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Ethical Principles in European National Dementia Strategies: A Framework Analysis

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ABSTRACT

The prevalence of dementia is rising rapidly across the European Union, necessitating comprehensive national and international responses. National Dementia Strategies serve as key policy instruments, outlining priorities for dementia care across European countries. While numerous organizations have proposed ethical principles to guide dementia policy, limited knowledge exists on ethical priorities in EU dementia policies. This study examines the ethical principles embedded in European national dementia atrategies, analyzing their definitions, contexts of application, and relative emphasis. Using framework analysis, this study systematically analyzed 17 European national dementia atrategies, identifying commonalities and variations in ethical priorities. Findings reveal a broad spectrum of ethical principles present across national dementia strategies throughout the EU. However, findings also suggest significant variations in how principles are interpreted.

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Introduction

The prevalence of dementia is steadily increasing across Europe and globally. According to the World Health Organization (WHO), an estimated 55.2 million people were living with dementia in 2018, a figure projected to rise to 152.8 million by 2050 (Nichols et al., 2022; WHO, 2018b). In Europe, Alzheimer Europe estimates a similar trajectory, with nearly 19 million people expected to live with dementia by mid-century (Alzheimer Europe, 2019).

Most notably, WHO has emphasized the need for coordinated, multisectoral strategies to meet this challenge, highlighting the development of policies, strategies, and cohesive dementia programs as essential components of an effective response (WHO, 2018a, 2021). The WHO's *Global Action Plan on the Public Health Response to Dementia 2017–2025*, which has been extended to 2031, calls for national dementia strategies (NDSs) that are not only effective but also ethically grounded—encompassing human rights and dignity and emphasizing that policies, plans, and actions should be sensitive to the needs and human rights of people with dementia and align with the *Convention on the Rights of Persons with Disabilities* (WHO, 2017).

In parallel, the Glasgow Declaration, launched by Alzheimer Europe in 2014, urges all European governments to develop comprehensive NDSs to help ensure protection of rights of people living with dementia as well as preservation of their dignity and autonomy (Alzheimer Europe, 2021b). NDSs —defined by the WHO as a "*written organized set of principles, objectives or actions for reducing the burden attributable to dementia in a population in a stand-alone, dementia-specific document*."—serve as key policy instruments in this effort (WHO, 2018b).

Across Europe, an increasing number of countries have adopted NDSs to address the needs of people living with dementia and their caregivers through structured policy initiatives (Alzheimer Europe, 2018, 2024).

At the heart of these strategies lies a set of ethical priorities. Ethical principles—in the authors' view broadly defined as generic normative claims about what ought to be done—include formal ethical concepts such as dignity, autonomy, justice, and beneficence, as well as related notions such as human rights, entitlements, and obligations. These principles are not merely abstract ideals; they provide actionable guidance for organizing care, identifying which rights to uphold, and determining how services should respond to the needs of people living with dementia. Grounding dementia strategies in ethical principles is therefore not only a matter of normative coherence but also essential to ensuring that strategies support people with dementia and their caregivers in living well across the care continuum.

Various organizations and academic bodies have developed ethical frameworks and care recommendations specifying an array of such principles, including Alzheimer Europe (Alzheimer Europe, 2017, 2021a; Gove et al.,

2021), Alzheimer's Disease International (Pot & Petrea, 2013), and national Alzheimer associations (Fazio, Pace, Flinner, et al., 2018; Fazio, Pace, Maslow, et al., 2018). Moreover, academic contributions such as the Nuffield Council on Bioethics (2009), The American Academy of Neurology (Chiong et al., 2021), and recent European initiatives like the COST Action "Ethics in Dementia" have further emphasized the importance of embedding ethical principles—such as autonomy, solidarity, dignity, andrecognizing personhood—as foundational to organizing and delivering dementia care.

However, while many of these documents offer high-level guidance, they are not binding, and it is unclear how—or whether—these ethical principles are concretely adopted at the national policy level as well as how they are defined and applied across different national contexts. Despite growing emphasis on the ethical foundations of dementia policy, there is currently no comprehensive overview of how such principles are articulated or prioritized within NDSs in Europe.

This study addresses this gap by systematically examining 17 European NDSs. It aims to identify whether and how ethical principles are included, how they are defined, in which domains (e.g., care, policy, research) they are applied, and the degree to which they are emphasized. In doing so, the study contributes to a better understanding of the ethical landscape underpinning dementia policy in Europe and offers insights for future strategy development and evaluation.

Methods

In this study, we employed framework analysis to comprehensively examine the ethical principles present in European NDSs. Framework analysis is a structured method of qualitative data analysis that enables researchers to consistently apply a coding template across large datasets (Goldsmith, 2021). This structured approach enabled us to identify predefined ethical principles within the NDSs while also allowing for the emergence of new principles through the analytical process. To ensure transparency and rigor, we adhered to the Standards for Reporting Qualitative Research (SQSR) as indexed by the EQUATOR network (O'Brien et al., 2014).

