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RESEARCH

Ethical Principles and Frameworks in Dementia Care: A Scoping Review

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Abstract Providing ethical care for people living with dementia is essential for safeguarding their rights, dignity, and well-being. However, ethical decision-making in dementia care is complex, often involving tensions between competing moral claims such as autonomy, beneficence, nonmaleficence, justice, and non-discrimination. This scoping review aimed to map and describe the ethical principles, related normative considerations, and ethical frameworks discussed in the scientific literature on dementia care, and to identify how these have been conceptualized. Following the methodological guidance of Arksey and O'Malley (2005), Levac et al. (2010), and Peters et al. (2021, 2022), a comprehensive search across five databases (Web of Science, Scopus, CINAHL, Medline/PubMed, and PsycInfo) identified peer-reviewed papers published in English. In total, 388 papers published between 1981 and 2024 were included. The results revealed a wide range of ethical principles and related normative considerations frequently cited in the literature,

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although they were typically discussed in an isolated way without reference to other principles or broader ethical frameworks. In contrast, ethical frameworks were mentioned far less often, and when they were, they mostly reflected traditional approaches such as principlism. Four gaps were identified: the plurality of ethical frameworks and limited conceptual integration underpinning dementia care research and practice; insufficient attention to ethnic and socioeconomic diversity among people living with dementia; limited consideration of diverse care settings and geographical regions; and the limited inclusion of people living with dementia themselves in the studies reviewed. These findings underscore the need for conceptually integrative, inclusive, and context-sensitive approaches to dementia care ethics that can better inform both ethical reflection and care practices.

Keywords Dementia · Care ethics · Ethical principles · Ethical frameworks · Person-centered care · Scoping review

Introduction

Individuals living with dementia may gradually lose the capacity for autonomous and competent decision-making, rendering them dependent on others to act on their behalf. In this context, family members and professional caregivers often encounter complex moral situations that demand careful ethical reflection [1, 2]. These situations, commonly referred to as *ethical issues*, arise when competing moral requirements or normative claims come into tension [3]. For instance, a caregiver may struggle to balance the principle of autonomy, understood as respect for an individual's self-determination, with the principle of beneficence, which emphasizes safety and well-being. Similarly, tensions can emerge between the preservation of dignity and the demands of justice, or between the pursuit of truth and the need to prevent harm.

Addressing these ethical issues is inherently interpretative, depending on how moral concepts are understood and prioritized within specific relational, socio-cultural, and institutional contexts. This context-sensitivity is widely acknowledged in the literature,

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with there being no one-size-fits-all prescriptive method for resolving such dilemmas [4–6]. Consequently, ethical decision-making in dementia care remains complex and heterogeneous. This uncertainty can give rise to *moral distress*, a form of psychological discomfort experienced when one perceives the morally right course of action but feels unable to pursue it due to external constraints or conflicting obligations [7, 8]. Moral distress may, in turn, lead to caregiver burden and fatigue, arising from the inability to effectively manage these ethical challenges [9, 10].

Nevertheless, providing ethical care to individuals living with dementia is an expression of society's moral commitment to uphold human value and vulnerability [11]. The notion of ethical care can be understood as the deliberative engagement with normative considerations that guide action, justify evaluation, and orient decision-making within caregiving relationships [12]. In the present review, we focus on what are commonly referred to in the literature as ethical principles. The focus on ethical principles in this review is grounded in their central role in ethical deliberation and decision-making, functioning as action-guiding, normative considerations that help structure moral reasoning, justify judgments, and orient decisions in concrete situations [6].

That said, the term "principle" is used inconsistently across disciplines and is often applied to a heterogeneous range of normative concepts, which are variously referred to as values, principles, or rules [13]. In a narrower philosophical sense, ethical principles are typically understood as general, action-guiding norms that possess prima facie normative force and can be balanced against one another in concrete situations [14]. Such understanding of ethical principles is most clearly exemplified in the philosophical framework of principlism (e.g., autonomy, beneficence, nonmaleficence, and justice) [15]. These principles are often grounded in widely shared moral intuitions and function as mid-level guides for ethical reasoning.

However, the dementia care literature does not always distinguish clearly between formal ethical principles, moral values, relational orientations, rights-based claims, and other normative concepts. Across disciplines and contexts, concepts such as dignity, person-centeredness, relationality, respect, or social inclusion are frequently invoked as ethically action-guiding considerations, even when they are not presented as ethical principles in the strict philosophical sense [6, 12, 16]. This conceptual heterogeneity poses methodological challenges for attempts to systematically map the normative dimensions of dementia care literature.

For the purposes of this scoping review, the term ethical principles is used operationally and inclusively to refer to generic normative claims invoked to guide action, justify ethical judgments, or orient caregiving practices in dementia care literature. These include both ethical principles in the narrower philosophical sense (e.g., autonomy, beneficence, nonmaleficence, justice) and other normative concepts frequently treated as ethically guiding in dementia care literature, such as dignity, person-centeredness, or relational responsibilities [6, 12, 16]. We do not assume that all such concepts qualify as ethical principles in the strict philosophical sense; rather, the review maps how normative concepts are articulated and mobilized across the field.

These normative considerations do not necessarily operate in isolation but are often organized within broader *ethical frameworks*, defined as structured systems of moral reasoning that organize, justify, and relate principles to one another in order to guide judgment and action. Examples of such frameworks include the Nuffield Council on Bioethics [6], the Universal Declaration of Human Rights [17], or broader moral theories.

Ethical principles, related normative considerations, and frameworks serve as interpretive lenses through which the moral dimensions of care are perceived, negotiated, and applied. Importantly, the ethical concepts invoked in dementia care may differ considerably depending on the specific moral issue or topic under consideration. For instance, principles emphasized in end-of-life decisions often diverge from those central to discussions of sexuality, or use of technology in dementia care. This contextual variability underscores the need for a systematic understanding of how principles are applied and weighted across different domains and situations of dementia care.

Although recent scholarship has examined ethical concerns in dementia care from specific vantage points, such as the moral challenges that arise across different stages of the disease [18], ethical questions surrounding diagnosis and disclosure [19], the management of intimacy and sexuality [20], or the

dynamics of caregiving relationships [21], there has been no comprehensive review explicitly addressing the ethical underpinnings of this field. The existing literature, while thematically rich, remains fragmented with respect to how ethical principles and related normative considerations are identified, interpreted, and related to one another within structured ethical frameworks.

In response to this gap, this scoping review aimed to map and describe the ethical principles, related normative considerations, and ethical frameworks discussed in the scientific literature on dementia care, and to identify how these have been understood.

Methods

A scoping review was undertaken, as this methodological approach is particularly well suited to mapping existing evidence and identifying gaps on a given topic. This approach was considered appropriate considering the study's objectives and the need to comprehensively capture the breadth and nature of research in a complex field. Such an approach is especially relevant for examining multifaceted and conceptually nuanced topics [15, 22], such as ethical principles, related normative considerations, and ethical frameworks in dementia care. In identifying principles, rather than imposing restrictive philosophical definitions that would exclude a substantial portion of the literature, this review adopts an analytically inclusive approach. Accordingly, we use the term ethical principles as an umbrella category to capture general normative considerations that are invoked to guide action or justify ethical judgments in dementia care. These concepts are inherently complex and have been interpreted in diverse ways across disciplines and contexts, leading to a fragmented body of evidence and limited conceptual integration in the existing literature. Consequently, a scoping review provided a suitable means to systematically map and summarize the range of available studies and to identify areas requiring further conceptual and empirical development.

The review followed the five-stage methodological framework originally outlined by Arksey and O'Malley [23], as refined by Levac et al. [22], as well as more recent guidelines on conducting scoping reviews [15, 24]. To ensure comprehensive and transparent reporting, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) [25] was applied (see Supplementary File 1). A systematic, team-based approach was employed throughout each stage of the review process.

The protocol for this scoping review was preregistered in the Open Science Framework (https://osf.io/achfu/overview) to ensure transparency and methodological rigor.

