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Regular Article

Exploring advance care planning discourses in scottish dementia policies: A critical discourse analysis

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A B S T R A C T

Advance Care Planning (ACP) is a continuous process that enables individuals to discuss and document their preferences for future care in the event of terminal illness or incapacitation. In Scotland, the creation of ACPs is encouraged and integrated into current dementia policies as a means of safeguarding the human rights of people living with dementia (PwD). However, the uptake of ACP amongst PwD remains low, potentially due to PwD's fluctuating mental capacity and symptoms of forgetfulness. Moreover, the ACP process, which is typically aimed at healthcare professionals (HCPs), may not be suitable for PwD due to the lack of appropriate support they might need to fully engage with the ACP process which includes meaningful conversations, documentation and regular review.

This study employed Fairclough's Critical Discourse Analysis to explore how the discourses in Scottish dementia policies influence the initiation and revision of ACP for PwD. It examined how the voices of PwD, family carers, and HCPs shaped dementia policies regarding the initiation and revision of ACP.

Three discourses were identified: Shifting Agencies, Formulaic Rightness, and Visibility and Voices. The analysis revealed that dementia policies inadequately supported the initiation and revision of ACPs for PwD. This is attributed to the responsibility for initiating ACPs being variously ascribed to different stakeholders, creating ambiguity regarding process ownership. The ACP process is presented in policy as formulaic, ignoring the nuances of PwD's circumstances. The input and participation of PwD, family carers, and HCPs in policy related to ACPs was less visible, thus calling into question the legitimacy of those policies.

In light of these findings, the person(s) responsible for supporting the ACP process with and for PwD should be made explicit. The notion of ACP revision, which aims to reflect PwD's changing needs, warrants greater emphasis within these dementia policies.

1. Introduction

Approximately 50 million people worldwide are living with dementia, and this number is expected to rise to around 152 million by 2050 due to increasing life expectancy (Döpp et al., 2021). This trend is similar in the UK, where over one million people are projected to have dementia by 2025, doubling by 2050 (Alzheimer's Research UK, 2021).

Given that dementia is incurable, dementia policies mainly aim to ensure that people living with dementia (PwD) can live independently within the community as long as possible, with appropriate support for their daily activities (NHS, 2021). This is paralleled by strategies for healthcare professionals (HCPs) to ensure that PwD receive good quality care while mitigating the escalating cost of dementia care (Wittenberg et al., 2020). One strategy to safeguard PwD's personal values, life goals, and preferences for future care is through the process of Advance Care Planning (ACP) (Sudore et al., 2017).

ACP is an iterative process that '... supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care' (Sudore et al.,

2017) (p. 286). Creating an ACP has several advantages for PwD, including enhanced quality of life (Harrison Denning et al., 2019), reduced non-beneficial medical care towards the end of life (Keijzer-van Laarhoven et al., 2020), and care goals aligned with individuals' personal values and care priorities (Wendrich-van Dael et al., 2020). The creation of ACP reduces the likelihood of unnecessary hospitalisations (Wahid et al., 2018), as well as lowers both direct costs (e.g., costs associated with medical expenditures) and indirect costs (e.g., loss of work, unpaid care) (Wimo et al., 2017).

The latest Scottish Government dementia policies advocate for the creation of an ACP for PwD, aiming to ensure that PwD can discuss their needs and wants within their ACP before any health crisis or decline (The Scottish Government, 2017, p. 29). However, despite endorsement, there appears to be a 'landscape of assumptions' (Brookes, 2021) underpinning the development of dementia policies. Specifically, the Scottish Government advocates for human rights and person-centred care, justifying them as a mandate for its dementia policies (The Scottish Government, 2017, 2020, p. 29, p. 28). This includes the five principles of human rights: Participation, Accountability,

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Non-discrimination and equality, Empowerment and Legality (Diaz-Gil et al., 2023).

Advocating for PwD’s human rights is apt, as PwD often face discrimination in everyday life as well as in healthcare service due to stigmas associated with the condition (Diaz-Gil et al., 2023). This includes, and is not limited to: i) ageism (e.g., people living with young-onset dementia may be excluded from or not fully considered in policies, or the oldest old population may not be represented and thus are also excluded) and ii) assumptions around PwD’s lack of capacity to make decisions, resulting in their reduced involvement in certain activities such as participating in research or making decisions related to their care (Diaz-Gil et al., 2023).