Data collection

This study used European NDSs as the primary data source. To ensure consistency, the eligibility criteria for data inclusion were as follows:

(1) Only published NDSs were included, excluding drafts or policy discussions.
(2) NDSs had to possess formal policy authority. In accordance with the Global Dementia Observatory (GDO) Reference Guide's criteria for public policy, they must have been "*approved/published by the Ministry of Health (or equivalent) or parliament*" in the country of publication (WHO, 2018b).
(3) Only NDSs from countries within the European Union were included.
(4) If multiple NDSs existed for a single country, only the most recent version was considered.

The NDSs were retrieved using Alzheimer Europe's Index of NDSs (Alzheimer Europe, 2024) as a primary data repository. This index provides comprehensive country profiles, offering links to each NDS, which were retrieved for analysis. Alzheimer Europe also maintains records of past strategies for countries without active plans and tracks which nations lack NDSs altogether, highlighting recent national developments. For a full overview of the analyzed NDSs, refer to Table 1.

The analysis of each specific NDS first verified that the respective strategy was the most up-to-date version before inclusion. In addition, to ensure retrieval of all relevant EU strategies, author [KP] conducted targeted searches of relevant government health ministries to identify any strategy not yet listed in Alzheimer Europe's Index, particularly in cases where recent developments had been noted, especially within the past year. Strategies available in officially translated English were included in their translated form; however, given that many of the NDSs were not available in English, the involvement of native speakers enabled the analysis of these documents in their original language, ensuring accuracy. Data werecollected between March and May 2024.

Table 1. National Dementia Strategies Analyzed.

Country	Reference number	Year
Austria	[1]	2019
Belgium (Flanders)	[2]	2021
Belgium (Wallonia)	[3]	2010
Cyprus	[4]	2012
Czech Republic	[5]	2020
Denmark	[6]	2017
Finland	[7]	2013
France	[8]	2014
Germany	[9]	2019
Greece	[10]	2015
Ireland	[11]	2014
Italy	[12]	2014
Malta	[13]	2024
Netherlands	[14]	2021
Portugal	[15]	2018
Spain	[16]	2019
Sweden	[17]	2018

Data analysis

The coding and analysis of all NDSs followed a standardized analytical framework, which also served as a shared reporting template among analysts. This approach was chosen for its effectiveness in ensuring consistency and coherence when multiple analysts collaborate on data analysis, while allowing for the charting of both deductively defined principles and emerging principles within the NDSs. The analytical process adhered to the five stages of framework analysis: data familiarization, thematic framework identification, indexing, charting, and mapping and interpretation (Goldsmith, 2021). The analytical team consisted of 22 researchers from EU member states, bringing together expertise in public health, bioethics, psychology, psychiatry, gerontology, philosophy, and dementia care. Contributors included both senior and early-career researchers, with roles ranging from professors and associate professors to PhD students.

Framework development

The framework was developed collaboratively by authors [FS-J], [RSe], [CH], and [SL], and included descriptive domains including country, publication date, strategy activity, and relevant ethical principles. Through multiple iterations of applying the framework, it was progressively refined. To facilitate data familiarization and inform the identification and development of the analytical framework, an initial coding of a subset of NDSs was conducted. This process was supplemented by a review of relevant literature to identify the relevant ethical principles for inclusion in the framework. [FS-J] and [RSe] conducted this initial coding for two strategies, following Braun and Clarke's thematic analysis approach (Braun & Clarke, 2021). Ethical principles were coded based on individual words, phrases, or paragraphs conveying relevant principles. To enable a comprehensive and broad investigation of ethical principles in European NDSs, these principles were defined broadly as generic normative claims, encompassing values, obligations, entitlements, and more.

A set of preidentified principles were drawn from sources including Beauchamp and Childress's biomedical ethics (Beauchamp & Childress, 2001), the Universal Declaration of Human Rights (UN, 1948), and the American Nurses Association Code of Ethics (American Nurses Association, 2015). These sources were selected for their comprehensive coverage of core ethical principles and their widespread recognition in the field of bioethics.

To ensure the framework's relevance to dementia care, additional documents were also reviewed, including the Nuffield Council on Bioethics' report on dementia (Nuffield Council on Bioethics, 2009) and the American Academy of Neurology's position statement on ethical considerations in dementia diagnosis and care (Chiong et al., 2021).

[FS-J] and [RSe] then grouped thematically adjacent principles under overarching themes to minimize confusion in subsequent analysis. For example, principles such as self-determination, autonomy, and decision-making influence were categorized under a unified theme. Subsequently, the framework was applied to two randomly selected strategies in English by [FS-J], [RSe], and an additional analyst [CH], with codes compared in parallel to ensure consistency and intuitive use.