Step 1: Identifying the Research Question(s)

As recommended by Peters et al. [26], the Population-Concept-Context (PCC) framework was used to formulate the research questions, ensuring a consistent focus on the key elements relevant to this review. The population refers to people living with dementia; the concept encompasses ethical principles and related normative considerations, and the ethical frameworks that structure these; and the context includes the care of people living with dementia across all care settings. Guided by this framework, the review addresses the following research questions:

- What ethical principles and related normative considerations are described in scientific literature on the care of people living with dementia?
- Are these ethical principles and related normative considerations identified in the literature organized within broader ethical frameworks, and if so, which frameworks are used?

Step 2: Identifying Relevant Studies

With the support of BLINDED FOR REVIEW, a professional librarian at the University of BLINDED FOR REVIEW, we developed and refined our search strategy through an iterative process involving the selection of both keywords and databases. This process unfolded in three main stages. In the first stage, we identified preliminary keywords based on a thorough review of the core literature relevant to the topic. Next, we conducted an initial search in two databases considered most broad, Scopus and Web of Science. By closely analyzing the titles, abstracts, keywords, and index terms of the records retrieved in this initial search,

we refined both the keyword list and the overall search approach for the subsequent scoping review. In the final stage, comprehensive searches were performed in March/April 2024 across five databases: Web of Science, Scopus, PsycInfo, Medline/PubMed, and CINAHL. These databases were chosen for their relevance and complementarity, ensuring broad disciplinary and geographical coverage. Web of Science and Scopus served as multidisciplinary sources; PsycInfo provided depth in psychology, behavioral sciences, and social work; Medline/PubMed offered extensive coverage of biomedical, gerontological, and ethical aspects of healthcare; and CINAHL focused specifically on nursing and allied health literature.

The specific search terms, and their variations and combinations, are listed in Table 1, while detailed search strategies tailored to each database can be found in Supplementary File 2. Only peer-reviewed articles were considered, with no restrictions on the publication date. Although the research team is multilingual, this review was limited to English-language publications to ensure clear and consistent keywords and inclusion criteria, reduce subjective bias in source selection across languages, and enhance replicability and transparency.

Step 3: Study Selection

All search results were imported into Covidence (Veritas Health Innovation, Melbourne, Australia) for study selection and data management. Before the screening process began, all reviewers participated in a structured training session in which the inclusion criteria, key concepts, and screening procedures were reviewed. To ensure consistency, the team conducted a pilot screening of a sample of 20 studies to calibrate decision-making and align interpretations of the eligibility criteria across reviewers. Following the pilot test, a consensus meeting was held to discuss discrepancies and refine the screening approach. Support materials, including detailed screening instructions (see Supplementary File 3), were provided to all reviewers throughout the process. After this preparatory phase, each record was independently screened by two reviewers based on title and abstract. In total, 20 reviewers participated in the screening process.

Inclusion Criteria

Peer-reviewed theoretical, empirical studies, including quantitative, qualitative, mixed-methods research, and review articles, were eligible for inclusion. Following the Population–Concept–Context (PCC) framework, the inclusion criteria were defined as outlined below.

Population

Studies were included if they primarily focused on individuals living with dementia, regardless of type or severity (e.g., Alzheimer's disease, vascular, frontotemporal, or Lewy body dementia). Studies were excluded if they focused on other conditions (e.g., mild cognitive impairment or non-dementia neurodegenerative disorders) or involved mixed populations.

Concept

Eligible papers addressed ethical principles or ethical frameworks related to dementia care, as defined in the introduction:

- *Ethical principles* were operationally defined in an inclusive manner to encompass both ethical principles in the narrower philosophical sense (e.g., autonomy, beneficence, nonmaleficence, justice) and other generic normative claims frequently invoked to guide ethical reflection and caregiving practices in dementia care literature (e.g., dignity, person-centeredness, relational responsibilities, respect, or social inclusion).
- *Ethical frameworks* were defined as structured systems of moral reasoning that organize and relate ethical concepts and principles in order to guide ethical judgment and decision-making (e.g., Nuffield Council on Bioethics, Universal Declaration of Human Rights, or broader moral theories).

Context

Studies conducted in any care setting involving people living with dementia were eligible, including institutional settings (e.g., nursing homes, assisted living, long-term care, hospices, day care centers) and non-institutional or community-based settings (e.g.,

Table 1 Keywords used in the scoping review

Population: People Living with Dementia		
Dement*		
Alzheimer		
Cognitive impairment		
Cognitive decline		
Cognitive loss		
Cognitive disease		
Cognitive dysfunction		
Cognitive disorder		
Cognitive deficit		
Memory impairment		
Memory decline		
Memory loss		
Memory disease		
Memory dysfunction		
Memory disorder		
Memory deficit		
Neurocognitive impairment		
Neurocognitive decline		
Neurocognitive loss		
Neurocognitive disease		
Neurocognitive dysfunction		
Neurocognitive disorder		
Neurocognitive deficit		
Neurodegenerative impairment		
Neurodegenerative decline		
Neurocognitive loss		
Neurodegenerative disease		
Neurodegenerative dysfunction		
Neurodegenerative disorder		
Neurodegenerative deficit		
Concept: Ethical Principles and Ethical Frameworks		
Ethical prefix	*Ethical frameworks*	*Ethical principles*
Ethic*	Framework	Princip*
Normative	Guideline*	Value*
Moral*	Best practice*	Virtue*
Value-based	Recommendation*	Duty
Philosoph*	Proposal*	Duties
Principl*	Decision mak*	Ideal*
	Decision-mak*	Imperative*
	System*	Axiom*
	Structure*	Maxim*
	Advi*	Precept*
	Polic*	Sensit*
	Norm*	Consideration*
	Precaution*	Right*
	Warning*	Entitle*
	Standard*	Responsib*
	Code*	

Table 1 (continued)

Context: Care Provided for People with Dementia
Care*
Respite*
Day cent*
Nursing home*
Nursing facilit*
Nursing institution*
Convalescen* home*
Convalescen* facilit*
Convalescen* institution*
Assisted living home*
Assisted living facilit*
Assisted living institution*
Long-term home*
Long-term facilit*
Long-term institution*
Hospice*
Continuous support
Palliat*
Home-dwelling*
Community-dwelling*

home care, in-home support). Studies were excluded if the context did not involve dementia care provision (e.g., diagnostic or research-only contexts).

Following title and abstract screening, reviewers independently assessed the full texts of the selected papers. For quality assurance, one-third of the full-text articles were double-reviewed to ensure consistency in applying the inclusion criteria; the remaining papers were assessed by a single reviewer.

Disagreements at any stage (title/abstract or full-text review) were resolved by the first and last authors through discussion and re-evaluation of the paper against the criteria. Regular team meetings were held throughout the screening process to address ambiguities, ensure alignment with the review objectives, and maintain consistency in study selection.

Step 4: Charting the Data

Key data from the included studies were extracted using Covidence (Veritas Health Innovation, Melbourne, Australia). A core team consisting of the first, second, third, and last authors developed an initial version of the data-charting form. This preliminary form was piloted by the four reviewers on a random sample of 25 included papers to assess clarity and applicability. The results of this pilot were discussed collectively, and the form was refined accordingly (the final data-charting form is provided in Supplementary File 4). Normative concepts explicitly discussed in the included publications were identified inductively and subsequently grouped into broader analytical categories for synthesis purposes. These categories included both principles in the narrower bioethical sense (e.g., autonomy, beneficence, justice) and other ethically action-guiding concepts frequently invoked in dementia care literature (e.g., dignity, person-centeredness, relationality). All relevant data were subsequently charted directly into Covidence, which facilitated consistency, transparency, and team-based data management throughout the review process.

In addition to bibliographic information, the final version of the charting form recorded details on each study's aims or research questions, main topic, ethical principles and related normative considerations discussed and how they were addressed, ethical frameworks identified (if any), and any consideration of diversity among people living with dementia. It also included the classification of each paper as conceptual, empirical, or review. For empirical studies, further information was extracted on research design, data collection methods, and sample characteristics.

Ethical principles were coded as non-mutually exclusive categories, allowing individual studies to be associated with multiple principles. Distinctions between closely related principles were established iteratively through team discussion and reference to conceptual definitions developed during pilot coding. Disagreements in classification were resolved through consensus meetings involving the core team.

A total of 20 reviewers participated in the final data extraction. To ensure the trustworthiness and consistency of the process, one-third of the studies were charted independently by two reviewers, who compared their results, resolved discrepancies, and agreed on a consistent approach. The remaining studies were charted by a single reviewer. Throughout this phase, the core team held regular meetings, both internally and with the other reviewers, to discuss uncertainties, ensure consistency in data extraction, and make collective decisions based on a careful examination of the papers.