However, the implications of these policy texts, which are largely based on dominant assumptions of human rights and person-centred care, may inadequately support HCPs and PwD in the initiation and revision of ACP. To date, no analysis has explored how policy texts created with these particular discourses of human rights and person-centred care influence the ACP process for PwD. Consequently, this study explored how the discourses in Scottish dementia policies affected the initiation and revision of ACPs for PwD, and examined how the voices of PwD, family carers, and HCPs influenced dementia policy regarding the initiation and revision of ACP.

The two research questions were.

1. What discourses are evident in Scottish dementia policy that may influence the initiation and revision of ACPs for PwD?
2. How do the voices of PwD, family carers, and HCPs shape dementia policy concerning ACP initiation and revision?

2. Materials and methods

Two Scottish dementia national policy documents were identified and analysed between June 2021 and March 2022. The first publication, *Scotland’s National Dementia Strategy 2017–2020*, was released in June 2017 and scheduled for review in 2020 (The Scottish Government, 2017, p. 29). Due to the impact of the COVID-19 pandemic and the shifting

priorities of the Scottish Government at the time, the revision of the policy was postponed (The Scottish Government, 2020, p. 28); an additional policy document was created in December 2020 as an addendum to the 2017 publication. Two latest policy documents, *Dementia in Scotland: Everyone’s Story* (The Scottish Government, 2023, p. 92) and *Dementia strategy: initial 2-year delivery plan - 2024 to 2026* (The Scottish Government, 2024), were further identified and analysed in March 2024.

The focus of the analysis was on the texts and statements within these policy documents that were related to ACP for PwD (hereafter referred to as texts). Additionally, the historical context of the enactment of these dementia policies and the structure of the texts in relation to ACPs were explored and scrutinised.

2.1. Theoretical framework and methodology

Bronfenbrenner’s bioecological theory was applied as the theoretical framework (Bronfenbrenner, 1979; Koller et al., 2019). Bronfenbrenner posits that individuals are nested under several environmental systems, ranging from their immediate setting (e.g., family, friends) to the more remote and abstract influences of culture, societal values, and policies (Rosa et al., 2013). Consequently, each environment can interact with and influence each other over time. For this study, the macro-influence of dementia policies and their impact on the ACP process for PwD over time were examined under the macrosystem level of Bronfenbrenner’s bioecological theory. Another study that explored other ecological systems was conducted by the authors but is beyond the scope of this article (Phenwan et al., 2025) (see Fig. 1).

Fairclough’s Critical Discourse Analysis approach (CDA) was employed (Fairclough, 2003) to examine how language is used to create or sustain the status quo (Wodak et al., 2001), power dynamics, relationships as well as to analyse elements beyond the texts, such as (in) visible ideologies, hegemonies, and assumptions (Fairclough, 2013; Mullet, 2018). The social contexts in which the texts are produced and used are integral to this analysis. Consequently, this approach allows the researchers to thoroughly examine how Scottish dementia policies