During the iterative application of the framework, several principles—such as *Holistic and Synergetic Approach to Care*, *Evidence-based Practice and Care*, and *High-Quality Training*—emerged inductively from the data. These were not part of the preidentified set drawn from foundational sources but were included due to their recurrent emphasis across the NDSs.

Data coding and interpretation

The framework was then systematically applied to all included NDSs by [FS-J], [RSe], [YIU], [SL], [NK-Y], [RSi], [TBr], [CP], [VC], [CH], [JA], [BG], [LJ], [RB] [DS], [RO] and [TBi], while also allowing the analyst to inductively identify other principles not present in the framework.

Before applying the framework, an instructional exercise was conducted to ensure uniform application of the framework and familiarity with it. Two follow-up meetings were held in April and May 2024 to enhance coding reliability and address any uncertainties regarding the framework's application. Given that each dementia strategy was analyzed by a single analyst, these meetings also served as a means to mitigate the risk of subjective interpretation by ensuring consistency in coding through structured onboarding and collaborative discussions. For instance, the issue of double coding of principles was discussed, and it was agreed that paragraphs expressing multiple principles should be coded under all relevant principles without forcing a choice among them. Data indexing and subsequent charting of the respective strategies were conducted using various analysis software, including NVivo and MAXDA, with results reported in Microsoft Excel for synthesis and comparison across all data. Each analyst provided a qualitative analysis of each identified ethical principle within the strategy, including the text excerpts where the principle appeared in the NDS, and indicating whether it was used implicitly or explicitly. This ensured that the second phase of analysis was grounded in primary data rather than solely relying on the coder's interpretation. Furthermore, the intensity of each principle was assessed (• = low intensity, •• medium intensity, ••• high intensity), as recommended by Goldsmith (2021).

The second phase of mapping and interpreting principles across NDSs involved synthesizing principles identified within the strategies to discern commonalities, variations, and emerging themes throughout the European

NDSs. This phase was performed by [FS-J], [RSe], [JR], [IH], [RO], [GJ-F], [RB], [DS], [CH], [LÖ] and [CP].

A third validation phase of the coded data was conducted by [FS-J], [RSe], [SL], and [CP] to ensure uniform interpretation of ethical principles across all analyses of the respective strategies and address any potential discrepancies in interpretation. Particular attention was given to principles that appeared infrequently within the strategies, ensuring that no principle was misrepresented or falsely attributed where it was absent.

Results

The analysis of European NDSs revealed a broad range of ethical principles across the strategies. While many countries shared common goals in their strategies and emphasized similar principles like person-centered care, dignity, and autonomy for people with dementia, they differed in how they interpreted and emphasized these principles.

Additionally, the intensity with which these principles were advocated differed markedly (see Table 2 for an assessment of the intensity of each principle within the strategies). Person-centeredness and individuality, along with other principles like inclusive and adapted living environments or destigmatization, emerged consistently across the European NDSs, with high-intensity ratings (•••) in several countries, reflecting a strong commitment to individual rights and tailored care. Dignity and beneficence were also frequently prioritized, though with moderate to high intensity (•• to •••), underscoring efforts to maintain respect and well-being in dementia care.

However, principles such as privacy, fidelity, and veracity were generally less emphasized, with low to moderate intensity (• to ••) or being absent altogether in some strategies. This variation suggests that while core ethical principles are comprehensively acknowledged, other principles receive differing attention depending on national priorities and policy structures. Table 2 illustrates these distinctions, providing a comparative view, where ethical principles are listed in descending order based on their presence across national strategies and overall intensity to aid interpretation.

The following sections outline the most prevalent ethical principles identified in the strategies, providing insight into common themes and their application variations. Differences emerged not only in the principles emphasized but also in the specific contexts—such as care, policy, or public awareness—where these principles were applied. These sections will explore these nuances, highlighting the ethical foundations that shape national approaches to dementia care across Europe.

Table 2. Intensity of Ethical Principles in European National Dementia Strategies.