Step 5: Collating, Summarizing, and Reporting Results

This step involved two types of analysis. For the quantitative data included in the data charting form, we calculated frequencies and percentages using IBM SPSS Statistics 27. This allowed us to describe the main trends and characteristics of ethical principles, related normative considerations, and ethical frameworks as reported in the scientific literature on the care of people living with dementia.

For the qualitative data included in the charting form, specifically the textual descriptions provided by reviewers in the previous phase on how ethical principles were presented in the literature (see data charting form in Supplementary File 4), we conducted an inductive content analysis. Content analysis is a systematic approach to interpreting textual data by identifying patterns and meaningful categories that emerge from the material itself, allowing researchers to make valid inferences about the underlying concepts [27]. Two reviewers formed a pair for each ethical principle and were responsible for analyzing the associated data. They received detailed instructions and an illustrative example to guide the process. The analysis of each principle was informed by its relative frequency across the topics of the included papers (see Supplementary File 5), helping ensure a structured yet inductive and comprehensive exploration of how each principle was described. The core team oversaw and coordinated the process to ensure consistency across reviewer pairs.

Results

A total of 4,097 papers were identified through the initial search after duplicates were removed (Fig. 1).

Title and abstract screening excluded 3,429 papers that did not meet the inclusion criteria. Full texts were retrieved for 656 studies. For papers that were not initially accessible through our institutions' subscriptions, we used interlibrary loan services, searched the institutional repositories of other universities, and, when possible, contacted the authors directly. Despite these efforts, the full texts of 12 studies could not be obtained and were therefore excluded from further analysis.

Full-text screening led to the exclusion of an additional 268 papers that either did not meet the inclusion criteria for the type of evidence (n = 48), were not focused on people living with dementia (n = 34), did not address ethical principles and/or frameworks (n = 177), or were not focused on a care context (n = 9).

The analyses were therefore conducted on 388 papers, which are presented in three sections. First, we provide a descriptive analysis of the characteristics and trends of the literature. Next, we present the results addressing each of the two research questions of the scoping review.

The full list of the 388 papers included in the review is provided in Supplementary File 6, and the numbering in this list corresponds to the references cited in the results section for ease of reference.

Descriptive Analysis

The 388 papers analyzed in this scoping review span the years 1981 to 2024. Overall, academic interest in this topic has shown a steady increase over time, with notable peaks in 2012, 2017, and 2021 (Fig. 2).

Table 2 summarizes the main topics addressed in the 388 papers reviewed. The most common themes were care of people living with dementia (17.3%), use of technology (11.3%), and decision-making (9.3%). Other frequent topics included end-of-life

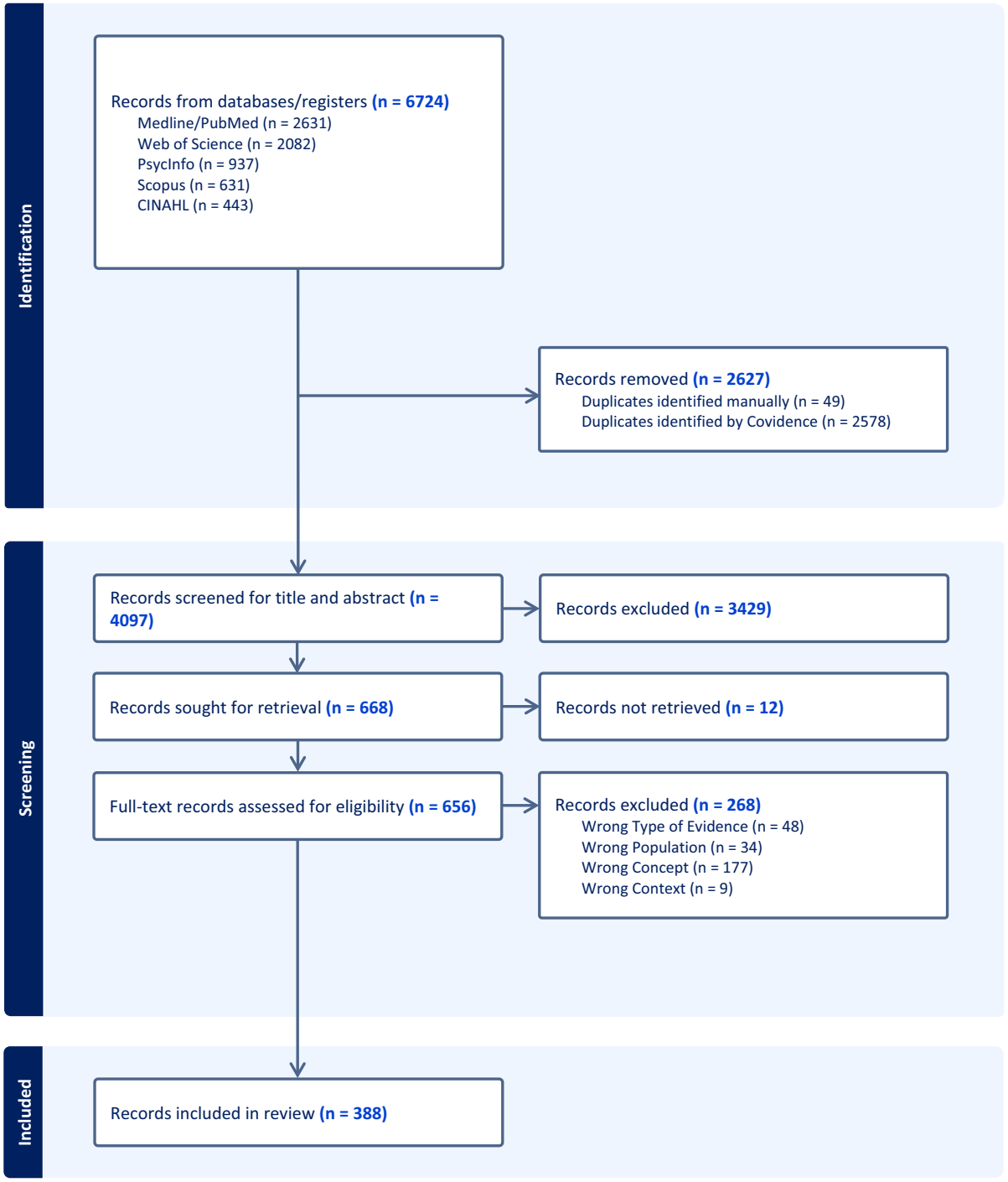


Fig. 1 Flow chart. Scoping review on ethical principles for the care of people with dementia described in the scientific literature

and palliative care, autonomy and self-determination, and person-centered care. Less common themes covered issues such as truth-telling, euthanasia, dignity, and behavioral concerns, while a smaller number of papers discussed interventions, well-being, and dementia-friendliness.

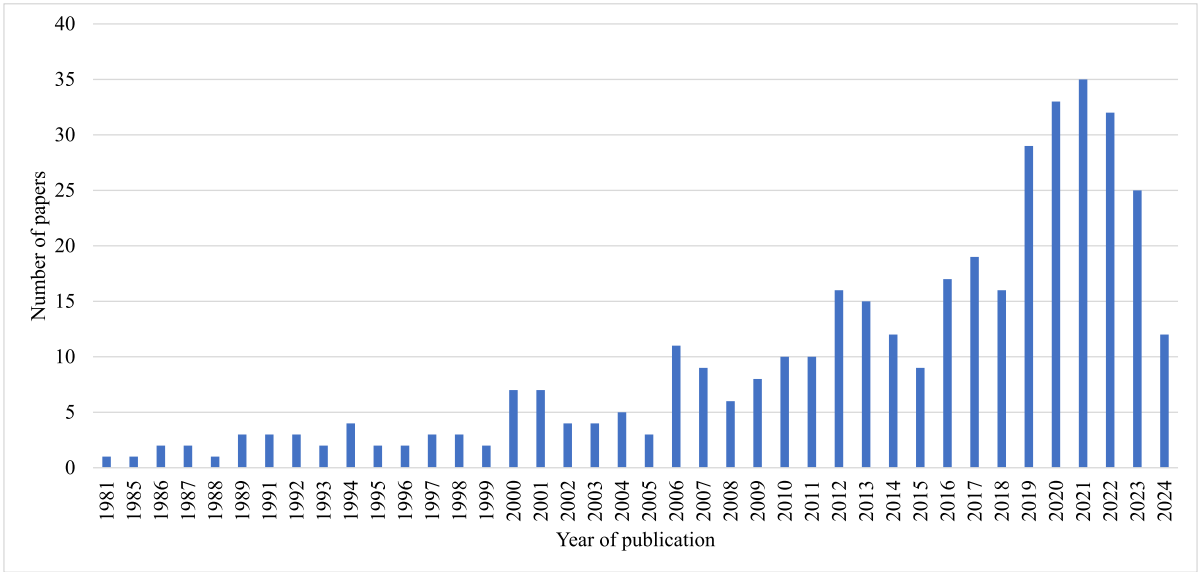


Fig. 2 Number of publications, by year of publication. Period 1981–2024 ($N = 388$)

