduced the individual depth typical of IPA. Additionally, mixing online and face-to-face data collection may have influenced participant interactions. The focus on a specific geographic and healthcare system context may also limit transferability.

Conclusion

This study highlights the complex realities of community-based dementia care. Effective care requires coordination across clinical, emotional, social, and ethical domains. Findings reveal under-resourced systems, inadequately supported caregivers, and significant ethical tensions regarding autonomy and justice. These challenges emphasize the need for enhanced professional education, transparent supervision of financial aid, and structured ethics consultation mechanisms. Strengthening integrated health and social care systems is essential to ensuring person-centered, safe, and dignified dementia care in both home and institutional settings.

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