Ethical Principles	Austria	Belgium - Flanders	Belgium - Wallonia	Cyprus	Czech Republic	Denmark	Finland	France	Germany	Greece	Ireland	Italy	Malta	Netherlands	Portugal	Spain	Sweden
Person-Centeredness and Individuality	•••	•••	•••	•	••	•••	••	••	••	•	•••	••	•••	••	•••	••	•
Inclusive and Adapted Living Environments	••	•••	•	•	••	•••	•••	••	•••	•	••	•	••	•	••	•••	••
De-stigmatization	•••	•••	••	••	•	•	•	••	••	••	•••	•••	•	•	•	••	•
Beneficence and Care	•••	•••	•	••	•••	•	•••	••	Ø	••	•••	•••	•••	•	•••	•••	••
Autonomy/Self-Determination	••	•••	Ø	•	•	••	•	•••	•	•	•••	••	•••	•	•	•••	•
Social Engagement, Meaningful Activities, and Experiences	••	•••	•	•	•	•••	••	••	•	Ø	••	••	••	••	•	••	••
Holistic and Synergetic Approach to Care	Ø	••	••	••	•	Ø	•••	•••	••	••	•••	•••	••	••	•••	•••	•
Evidence-based Practice and Care	Ø	•••	••	••	•	Ø	•••	•	•	••	••	•••	•••	•	•••	••	•
Justice/Equity/Fairness	•	•	Ø	••	••	•	••	••	Ø	•••	••	•	•••	Ø	••	•••	••
Nonmaleficence	••	••	Ø	•	•••	••	Ø	•	•	•	•	•	••	Ø	••	••	•
Dignity	•	•	Ø	•	•	•••	••	•	•	Ø	••	•	•••	•	•	••	Ø
Non-Discrimination	•	•	Ø	••	•	Ø	Ø	•	•	Ø	•	•	•	•	•	••	•
High-Quality Training	Ø	•••	•	•	••	Ø	Ø	•••	••	Ø	•••	••	Ø	•	••	Ø	Ø
Political and Democratic Participation	••	Ø	Ø	•	Ø	Ø	Ø	•	••	Ø	•••	•	•	•	•	••	Ø
Confidentiality	•	Ø	Ø	•	•	Ø	Ø	•	•	•	Ø	Ø	Ø	Ø	Ø	Ø	Ø
Privacy	Ø	Ø	Ø	Ø	•	Ø	Ø	•	Ø	•	Ø	Ø	Ø	Ø	Ø	Ø	Ø
Veracity/Truthfulness	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	•	Ø
Fidelity/Loyalty	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø
Possession of Things and Property	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø	Ø

Legend:
••• indicates high intensity
•• indicates medium intensity
• indicates low intensity
Ø indicates that the principle was not identified

Person-centeredness and individuality

All strategies included the approach of person-centeredness and individuality, though to varying degrees [1–17]. This was defined as recognizing and promoting each person's unique "*specific individual resources and potential*" [1] and "*individualisation in care*" [4, 5, 14]. Malta's strategy described a person-centered approach that "*respected and responded to the preferences, needs, and values of those receiving care*" [13]. In Austria, individuality was emphasized through a focus on strengthening knowledge and competence as well as person-centered concepts in interaction and communication [1]. The Irish strategy highlighted "*taking an individualized and person-centered approach*" [11], a focus that was similarly emphasized in Italy [12]. Finland stressed case management based on a "*comprehensive and careful assessment of each patient's personal circumstances*" [7], while France promoted a "*truly personalized health program that respected their life plan and their choices*" [8].

This principle was relevant across different contexts, with care being the most frequently mentioned [13–17], described as "*individualized interventions*" and "*personalized support*" [12]. In the Czech Republic, this principle extended to education, particularly in the context of individualization for young people [5]. Portugal operationalized this principle through "*Diverse Contexts, Principles of Care, Needs and Preferences, Individualized Care Plans (ICP), and Person-Centered Care*" [15].

Inclusive and adaptive environment

Generally, the principle of inclusive and adaptive living environments in NDSs was both prevalent and significant, focusing on supporting people with dementia to create environments where their dignity was preserved [13, 16], promoting inclusion in society [1, 13, 16], autonomy [8, 9, 16], participation in society [1, 2, 9, 13, 14, 16, 17], quality of life [13, 16, 17], and independence [8, 17]. This principle was viewed from multiple perspectives, including the provision of suitable living conditions and housing [11, 6, 8, 10, 13–15], the possibility of remaining in one's natural environment or community [1, 3, 5, 13], and the removal of barriers, promotion of safety, and adaptation of environments to serve all citizens [1, 13], particularly those living with dementia [1, 6, 8, 9, 12–14]. It was also seen as supporting carers of people with dementia [5, 10, 13, 16]. The application of this principle was further linked to the use of new technologies that helped people with dementia benefit from inclusive and adapted living environments [6, 8, 12], as well as the availability of services [2, 7, 9, 12, 16, 17].

Destigmatization and nondiscrimination

Across European NDSs, nondiscrimination and destigmatization were an integral theme, though with varying emphasis. Some strategies placed these principles at the center, with clear guidelines for public campaigns and healthcare policies [9, 14, 16], while others approached them more indirectly, focusing on inclusion and person-centered care without explicitly naming them [6, 7]. Nondiscrimination, present in most strategies [1, 2, 4, 5, 8, 9, 11–17], was typically framed around ensuring equal access to healthcare, diagnosis, and services, regardless of race, age, gender, or socioeconomic status. Many strategies emphasized equitable access for marginalized groups, including minorities, the homeless, and people with disabilities [1, 4, 8, 9, 13], while others implied the principle through broader commitments to equality in care, such as culturally appropriate services and full participation for people with dementia [11, 12, 16].