The characteristics of the papers in terms of the consideration of diversity and study type were also analyzed. As shown in Table 3, only 5.4% of the papers explicitly addressed aspects of diversity, most frequently focusing on ethno-cultural diversity (3.1%) and, to a much lesser extent, on migrant backgrounds, people with disabilities, LGBTQ + populations, and other specific groups such as low-income individuals, people living with AIDS, or those in rural or prison settings.

The reviewed papers were almost evenly divided between empirical (40.5%) and conceptual (39.2%) studies, with reviews accounting for the remaining 20.3%.

Table 4 summarizes the methodological characteristics of empirical studies included in the review. Most studies (81.5%) employed qualitative methods, while mixed methods (9.6%) and quantitative approaches (8.9%) were less frequent. Most studies were conducted in long-term care settings (50.3%) or in the community (42.7%), with fewer in hospitals or general healthcare environments (21.7%) or day-care centers (9.6%). Geographically, the literature was dominated by studies from the United States and Northern Europe (e.g., the United Kingdom, Norway, Sweden, and the Netherlands), while other regions of the world were clearly underrepresented (e.g., Latin America countries) or entirely absent (e.g., African countries). Finally, most studies included formal caregivers or professionals (68.2%) in their samples, while fewer included informal caregivers (44.0%) or people living with dementia themselves (32.5%), highlighting a tendency to explore ethical principles and related normative considerations in dementia care primarily from the perspectives of care providers rather than care recipients.

RQ1: • What ethical principles and related normative considerations are described in scientific literature on the care of people living with dementia?

Table 5 outlines the ethical principles addressed in the 388 papers included in the review. The most frequently discussed principles were autonomy and self-determination (73.2%), beneficence and well-being (56.4%), and nonmaleficence or prevention of harm (45.6%). Other prominent principles included person-centeredness, dignity, and justice or fairness. Less commonly explored were veracity, privacy, non-discrimination, fidelity, and confidentiality. A small number of papers referred to other principles, such as authenticity, ethics of care, spirituality, and vulnerability. Supplementary File 5 presents a cross-tabulation table showing the frequency with which ethical principles were discussed across the topics addressed in the included papers.

Table 2 Topics covered in the papers included in the review ($N = 388$)

Topic of the paper	n	%
Care of people with dementia in general	67	17.27
Use of technology	44	11.34
Decision-making	36	9.28
End-of-life and palliative care	31	7.99
Autonomy, self-determination, agency	27	6.96
Person centered care	24	6.19
Advance directives	23	5.93
Feeding issues	21	5.41
Behavioral issues	19	4.90
Aggression (verbal or physical)	*2*	0.52
Behavioral and psychological symptoms of dementia (BPSD)	*1*	0.26
Sexual behavior or sexuality	*9*	2.32
Use of restraints or force	*4*	1.03
Wandering	*3*	0.77
Truth-telling	17	4.38
Euthanasia & assisted dying	15	3.87
Personhood and identity issues	13	3.35
Dignity	12	3.09
User involvement	8	2.06
Non-pharmacological interventions	7	1.80
Dementia-friendliness	6	1.55
Pharmacological interventions	5	1.29
Wellbeing and quality of life	4	1.03
Forced and life sustaining treatments	3	0.77
Abuse and mistreatment	1	0.26
Management of health issues with people with dementia	1	0.26
Oral health and dentist treatments	1	0.26
Other	3	0.77

Table 3 Diversity dimensions addressed in the papers included in the review ($N = 388$)

Diversity	n	%
No	367	94.59
Yes	21	5.41
Ethno-cultural diversity	*12*	*3.09*
Migrant backgrounds	*3*	*0.77*
People with disabilities	*1*	*0.26*
LGTB & Queer	*1*	*0.26*
Low-income	*1*	*0.26*
People with AIDS	*1*	*0.26*
People living in prisons	*1*	*0.26*
Rural settings	*1*	*0.26*

The results of the qualitative content analysis are presented according to the frequency with which different ethical principles appeared in the reviewed papers. The analysis was organized based on the relative frequency of each principle across the various topics addressed in the papers (see Supplementary File 5), to ensure a structured and comprehensive examination of each principle discussed. For each ethical principle, illustrative examples were provided using the numbering from Supplementary File 6, which contains the full list of papers included.

Autonomy/Self-Determination

Autonomy and self-determination emerge as central principles in dementia care, particularly in supporting participation in decisions about one's life and care.

Table 4 Methodological and contextual characteristics of the empirical studies included in the review ($N = 157$)

Methodological approach	n	%
Qualitative	128	81.53
Mixed	15	9.55
Quantitative	14	8.92
Study time frame		
Cross-sectional	136	86.62
Longitudinal	21	13.38
Study approach		
Observational	151	96.18
Experimental	6	3.82
Data collection methods		
Interview	103	65.61
Survey/Questionnaire	27	17.20
Focus Group	26	16.56
Other	40	25.48
Study context		
People with dementia in long-term care setting (of any type)	79	50.32
People with dementia living in the community	67	42.68
People with dementia in hospitals/general health care settings	34	21.66
People with dementia attending day-care	15	9.55
Other	2	1.27
Geographical distribution		
United States of America	22	14.01
United Kingdom	21	13.38
Norway	17	10.83
Sweden	14	8.92
The Netherlands	14	8.92
More than one country	10	6.37
Australia	8	5.10
Israel	8	5.10
Canada	6	3.82
Finland	5	3.18
Belgium	4	2.55
Denmark	4	2.55
Ireland	4	2.55
Germany	3	1.91
Japan	3	1.91
Netherlands	3	1.91
China	2	1.27
Austria	1	0.64
Brazil	1	0.64
Czech Republic	1	0.64
France	1	0.64
Hong Kong	1	0.64
Iran	1	0.64
Italy	1	0.64
Malta	1	0.64
Republic of Korea	1	0.64

Table 4 (continued)

Methodological approach	n	%
Singapore	1	0.64
Switzerland	1	0.64
Taiwan	1	0.64
Sample composition		
Includes formal caregivers (professionals)	107	68.15
Includes informal caregivers	69	43.95
Includes people with dementia	51	32.48
Other	35	22.29

Table 5 Ethical principles discussed in the papers included in the review ($N=388$)

Ethical principle	n	%
Autonomy/Self-determination	284	73.20
Beneficence/Care/Wellbeing	219	56.44
Nonmaleficence/Prevention of harm	177	45.62
Person-Centeredness and Individuality	168	43.30
Dignity	142	36.60
Justice/Equity/Fairness	92	23.71
Veracity/Truthfulness	52	13.40
Privacy	51	13.14
Non-discrimination/De-stigmatization	46	11.86
Fidelity/Loyalty	45	11.60
Confidentiality	17	4.38
Other principles*	22	5.67

*Other principles include Authenticity ($n=1$), Citizenship ($n=1$), Confucian ethical principles ($n=2$), Courage ($n=2$), Daoist ethical principles ($n=1$), Empowerment ($n=1$), Ethics of care principles ($n=4$), Family solidarity ($n=1$), Relational ethics principles ($n=2$), Sanctity of life ($n=1$), Social engagement, meaningful activities, and experiences ($n=4$), Spirituality ($n=1$), Virtue ethics principles ($n=1$), and Vulnerability ($n=1$)

Authors distinguish capacity, competence, and legal authority, separating cognitive from legal dimensions (see, for example, #252, #255, #262, #345, #352, #366, #375) and they also differentiate negative autonomy, understood as freedom from interference, from positive autonomy, understood as the capacity for action (see #256). Recognized as a right (#229), autonomy implies presuming capacity unless clearly refuted and understanding it as task-specific (#255). Decision-making capacity is described as dynamic, relational and context-dependent (e.g., #194, #195, #258, #267, #281, #287, #305, #309, #328, #359, #363), including emotional and relational dimensions.

Shared decision-making grounded in communication and empathy supports negotiation among caregivers and the person with dementia (#305, #328). Such supported decisions apply to daily care situations (e.g., treatment refusal, wandering, hygiene resistance), helping maintain dignity despite cognitive decline (#258, #267). However, decision-making must be adapted to individual circumstances, care dependency, institutional culture and wider cultural values (e.g., #283, #292, #305, #309, #321, #322, #359, #363, #383).

Cultural contexts reveal tensions between duty of care and respect for autonomy (e.g., #214, #217, #250, #259, #355, #368, #374, #387). This tension is often stronger in collectivist traditions that emphasize relational agency (#13, #241, #316). It becomes especially salient in treatment refusal, artificial feeding or hydration (#218, #241, #246–#248) and end-of-life decisions (#4, #21, #54, #64, #67, #68, #70, #79, #104, #124).

Across settings, beneficence frequently overrides autonomy, leading to paternalistic practices (#318, #336, #340). Person-centered approaches aim to promote self-sufficiency and purpose (e.g., #134), although implementation may be constrained by organizational pressures (#286, #324, #325, #327). Professionals often adjust procedures to preserve empathy and relational care (#209, #217, #224, #359, #363, #366, #383).

Discussion on advance care planning (#196–#381) debates the authority of precedent autonomy when past and present values diverge (#296, #320). "Geriatric consent" (#228) offers an intermediate view, emphasizing narrative continuity and supported decision-making (#333, #345).

Technological mediation may support or constrain autonomy (#198–#379), reinforcing the need for participatory consent and co-design (#347). Emerging perspectives on distributed autonomy emphasize interdependence and ethical co-agency (#283, #284, #358, #369, #371, #379).

Beneficence/Care/Well-Being

The principle of beneficence is often discussed in relation to tensions between respect for autonomy and promotion of well-being, for instance in decisions about living arrangements, driving, feeding, and treatment refusal (#8, #49, #77, #81, #166, #201, #268, #277, #309, #360). Such tensions are also debated in the context of advance directives (#120, #127, #160, #179, #201, #277, #330, #360, #370), where conflicts between prior wishes and current wishes or proxy decisions may arise (#49, #51, #67).

Beneficence is suggested as the guiding principle when autonomy cannot be exercised due to cognitive incapacity (#156, #214, #218, #233, #264, #335) but appeals to the best interest of people living with dementia are also discussed as potentially leading to unjustified paternalism (#85, #143, #214, #336) or to reducing beneficence to survival (#286, #329).

Furthermore, beneficence is described as a strong motivation for caregivers and clinicians (#78, #81, #148, #149, #190, #309), justifying for instance lying (#61, #123, #190, #345), change of living conditions, feeding and treating without consent (#77, #148, #309, #370). Often, beneficence is prioritized over autonomy in end-of-life decisions (#77, #78, #148, #353, #370), and the precedence justified by appealing to the safety of people living with dementia (#77, #275, #280, #339, #360, #379).

Cultural norms and family expectations may complicate feeding decisions (#94, #246), but careful hand feeding is highlighted as more compassionate, comforting and as preserving dignity (#39, #46, #241, #306). Beneficence as promotion of well-being is generally seen as requiring a compassionate, person-centered, dignity-preserving approach, involving meaningful engagement and relational connectedness (#12, #14, #21, #38, #39, #40, #42, #47, #79, #85, #98, #137, #165, #167, #170, #196, #182, #197, #223, #235, #240, #241, #245, #258, #260, #280, #286, #301, #330, #340, #343, #356, #359, #363).

Promotion of well-being is often a central issue in discussion of technology adoption, including GPS, sensors and robotics, which offers safety and engagement benefits but also raises privacy concerns, (#7, #11, #17, #105, #107, #144, #161, #171, #215, #237, #282, #283, #371). The principle of beneficence is often discussed within Beauchamp and Childress's four-principles approach (#8, #57, #125, #151, #280, #355, #386).

Nonmaleficence/Prevention of Harm

In dementia care, the principle of nonmaleficence, closely tied to harm prevention, requires reducing foreseeable risks while avoiding interventions that may generate new forms of suffering. Common ethical challenges involve managing health issues, behavioral problems, pharmacological interventions, feeding, and sexual behavior. Conflicts frequently arise in treatment decisions, behavioral management, use of restraints (#267, #278, #279), and management of sexual behavior (#250, #259, #269). Measures intended to protect (e.g., physical restraints, sedative medication, or feeding tubes) can themselves cause harm, injury, confusion, social withdrawal, and loss of autonomy (#212). Healthcare professionals and caregivers often face dilemmas in such situations (#213, #216, #221), sometimes overlooking opportunities to promote well-being (#216) or adapt daily activities to prevent harm (#255).

A balanced approach involves "calculated risk" (#229), ensuring that protective actions are proportionate and do not restrict autonomy. While professionals are trained to prevent harm, family caregivers may unintentionally increase risks due to limited knowledge or skills (#225). Professionals may also act on cognitive biases leading to unnecessary interventions (#239). Tension between nonmaleficence and autonomy is clear when respecting the identities of people living with dementia or their seemingly irrational wishes (#236–#238). Deception (#117, #345) or excluding individuals living with dementia from decision-making can, itself, cause harm by undermining dignity and self-determination (#243). Intelligent assistive technologies may reduce risks (#244, #252, #281), but can also compromise privacy and autonomy (#214, #252, #253). Ultimately, nonmaleficence guides the balancing of safety, autonomy, dignity, and the avoidance of suffering across clinical, technological, and relational domains (#1, #16, #33, #46, #83, #90, #103, #210, #270, #345, #363).

Effective harm prevention depends on planned interventions, transparent communication, and collaboration with families (#248).

Person-Centeredness and Individuality

Person-Centeredness and Individuality emerge as a multidimensional ethical principle grounded in the recognition of everyone's uniqueness (#55, #382). It seeks to humanize care by enabling personhood (#354), valuing the person beyond the illness (#50, #340, #354) and recognizing their individuality (#276). Biographical knowledge, understanding a person's history, preferences, and values, guides individualized care and supports the continuity of self (#14, #22). This principle is frequently addressed in ethical and clinical debates concerning decision-making, dignity, and the quality of care provided (#3, #19, #23, #32). In this sense, regarding family involvement, some authors highlight the relevance of incorporating the life stories of persons living with dementia to guide decision-making, ensuring consistency with their personal and family history (#78), and recommending personalized practices such as life stories (#14, #90). Similarly, in palliative and end-of-life contexts, person-centeredness guides shared deliberation and compassionate presence (#21, #49, #50, #106, #138, #170, #179, #182), while in studies on technology and digital assistance it becomes a moral measure for balancing safety, autonomy, and privacy (#7). Nursing and training literature emphasizes the empathetic and moral competencies required to embody this principle in daily practice (#3, #23, #31, #33, #42). Finally, regarding dementia-friendly communities, greater empowerment and active involvement are still needed, while barriers such as staff attitudes and values should be overcome (#3). Fostering meaningful social connections (#23) is essential, as person-centered care can serve as an ethical and practical framework for dementia-friendly initiatives (#114).