Destigmatization was addressed in all strategies, focusing on reducing stereotypes and misconceptions [1–17]. The "Forget Dementia, Remember Person" campaign highlighted public awareness and media outreach as key tools for challenging stigma [2], with similar efforts seen in other countries to promote empathy and transform societal attitudes [4, 12, 16]. Access to healthcare and professional training also aligned with these goals, incorporating anti-stigma training programs [5, 8, 9]. While public awareness was a common strategy, its scope varied: Some strategies emphasized responsible media portrayals and dementia-friendly communities [1], while Spain and Portugal focused on broader educational efforts [15, 16]. Others, like Cyprus, recognized the need to address stigma but lacked concrete actions, reflecting the challenge of translating principles into practice [4].

Beneficence, care, and non-maleficence

The principle of beneficence was central in most EU dementia strategies [1–8, 10–17]. It was typically defined as prioritizing the well-being and quality of care for people with dementia, with an emphasis on high-quality, person-centered care and service improvement [1, 2, 5, 14, 15]. Early diagnosis and treatment were noted for their benefits to individuals and society [4, 6, 7, 15]. Support for caregivers was common, either through education and resources [2, 5, 12, 14] or community-based care [2, 5]. Several strategies emphasized continuity of care and care coordination [5, 11, 12, 15]. Some focused on social inclusion and community involvement [2, 14, 17], while others stressed improving care standards and long-term care provision [1, 5, 15].

The principle of non-maleficence was also widely featured in EU dementia strategies [1–2, 5–6, 8, 10–13, 15, 17]. It focused on safeguarding against harm, ensuring safe environments, and avoiding inappropriate medications [1, 5, 8,

12, 17]. Many strategies emphasized preventing physical and chemical restraints [2, 10, 11, 17] and minimizing risks through caregiver education [1, 15]. Protection from abuse and reducing caregiver burden were also key priorities [1, 5, 9, 10, 16, 17], with some strategies focusing on managing behavioral issues to prevent harm [1, 2, 12, 15].

Autonomy

The notion of autonomy was a prominent ethical principle in NDSs throughout the EU [1, 4–13, 15–17]. In some strategies, autonomy was explicitly defined as the right of people with dementia to independently make decisions about their own lives [7] or as the capacity of individuals to decide for themselves [8]. Autonomy was also interpreted as involving people with dementia in decision-making and respecting their wishes and preferences [11, 13, 16] or defending individual freedom of choice and self-interest [4]. Some strategies promoted autonomy through advance directives or care planning [1, 11, 12]. Independence was another expression of autonomy [1, 6–8, 13, 15–17], as exemplified by France's strategy, which highlighted the need to "*preserve as much as possible their ability to decide and do things independently*" [8]. Several strategies regarded autonomy and its alternatives as a right [7, 9, 10, 12, 15], noting that "*people with dementia have a right to self-determination*" [9], or the right to make their own choices and decisions regarding their actions and movements [15]. The German strategy emphasized that it was "*the responsibility of all society to support people with dementia in leading a life of self-determination*" [9].

Social engagement, meaningful activities, and experiences

The concept of social engagement was included in all but one of the national strategies [10]. However, the emphasis on this principle varied significantly, with some strategies highlighting it extensively [2, 6], while others mentioned it only marginally [3–5, 9, 15]. Social engagement was broadly defined as the participation of people with dementia in meaningful relationships, social activities, and everyday community and neighborhood life, aiming to promote their quality of life and well-being [1, 2, 6, 7, 12, 16]. It was often discussed in the context of addressing social exclusion and ensuring that " ... *despite existing impairments, the participation of people with dementia in social processes was guaranteed as much as possible*" [1]. In this context, social engagement was sometimes linked to broader policy initiatives, such as the UN Convention on the Rights of Persons with Disabilities [1] and the promotion of Dementia-Friendly Environments [2, 9, 13]. For example, Austria's strategy stated that, " ... *disabilities arose from the interaction between people with*

disabilities and barriers in the form of attitudes and the physical environment. These barriers could obstruct full, effective, and equal participation in society. Breaking down these barriers was also one of the goals of the dementia strategy" [1].

Holistic and synergetic approach

Almost all dementia strategies in the EU included the ethical principle emphasizing the importance of a holistic and synergistic approach to care [2–5, 7–17]. Most strategies addressed this approach as an emerging need that did not yet exist, as Cyprus stated: "*What was lacking today was the holistic approach to the problem*" [4]. This principle was primarily described as the need for a collaborative approach involving different stakeholders (from the public, private, social, and voluntary sectors) across various domains. Cooperation, integration, and shared responsibilities were key themes [5, 9, 13]. Although diverse, this principle was associated with diagnosis, care, education, treatment, research, and policy, considering the complexity of the issue and the varying needs of patients and caregivers [12, 13]. It was a prominent theme in the strategies, though some provided only a general vision of how this approach should be implemented, such as Wallonia in Belgium [3], while others, including Cyprus and Portugal, detailed the responsibilities of the agencies involved at this level [4, 7, 12, 13].

Evidence-based practice and care and high-quality training

The principle of evidence-based quality care was defined as the integration of scientific research and empirical data into care, emphasizing continuous education and training for healthcare professionals. Countries such as Belgium emphasized "*evidence-based prevention measures (. . .) appropriate in preventing dementia*" [2], while Finland highlighted the need for "*more research regarding psychosocial support and technology*" [7]. In Germany, the focus was on developing "*research-based interventions with proven benefits*" [9]. This principle was applied in various contexts, including care [2, 13], diagnostics [11, 12], education [7, 15], and public awareness [16, 2]. Common themes included reliance on up-to-date research for care decisions and continuous training for professionals. Some countries, including Germany and Ireland, emphasized integrating research into policy frameworks, while others, including Finland and Portugal, focused on professional education. While the principle was more implicit or only mentioned in passing in some countries [1, 3, 4], it was somewhat prominent in others [9, 11] and central in still others [2, 15, 13].

Justice, equity, and fair distribution

The ethical principle of justice, equity, and fair distribution appeared in almost all NDSs [1, 2, 4–13, 15–17]. Central aspects included "*equal distribution of resources*" and "*equal access to services*" [1–2, 8, 10–12, 15–17], ensuring nondiscriminative care for individuals with dementia, regardless of location, gender, socioeconomic status, or age. For example, the strategy from Cyprus advocated for "*equal access to diagnostic tests, treatment, medication and care, away from gender, age, race, occupation, origin, and income discrimination*" [4]. Providing "*equal opportunities*" was also emphasized to ensure that all individuals with dementia could access services and participate in society [1, 9, 11, 16]. Some strategies addressed human rights [7, 13, 16], such as the Finnish strategy, which mandated that authorities ensure "*the basic rights and liberties of people with dementia and their families*" [7]. Gender rights [5], gender equality [5, 17], and legal rights [7] were also included to ensure that dementia care aligned with legal protections and addressed gender-specific needs.

The principle of justice, equity, and fair distribution spans various societal domains, including healthcare, social services, and education. It encouraged cross-sectoral collaboration [4, 13], raised awareness [13, 16], educated professionals [5, 10, 16], and promoted the creation of dementia-friendly environments [2, 6, 11]. The principle was integral to policy and legislative initiatives [4, 11, 13, 16].

Dignity

The notion of dignity was emphasized in the vast majority of EU strategies [1–2, 4–9, 11–16]. In some strategies, dignity was mentioned briefly [2, 4–5, 7–9, 11–12, 14–15], while others provided a more detailed focus on it [6, 13, 16]. Denmark's strategy highlighted dignity as one of the most central ethical principles: "*People with dementia should be able to live a safe and dignified life —regardless of where they are in the disease course and whether they are in their own home or in a care center*" [6]. Some other strategies explicitly mentioned dignity, but it was not always clear how this principle would be implemented concretely [2, 9]. The Czech Republic, for example, described a project called the Institute of Dignified Ageing, which aimed to ensure that "*people living with dementia were protected against the abuse of the consequences of their deteriorating health by others and against threats to their human dignity*" [5].

In Ireland's strategy, dignity was expressed as a key element of personhood and citizenship: The strategy sought "*to progress the dual and overarching principles of personhood and citizenship by enabling people with dementia to maintain their identity, resilience, and dignity, and by recognizing that they remained valued, independent citizens*" [11]. Some strategies included text about the importance of appreciation and respect for everyone, regardless of

disability, but did not explicitly mention the word dignity [1, 8]. Finland's strategy emphasized the importance of both society and care staff having knowledge about dementia to ensure that people with dementia were treated with dignity [7]. Dignity was further described alongside the right to autonomy, respect, and equality, as well as the importance of creating a dementia-friendly society [12–16].

Other principles

The principle of political and democratic participation was referred to, with varying relevance, in more than half of the strategies [1, 4, 8, 9, 11–13, 14–16]. In the Irish NDS, this principle was implemented from the outset during the drafting of the strategy, which involved the Alzheimer's Society of Ireland [11]. The notion of citizenship appeared, with different emphasis, in a few NDSs [8, 11, 16], signifying that people with dementia "*remained valued, independent citizens*" [11] and should "*participate in the community as active citizens with full rights*" [16]. Misconceptions about dementia and stigma were seen as barriers [1, 16] to achieving "*full, effective, and equal participation in society*" [1]. Participation was also understood as the opportunity to be heard [14], to take part in voluntary organizations [4], and to be involved alongside family and associations [12], as well as to contribute from the unique perspective of people with dementia to health-related processes and plans [9, 13].