Dignity

Dignity in dementia care is framed as inherent human worth that must be actively recognized through person-centered practices – life story work, respectful communication and treatment, and meaningful participation that affirm identity across the illness course (#14, #25, #60, #99, #115, #187, #192, #317, #349). Threats recur where care slips into infantilization, deception, coercion, or stigmatizing routines; treating people as "less than" (e.g., feeding while toileting or ignoring expressed choices) erodes personhood and dignity (#36, #45, #60, #115, #165). Physical restraints and routinized tube feeding are repeatedly described as dignity-undermining, with calls for least-restrictive approaches and relational alternatives such as careful hand-feeding and proactive ethical reflection (#1, #9, #46, #210, #241, #378, #384). Technology is portrayed as a double-edged tool: surveillance, tracking, and some care robots risk dehumanization, objectification, and stigma unless designed and governed with consent, discretion, and participatory input; conversely, well-designed tools can protect modesty in intimate care and support rights-based aims (#17, #18, #105, #107, #161, #171, #174, #237, #238, #253). Sexual identity and intimacy are treated as components of dignity warranting support without shame (#120, #166, #180, #352, #373). At life's end, dignity anchors debates over artificial nutrition and hydration, the voluntary refusal of food and drink, and physician-assisted dying, as well as the question of how to balance previously expressed wishes with the person's current interests. Honoring biography and earlier values is described as a way to uphold dignity while navigating these tensions between the "then-self" and the "now-self" and between best-interests judgments and personal autonomy (#33, #49, #124, #228, #231, #236, #298, #320, #330, #360, #370, #371).

Justice/Equity/Fairness

Justice in dementia care is a continuous problem of allocation, recognition, and procedure that runs from bedside to policy. At the coalface, time triage distributes scarce resources and staff: need-based arguments defend giving more when it meaningfully relieves suffering, provided others are not significantly harmed (#20), yet clinicians describe moral distress when one resident's legitimate claims divert care from the rest (#112, #148, #149, #219). Intensive attention to one person can disadvantage others (#151, #247). Underneath, familiar frameworks, utilitarian, egalitarian, maximin, animate judgments about who should get what, and when (#210, #280, #286, #383).

Families also negotiate justice intimately: caregivers often prioritize the person with dementia while suppressing their own claims, everyday maximin with emotional costs (#9, #125, #280), with gendered expectations burdening daughters in particular (#87). Social and civic inclusion are argued as an ethical substance of justice, not an optional add-on (#28, #29, #167), as well as creative practices that enable flourishing (#168) or support for everyday participation (#115). Technology sharpens distributive and procedural questions: affordability and design choices create uneven benefits and risks (#107, #161, #215, #282, #283, #361), prompting participatory design and organizational policies that allocate responsibilities fairly (#11, #44, #202). Across these scenes, labels and metrics structure access long before bedside choices (#126, #203); competency and guardianship practices must track the person's condition, not others' convenience (#156, #267); and stewardship agendas (e.g., deprescribing, antipsychotics) must not reproduce historic under-treatment of marginalized groups while remaining last-resort and value-concordant (#251, #355), and at a policy level, dementia should receive the same priority and resource allocation as other serious illnesses (#126, #259, #359).

Veracity/Truthfulness

Truthfulness emerges as a core ethical principle in dementia care, shaping how information is communicated and how honesty is balanced with the person's emotional and cognitive needs. It involves respecting the individual's right to truthful information while acknowledging that, in some circumstances, full disclosure may cause unnecessary suffering or confusion (e.g., #38, #41, #92, #137, #151, #154, #177, #261, #284). Within this principle, truth-telling is not an absolute rule but a context-sensitive practice that requires attention to the person's clinical condition, preferences, and capacity.

Therapeutic lying is discussed as an exceptional and carefully justified strategy aimed at reducing distress, grounded in beneficence but constrained by strict criteria of necessity, proportionality, and supervision. In this view, deception should never become routine or normalized (#40, #112, #186, #188, #196, #205).

Decision-making around truthfulness is described as relational: families, care teams, and, when possible, the person with dementia jointly negotiate how and when information should be shared. These negotiations consider cognitive capacity, psychological well-being, and the person's life story and values (#117, #123, #132, #136, #144, #159, #174, #247, #297, #306).

In technological contexts, the principle of truthfulness informs the ethical use of surveillance, monitoring systems, and consent procedures, emphasizing transparency and the protection of autonomy (#132, #141, #144, #174, #179).

Across the literature, truthfulness is presented as a spectrum rather than a binary: between blunt truth and outright falsehood lie practices such as omission, empathic validation, and carefully contextualized compassionate communication (#64, #117, #205, #208, #297). As a principle, truthfulness is closely tied to dignity, psychological well-being, relational ethics, and self-determination. It demands practical discernment, sensitivity, and shared deliberation rather than rigid adherence to a single rule.

Privacy

Privacy is a multidimensional ethical issue where questions concerning technology, behavioral aspects, consent, and dementia care intersect. Balancing safety and respect for privacy remains one of the main dilemmas in dementia care (#105, #171, #172, #173, #215, #352). Monitoring technologies such as GPS trackers, cameras, and sensors are described both as protective tools that enhance safety and autonomy, and as potential threats that risk violating privacy and intruding on personal space (#7, #17, #90, #107, #126, #164, #174, #361). Meanwhile, ethical and legal concerns persist regarding the collection, storage, and sharing of sensitive data (#11, #90, #161, #202, #272). Respect for autonomy in implementation, obtaining consent, ensuring physical privacy, and the importance of supported decision-making processes are emphasized (#142, #145, #175, #199). Participatory and value-sensitive design approaches are promoted to maintain transparency, prioritize user preferences, and share ethical responsibility among designers, caregivers, and institutions (#17, #18, #44, #90, #156). When individuals cannot make decisions, person-centered assessments should consider their

past and present preferences regarding privacy (#126, #180, #371).

Moreover, violations of sexual privacy, often through behavioral monitoring or information sharing (#103, #120), and inadequate care conditions (#19, #270) can undermine dignity and sense of self, emphasizing the need for supportive institutional privacy policies (#166, #194). The blurring of spatial perceptions in individuals may eliminate boundaries of privacy and emphasizing the role of sensitive environmental design (#195).

Ongoing discussions regarding roaming behavior also address the need for continuous monitoring and enabling individual intervention on the devices used (#379). Compulsory care practices in the home environment have been linked to privacy violations and infringement on decision-making rights (#97).

Non-Discrimination/De-Stigmatization

The principle of non-discrimination and de-stigmatization is fundamental to human rights and bioethics. It underscores the need for equitable treatment, the protection of dignity, and the promotion of justice within person-centered care.

Individuals living with dementia, particularly those who are nonverbal, are at high risk of having their experiences of ageing overlooked (#43, #165). Such neglect contributes to dehumanization and infantilization, denying them recognition as persons with meaningful life histories (#14, #24). To counter this, people living with dementia should be included in policy development, co-design processes, and decision-making forums (#161, #167).

Stigma compounds these risks. Double stigmatization increases the likelihood of being denied appropriate care (#21), which is strongly condemned in the literature (#52). Professional care plays a critical role in dismantling discriminatory practices and fostering more inclusive models of treatment (#42). Institutional and sociocultural biases also marginalize people living with dementia, especially those from ethnic minority groups, thereby silencing their perspectives and those of their families (#28). For example, in some Latino families, dementia symptoms may be interpreted through cultural narratives rather than clinical frameworks (#87).

Addressing social exclusion and the absence of inclusive policies requires both sociocultural and ethical transformation (#252, #311). This includes challenging entrenched stereotypes, such as assumptions that individuals living with dementia are asexual (#120). Approaches to sexuality should balance considerations of cognitive capacity with attention to relational and embodied dimensions (#166).

Greater societal awareness of dementia is essential to support individuals living with the condition and their families, improve quality of life, enhance community education, and reduce stigma (#22, #359). Ethical considerations remain central to strengthening services and identifying individuals who may require additional support (#3, #212).

Fidelity/Loyalty

Fidelity/loyalty, in dementia care refers to the sustained commitment of healthcare professionals to the well-being, autonomy, personhood, and values of those in their care (#148, #209). For formal caregivers, fidelity involves remaining steadfastly present and responsive, even when communication deteriorates (#14, #32, #101), when the suffering of people living with dementia cannot be alleviated (#43), when difficult decisions must be made (e.g., end-of-life or palliative care [#64]), or when institutional pressures challenge individualized care (#28). In such scenarios, respecting advance directives and previous decisions, appointing surrogate decision-makers, paying attention to subtle clues in the person's behavior, engaging in dialogue with the relatives of the person with dementia, or developing a meaningful and long-lasting therapeutic relationship between all of them can become means to demonstrate loyalty over time (#14, #28, #32, #47, #55, #101, #228). Fidelity/loyalty requires honoring the identity, history, emotional needs, preferences, and expressed or inferred wishes of people living with dementia; advocating for their interests; and maintaining the therapeutic relationship through attentiveness, honesty, and emotional integrity (#32, #270). Fidelity thus extends beyond procedural duty or compliance with legal regulations (#10, #69, #363). Actually, hiding behind procedural safeguards or defaulting to legal frameworks is sometimes seen as a threat to fidelity/loyalty (#10, #229).