Although not central principles, some strategies also referred to confidentiality [1, 4, 5, 8–10] and privacy [5, 8, 10]. Confidentiality, understood as the protection of personal data, was mentioned concerning the availability and accessibility of personal data [1] and the sharing of data among professionals while maintaining secrecy [8]. The protection of personal data was also referenced specifically regarding its use in research [5, 9]. Privacy was highlighted in affirming the rights of people with dementia to "*physical integrity*," "*private and family life*," and to "*be left alone*" [10]. Privacy was also discussed in the context of providing home care for people with dementia, respecting their "*private life and intimacy*" and guaranteeing "*the privacy of their living space*" [8].

The principle of veracity or truthfulness toward the person with dementia was mentioned only in the Spanish strategy [16], which considered communicating the diagnosis to the person who wished to know the first step in respecting autonomy. Finally, no strategy referred to the principles of fidelity/loyalty or possession of things and property.

Discussion

The aim of this study was to explore the ethical principles highlighted in European NDSs, examining how these principles are defined and applied in

various contexts, including care, diagnostics, education, public awareness, policy, and research. Additionally, the study assessed the prominence of these principles, evaluating whether they hold a central role or are mentioned peripherally. Finally, the study investigated variations in emphasis across national strategies. The analysis revealed a broad range of ethical principles present across the NDSs. However, significant variations existed in how principles were interpreted and emphasized. There seemed to be more focus on overall goals for dementia care, while they fall short in specifying how these goals are to be achieved.

Ethical variability in European dementia strategies

The analysis of European NDSs revealed widely shared commitments to ethical principles, including promoting person-centered care and ensuring inclusive and adapted living environments, as well as dignity and autonomy for people with dementia. The prominence of these principles across the NDSs may, in part, reflect a long-standing effort to challenge earlier paradigms in dementia care, which often equated a diagnosis with diminished capacity and legitimized paternalistic approaches. Emphasizing these principles represents a shift toward recognizing people with dementia as active agents whose preferences and rights should be upheld and may also reflect greater attention to enabling conditions that allow them to live with dignity and retain autonomy for as long as possible.

However, significant variations were observed in how these principles were interpreted, and the intensity with which these principles were advocated also differed markedly among countries. While some countries (e.g., France, Cyprus, or the Czech Republic) addressed a broad range of ethical principles in their NDSs but discussed them only briefly, others (e.g., Belgium [Flanders] and Malta) included fewer principles but engaged with them in greater depth. Determining whether future NDSs should prioritize breadth—by covering a wide array of ethical principles—or depth—by focusing on fewer principles with more comprehensive discussion—goes beyond what can be concluded from the findings of this study. However, the variation observed highlights an important tension that warrants further exploration. In any case, these differences may likely arise from cultural, political, and economic diversity, highlighting a potential key challenge: the lack of a standardized ethical framework to guide dementia care across the EU. This is also highlighted in other studies that, through interviews with professional experts, have compared dementia-specific services and care structures across 17 European countries, revealing significant differences among them (Schmachtenberg et al., 2022). Here, the authors reflected upon the need of transnational strategies for establishing quality-related minimum standards in dementia care across European countries (Schmachtenberg et al., 2022).

While the findings did reveal a variability in respect to ethical principles highlighted, person-centered care emerged as a widely endorsed principle across the NDSs. One reason for this can be that person-centered care in itself includes several ethical values. For instance, a literature review identified 17 components of person-centered care with holistic care, respect and value, choice, dignity, self-determination, and purposeful living being most dominant (Kogan et al., 2016). Despite this, concrete steps seem to be lacking to operationalize this principle, which is also emphasized in studies on its operationalization in real-world settings (Fridberg et al., 2022). For instance, while person-centered care emphasizes tailoring support to individual needs, preferences, and values, most NDSs focus on standardized policies yet fall short of providing specific tools, training, or protocols to translate these principles into practice.

In fact, the current NDSs arguably tend to prioritize a system-world perspective, focusing on standardized processes, policies, and measurable outcomes (Habermas, 1987), over the lifeworld perspective, encompassing subjective and relational experiences of individuals with dementia and their families. While a system-world perspective is essential for structuring policies, its dominance can overshadow person-centeredness, which relies on understanding and responding to the lived experiences of individuals within their unique social and relational contexts. In addition, although explicit implementation measures may help promote certain aspects of person-centeredness in dementia care and prevent it from remaining an abstract ideal, they may also, in some cases, restrict the lifeworld perspective in specific care settings. Achieving a balance between these perspectives is essential to ensure that ethical principles are not only acknowledged at a policy level but are meaningfully integrated into everyday care practices.

Many NDSs, for example, aim for broad inclusivity by adopting guidelines for "all people." While well intentioned, this approach often conflicts with the core of person-centeredness, which requires individualized consideration (Kitwood, 1997). While a strategy must address populations on a scale, it can still embed mechanisms that adapt high-level objectives into personalized care plans. This could include creating adaptable frameworks that empower local practitioners to customize care based on individual circumstances, thereby bridging the gap between universal guidelines and individual application. However, this is potentially further complicated by the division of responsibilities among local, regional, and national entities. With most responsibilities delegated to regional bodies and no overarching plan or strategy to guide the system, regional teams often lack the authority or resources needed to act effectively (Boeree et al., 2021).

Limitations

Certain limitations of this study should be acknowledged, as they may affect its trustworthiness. First, the study is based on NDSs from multiple EU countries. While acknowledging similarities and differences between countries is crucial for learning from one another and improving the quality of life for people with dementia, it also presents challenges. For instance, there are significant differences across nations in healthcare structures, sociocultural factors, and economic and political contexts, making cross-country analysis inherently complex.

Moreover, the results may carry some bias due to the involvement of multiple researchers with diverse backgrounds and experiences from different disciplines. While this diversity enriched the study by incorporating varied perspectives, it also posed challenges for ensuring consistency during analysis. To address this, several measures were implemented to enhance coding reliability throughout the study. During framework development, researchers conducted parallel coding exercises to align their approaches. Analysts also participated in introductory sessions designed to train them in applying the framework consistently, and regular follow-up meetings were held to resolve any discrepancies or uncertainties in framework application. By using framework analysis—a structured content analysis method—we ensured that all researchers applied consistent analytical approaches when exploring ethical principles in NDSs.

While most EU strategies were analyzed in their original languages by our multilingual team or in officially translated versions, a limitation of this study was our inability to include all EU NDSs. Specifically, Slovenia's strategy was excluded, as it was the only case for which we could not assign a native-speaking analyst. Nonetheless, involving researchers from different countries enabled us to include nearly all available national strategies within the EU without the need for translation. This represents a key strength of the study, as working with native-speaking analysts minimized the risk of misinterpretation and helped preserve the nuanced meanings of ethical principles, particularly where they were expressed implicitly.

Conversely, identifying implicit content—such as ethical principles not explicitly stated—still poses inherent challenges, which we acknowledge as a potential limitation. While using a predefined framework helps mitigate this limitation by guiding analysts toward potentially relevant principles, it also carries the risk of excluding data that do not fit neatly within its structure. To address this, we introduced an "other" category, enabling analysts to capture principles not explicitly covered by the framework and ensuring that all relevant data were utilized in alignment with the study's aims. Consequently, the developed framework used in the analysis allowed us to incorporate both pre-identified ethical principles and emergent principles identified in the data.

Finally, the study did not impose a strict time frame for included strategies, meaning that older strategies were analyzed alongside more recent ones. While the inclusion of older strategies might raise concerns about their contemporary political and practical relevance, excluding them could risk overlooking valuable insights from still-relevant strategies specific to individual countries. Despite these limitations, the study provides a comprehensive and systematic examination of ethical principles in European NDSs, offering valuable insights into the ethical foundations guiding dementia policy across the region.

Conclusion

This study provides a comprehensive analysis of the ethical principles embedded in European NDSs, highlighting both commonalities and significant variations across countries. While principles such as person-centered care, dignity, and autonomy are widely emphasized, their interpretation and implementation differ considerably. These variations point to an ethical discrepancy in how dementia strategies are structured across European NDSs. However, the underlying reasons for these differences remain unclear: Are they primarily shaped by cultural values, healthcare system structures, or economic constraints? Understanding these influencing factors is essential, as they have direct implications for the quality of life, rights, and care experiences of people with dementia. Further research is needed to explore these dynamics and assess the ethical priorities in dementia care across Europe.

At the same time, there is reason to be optimistic about future policy developments. The recent extension of the WHO Global Action Plan on the Public Health Response to Dementia through 2031 reinforces the global commitment to a human rights–based approach to dementia care. This updated timeline may encourage European countries to revise or develop new NDSs that are more firmly grounded in ethical and rights-based principles, offering an important opportunity to address current disparities and promote more equitable dementia policies.

Key points

- Ethical principles are defined and applied differently across EU dementia strategies.
- Person-centered care and inclusive living environments are key priorities.
- Dignity and autonomy are consistently highlighted as important.
- Alignment could enhance care quality and coherence across Europe.

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AI statement

AI-based tools were used for language enhancement. Specifically, QuillBot (https://quillbot.com/) and ChatGPT 3.5 and 4.0 were employed to improve the English language in certain sections. The use of AI did not influence the conceptual development, data analysis, or interpretation of results.

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