When it comes to informal caregivers, fidelity/loyalty denotes the sustained commitment of family

members to the well-being, dignity, and identity of the person with dementia amid cognitive decline (#50, #310). Grounded in bonds of duty, trust, love, reciprocity, and shared history (#9, #50, #123, #271), it reflects a continuing responsibility to honor the person's life story and values while responding sensitively to his/her present needs, and balancing past commitments with current realities (#78, #81, #137, #201).

Confidentiality

Confidentiality emerges as a complex and multifaceted ethical principle in dementia care, particularly as cognitive decline complicates informed consent and privacy management. A recurring concern is the risk of unauthorized access to sensitive personal information, particularly through digital technologies. The sharing of passwords, loss of capacity to manage settings, and cross-platform surveillance systems can expose individuals to privacy breaches by third parties, including family members or caregivers (#11, #202, #215, #361).

Moreover, technological monitoring systems, such as sensors and tracking devices, raise issues about data control, usage purpose, and consent, especially when individuals are unaware, they're being monitored or can no longer consent meaningfully (#202, #215, #283). These challenges are compounded by the potential misuse of data, prompting calls for stronger encryption, user data ownership, and explicit consent protocols (#17).

Legal and ethical complexities arise when people living with dementia lose decision-making capacity. In such cases, confidentiality decisions often shift to legal representatives, but this can create tension between protecting privacy and ensuring effective care (#126, #156, #177, #300). Professionals may struggle to balance confidentiality with the need to disclose information in the best interests of the person with dementia. This underscores the need for more straightforward guidelines to help professionals navigate these competing obligations (#339).

Finally, trust and consent remain central. While people living with dementia prefer control over disclosure, caregivers often feel they require access to provide adequate care, reflecting ongoing ethical dilemmas that underscore the need for clearer, context-sensitive guidelines (#137, #174, #307, #339).

Other Principles

Other principles included the ethics of care, which were discussed particularly in the context of communication and interaction with people living with dementia (#10, #62, #204, #354). These discussions often reflected Tronto's [28] four moral principles of care, attentiveness, responsibility, competence, and responsiveness, that together constitute the integrity of care. Principles of social engagement, meaningful activities, and experiences were discussed in relation to promoting the participation of people living with dementia in community and social life (#27, #111). These ideas were particularly emphasized within the framework of dementia-friendly initiatives (#114, #131). Other ethical principles, although discussed to a lesser extent, with only one or two papers addressing them, included authenticity (#370), Confucian ethical principles (#193, #248), and family solidarity (#331). A complete list of the additional principles identified can be found in Table 5.

RQ2: Are the ethical principles and related normative considerations identified in the literature organized within broader ethical frameworks, and if so, which frameworks are used?

Ethical frameworks were discussed to a much lesser extent than ethical principles. As shown in Table 6, only 38.4% of the papers explicitly referred to an ethical framework, while 61.6% did not. Among those that did, the most frequently mentioned frameworks were principlism (12.1%), personhood and person-centered care approaches (10.1%), and the ethics of care (5.4%). Other frameworks, such as relational ethics, human rights approaches, and the Nuffield Council of Bioethics framework, appeared less often. A small number of papers cited additional frameworks, including virtue ethics, deontological ethics, capability approaches, and various professional codes of ethics.

Across the literature analyzed, ethical frameworks were invoked in different ways. In some cases, they were used as explicit analytical tools guiding empirical or conceptual analysis (e.g., principlism in clinical ethics discussions). In other instances, they functioned as broader normative orientations, shaping interpretations of care practices (e.g., ethics of care or personhood approaches). A smaller subset of papers referenced frameworks primarily at the level

Table 6 Ethical frameworks discussed in the papers included in the review ($N = 388$)

Paper discussed ethical framework	n	%
No	239	61.60
Yes	149	38.40
Principalism	*47*	*12.11*
Personhood and person-centered care approaches	*39*	*10.05*
Ethics of care	*21*	*5.41*
Relational ethics	*14*	*3.61*
Human rights approach	*8*	*2.06*
Nuffield Council of Bioethics	*6*	*1.55*
Virtue ethics	*3*	*0.77*
Deontological ethics	*3*	*0.77*
Narrative care	*3*	*0.77*
Nordenfelt's typology of dignity	*3*	*0.77*
AMA Code of ethics	*2*	*0.52*
Capability approach	*2*	*0.52*
Discourse ethics	*2*	*0.52*
Hermeneutical-phenomenological ethics	*2*	*0.52*
Disability approaches	*2*	*0.52*
*Other frameworks**	*13*	*3.35*

*Other frameworks include ADI Global Dementia Charter ($n = 1$). ANA code of ethics ($n = 1$). European Association for Palliative Care (EAPC) Framework ($n = 1$). Fry's model ($n = 1$). IMIA code of ethics ($n = 1$). National Institute for Clinical and Care Excellence (NICE) Principles ($n = 1$). Oath of hippocrates ($n = 1$). Posthumanism ($n = 1$). Ronald Dworkin framework ($n = 1$). Spinozist ethics ($n = 1$). Teleological approaches ($n = 1$). The code nursing & midwifery council UK ($n = 1$). Utilitarianism ($n = 1$)

of background justification without operationalizing them in analysis.

Taken together, the findings from RQ1 and RQ2 indicate that while ethical principles are widely invoked across dementia care literature, they are often not explicitly situated within structured ethical frameworks. This pattern suggests that dementia care literature frequently engages with ethical principles and normative considerations without explicitly situating them within systematically articulated ethical frameworks.

Discussion

This scoping review aimed to map and describe the ethical principles, related normative considerations, and ethical frameworks discussed in the scientific literature on dementia care, examine how these principles have been conceptualized, and identify existing gaps and directions for future research. Overall, the results indicate a growing academic interest in ethical principles and related normative considerations related to dementia care over the past four decades, reflecting the increasing societal and professional concern for the ethical dimensions of caring for people living with dementia. However, despite this growth, our findings reveal conceptual and contextual constraints that continue to shape the current ethical discourse on dementia care.

Specifically, four main gaps were identified through the quantitative and qualitative analyses of the included literature: (1) a pattern of plurality and only partial integration among ethical frameworks, with ethical reasoning often relying on isolated principles or issue-specific approaches rather than more fully articulated and integrative frameworks, (2) insufficient attention to diversity in ethical reflection and research participation, (3) limited consideration of contextual variability across care settings and geographical regions, and (4) limited inclusion of people living with dementia themselves in empirical studies. Each of these gaps is discussed below.

Plurality of Ethical Frameworks and Partial Conceptual Integration

The most salient finding of this review is the plurality of ethical frameworks and partial conceptual integration underpinning dementia care research and practice. While a broad range of ethical principles and related normative considerations, such as autonomy, beneficence, nonmaleficence, justice, dignity, and person-centeredness, are recurrently invoked, they are often treated in isolation, with limited conceptual integration into broader ethical frameworks. Only 38.4% of the reviewed papers explicitly referred to an ethical framework, and those that did primarily relied on principlism [29].

Taken together, these findings suggest that ethical reasoning in dementia care is characterized less by the absence of frameworks than by the coexistence of multiple, only partially integrated frameworks and a predominance of principle-specific or issue-specific ethical discussion. It is also important to acknowledge that, while some scholars advocate for broader

and more integrative ethical models, others caution against top-down frameworks, arguing that ethical issues are inherently contextual and require attention to the specifics of each situation [5]. Thus, ethical reasoning in dementia care often involves balancing general guidance with careful, individualized reflection on the concrete circumstances faced by family or professional caregivers. Future conceptual development may aim to move beyond the additive use of individual principles toward integrative ethical approaches that capture the relational, contextual, and dynamic nature of dementia care [30].

Insufficient Attention to Diversity

Another notable gap revealed by this review is the striking lack of attention to diversity. Only a very small fraction of the included studies explicitly addressed issues related to ethno-cultural background, gender, sexual orientation, disability, or socioeconomic status. The predominance of Western-centric ethical assumptions, particularly those grounded in individual autonomy, limits the global applicability of existing frameworks.

Addressing diversity in dementia care ethics requires moving beyond universalist conceptions of ethics to acknowledge plural traditions and situated experiences of care [31, 32]. Cultural norms strongly influence perceptions of autonomy, filial duty, and collective responsibility [33, 34], underscoring the need for ethical principles, related normative considerations, and ethical frameworks that are adaptable to different relational and social contexts. Integrating perspectives from feminist ethics of care, postcolonial and decolonial studies, and social justice approaches can help uncover how power dynamics, inequality, and cultural narratives shape ethical reflection and caregiving practices. For example, feminist ethics of care highlights how gendered expectations and care relationships shape vulnerability and responsibility [35, 36]; postcolonial and decolonial perspectives draw attention to the historical and structural power imbalances affecting marginalized communities [37–39]; and social justice approaches help identify how socioeconomic conditions and systemic inequities constrain individuals' ability to exercise autonomy or access care [11, 40, 41]. Together, these perspectives offer conceptual tools for recognizing and addressing the culturally and socially embedded dimensions of ethical decision-making in dementia care.

Greater inclusion of underrepresented groups in research, such as migrants, LGBTQ + individuals, ethnic and racial minorities, and low-income populations, would deepen understanding of how intersecting identities and social positions influence ethical reasoning in dementia care. At the same time, it is essential to recognize that each person and each care situation requires individualized ethical reflection. While diversity-related factors may shape experiences and needs, they do not determine them; caregivers must remain attentive to the unique preferences, values, and wishes of the person living with dementia, regardless of group membership. Integrating both contextual sensitivity and individualized ethical judgment is therefore crucial to supporting ethically robust and person-appropriate care.

Limited Consideration of Context

Our findings also reveal limited consideration of contextual variability across care settings and geographical regions. Specific care environments such as day-care centers received minimal attention compared to long-term residential care. Furthermore, most of the studies originated from Anglo-Saxon and Northern European countries, while regions such as Africa, Asia, and Latin America were markedly underrepresented. This imbalance restricts understanding of how ethical principles, related normative considerations, and ethical frameworks are interpreted and enacted in different institutional, cultural, and socioeconomic contexts.

Dementia care unfolds within diverse social ecologies where moral values, caregiving norms, and conceptions of personhood vary substantially [42, 43]. Given that ethical challenges are shaped by the social organization of care [44], institutional norms [45], and resource availability [9], among other factors, a comparative and context-sensitive approach is needed to capture these variations. Incorporating cross-cultural ethical perspectives can help ensure that ethical principles, related normative considerations, and ethical frameworks are both globally relevant and sensitive to the specificities of local care contexts, supporting guidance that is meaningful across diverse lived experiences of dementia.

Limited Inclusion of People living with dementia in Research

A further limitation concerns the underrepresentation of people living with dementia themselves in empirical studies. Only about one-third of the empirical studies included in this review directly incorporated the perspectives of people living with dementia, with most focusing instead on professionals or family caregivers. This exclusion not only raises epistemic concerns, limiting understanding of lived ethical experiences, but also contradicts the very principles of autonomy, dignity, and person-centeredness that the literature advocates [46].

Incorporating participatory and inclusive research designs that engage people living with dementia as co-researchers or active informants is essential to capture the ethical dimensions of care as experienced from within [47]. Participatory approaches can help identify forms of moral distress, resistance, and agency that remain invisible in proxy accounts [48]. However, the application of participatory approaches brings ethical challenges of its own [48]. It is often the most vocal or already-empowered groups—such as dementia activists—who participate, raising questions about whose voices are amplified and whose remain silent. Individuals with advanced cognitive impairment, those from marginalized sociocultural backgrounds, or those facing socioeconomic barriers are especially at risk of being excluded. These concerns echo the broader need for diversity-sensitive ethical frameworks to ensure that participatory research does not inadvertently reproduce existing inequities.

Study Limitations

Several limitations of this review must be acknowledged. First, despite efforts to conduct a comprehensive search, the inclusion of only English-language publications may have introduced a language bias, potentially excluding significant research published in other languages, particularly in regions such as Asia. This restriction may also contribute to the limited representativeness of different geographic contexts, as relevant studies from non-English-speaking countries could have been overlooked. Second, the geographical distribution of the included studies may reflect broader global inequalities in research funding and life expectancy, as countries with longer average lifespans and more developed care infrastructures tend to produce more research on dementia care. Third, although every effort was made to apply the inclusion criteria consistently, the large number of reviewers involved may have introduced some degree of subjectivity or variation in interpretation during study selection and data extraction, despite calibration exercises and ongoing quality checks. Fourth, the categorization and interpretation of ethical principles, related normative considerations, and ethical frameworks are inherently interpretive processes. A further limitation concerns the conceptual breadth of the operational definition adopted in this review. Because the dementia care literature uses ethical terminology inconsistently across disciplines and traditions, the review employed an inclusive approach intended to capture not only principles in the narrower philosophical sense, such as prima facie action-guiding norms associated with principlism, but also other normative considerations that function as practical moral reference points in dementia care literature. This enabled a more comprehensive mapping of how ethically action-guiding concepts are articulated and mobilized across a heterogeneous body of literature. At the same time, this inclusive use risks blurring distinctions between different kinds of normative claims and considerations, including moral principles, values, duties, rights-based claims, and relational ideals. Consequently, the resulting conceptual heterogeneity limits the extent to which the findings can be interpreted as referring exclusively to ethical principles in the narrower philosophical sense. Nevertheless, we regard this broader approach as appropriate for a scoping review, given that the aim was to map the field as it is represented in practice rather than to determine in advance which concepts qualify as principles according to a single philosophical framework. Moreover, given the conceptual nature of the topic, the mapping of principles may reflect how they were described in the original publications rather than their meaning or application in practice. Important nuances or theoretical distinctions may have been simplified to ensure comparability across studies. Five, a further limitation of this review concerns the nature of the data analyzed. Although the extraction process was systematic and carefully conducted, the data consist primarily of metadata derived from 388 publications. Consequently, while the review offers a structured synthesis of how ethical principles, related normative considerations, and ethical

frameworks are represented across the literature, it cannot fully capture the conceptual richness or contextual nuances contained within individual studies. Finally, given the analytically inclusive definition of ethical principles adopted in this review, findings related to conceptual fragmentation should be interpreted with caution. The observed diversity partly reflects the plural, interdisciplinary, and context-sensitive nature of dementia ethics scholarship, rather than indicating a clear deficit in theoretical coherence. Accordingly, the results point to patterns of plurality and partial conceptual integration rather than an absence of coherence.

Conclusion

In summary, this scoping review mapped and described how ethical principles, related normative considerations, and ethical frameworks have been conceptualized in the scientific literature on dementia care. The findings point to an expanding and heterogeneous body of scholarship, characterized by recurrent reference to core ethical principles alongside a plurality of ethical frameworks that are only partially integrated. While this pattern may suggest a degree of conceptual fragmentation, it also reflects the interdisciplinary, pluralism, and context-sensitive nature of dementia care ethics, where multiple perspectives and approaches coexist, reflecting complexity and contributing to a shared understanding. Addressing the identified gaps, by fostering greater conceptual integration where appropriate, embracing diversity, attending to contextual variability, and including people living with dementia in research, represents an important step toward a more reflexive and inclusive ethical discourse. Future research should prioritize theoretically informed, culturally sensitive, and participatory approaches that operationalize ethics of care not as abstract principles but as lived, relational practices that honor the dignity, interdependence, and individual agency of people living with dementia. In practice, strengthening organizational support for ethical reflection, improving ethics training, and implementing clear policies that guide decision-making can help translate these principles into consistent, compassionate, and context-sensitive care.

Author Contribution R.S. and F.S.J. designed the study. S.L. and E.B.C. contributed to the study design and, together with R.S. and F.S.J., formed the core methodological team. J.P.V. conducted the searches and oversaw the methodology of the scoping review. The remaining authors participated as reviewers during the various stages of the scoping review, including title and abstract screening, full-text review, and data charting. R.S. drafted the manuscript, and all authors provided feedback on successive versions and approved the final manuscript.

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Data Availability No datasets were generated or analysed during the current study.

Declarations

Competing interests The authors declare no competing interests.

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