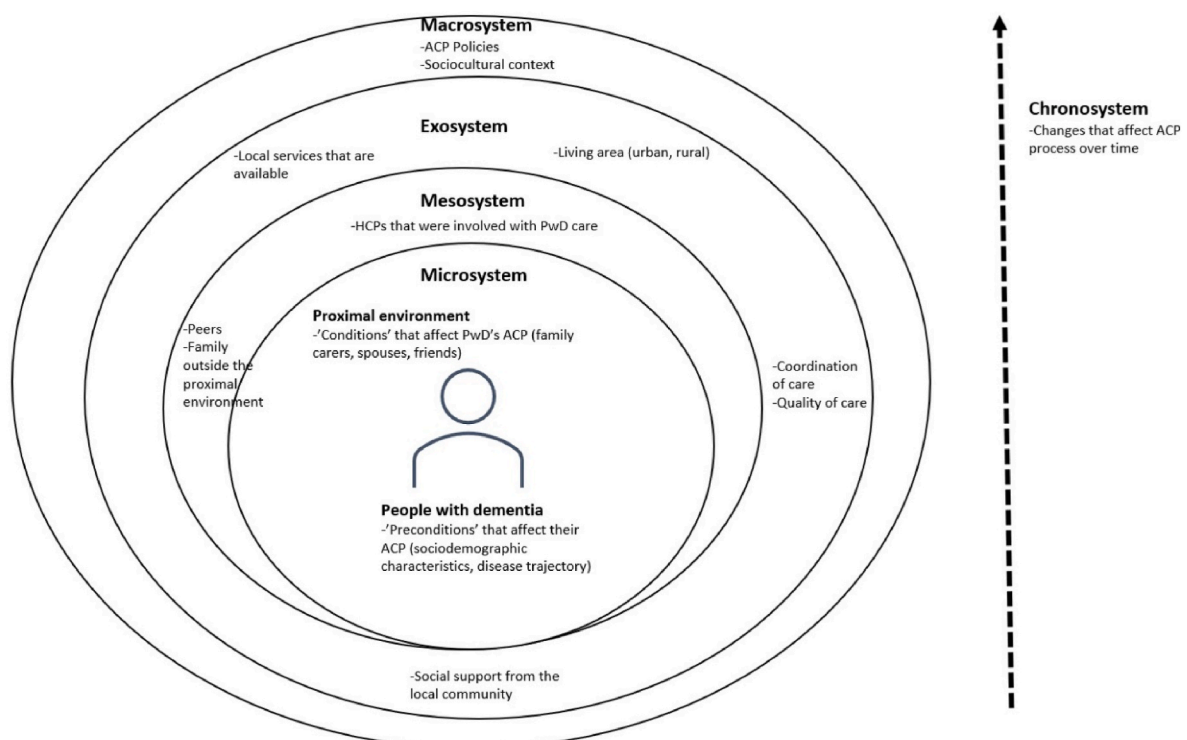


Fig. 1. Theoretical framework.

create or sustain certain discourses that, in turn, can affect the ACP process.

CDA researchers explicitly position themselves with respect to the research being undertaken, situating themselves within the context of the discourses they examine while remaining reflexive throughout the process (Wodak et al., 2009). This critical element of CDA is valuable for identifying ‘taken for granted assumptions’ within the texts (Fairclough, 2014) that are both implicit and explicit from the perspectives of the authors and for understanding how such assumptions may reinforce existing power inequalities. This has been evidenced by other works that have utilised the CDA approach, including dementia research (Hansen et al., 2022), palliative care research (Borgstrom, 2020), and obesity policy analysis (Brookes, 2021).

2.2. Researcher positionality as outsider

In relation to the current CDA, the first author is a family doctor and a qualitative researcher. He positioned himself as an outsider, given that he is not clinically active since his arrival in the UK as a PhD student, and therefore his clinical experiences are not influenced by existing dementia policies in the UK. Additionally, he is an international PhD student who uses English as a second language. With this background, he surmised that he should be able to identify additional insights that insiders may overlook as he is not embedded in UK cultural perspectives and health service practices. Consequently, this outsider positionality to the policy process can facilitate the exploration of taken-for-granted assumptions within the texts (Nowicka et al., 2015).

2.3. Data analysis

The analysis was undertaken through the following three interrelated dimensions of discourse (Fairclough, 2014).

- Textual analysis.
- Processing analysis.
- Social analysis (see Fig. 2).

The four policy documents were uploaded into Atlas.Ti to facilitate the analytical process. The aim was to reveal the underlying discourses that establish and influence the initiation and revision of ACP with and for PwD. The analysis specifically focused on identifying how the discourses within the documents articulated who would be involved in the ACP process, the powerful stakeholders influencing the process, and the extent of PwD and family carers’ involvement in the policy creation.

The documents were read, reread, and then coded by the first author and discussed with other authors. Keywords, phrases, and patterns that could lead to explicit and implicit discourses within the texts were identified and highlighted during coding and in subsequent discussions. This included the genre of the texts, the historical context surrounding the texts and discourses, the production context, the intended audiences, the intended purpose of the text, and the characteristics and background of the authors. Power dynamics and relationships within the texts were also examined. Similar codes were brought together and then categorised with meaningful descriptions, memos, and quotations from the texts.

To ensure a comprehensive understanding of the discourses, the interactions amongst different discourses were analysed, alongside their inferred ideological positions within texts. This included examining the external relations within the texts (i.e., the relations between different types of discourse) to identify ideological positions reflected in the authors’ statements, social and power relations that control the production of the texts, and subsequent discourses influencing the ACP process.

The internal relations within the texts, which suggested what the texts aimed to achieve and how this was accomplished, were also analysed. This analysis included examining the frequency of words, sensitizing words (e.g., ‘only’, ‘such’, ‘loved ones’), word choices, and

linguistic devices (e.g., the use of metaphors, turn-taking statements, use of active and passive voice). These represent: social relations, social contextual factors (e.g., events), and authors’ positionalities; headlines; leading statements; highlighted phrases; and the structure of the texts. Identified linguistic features within the texts were tabulated, such as the use of turn-taking statements, active and passive voice, and the tone of the language. The frequency of each word appearing in the documents was also counted to indicate the authors’ stance and how this changed over time.

The external and internal relations identified in this analysis were interpreted and organised along with the memos, insights identified during the process, and a reflexive analysis. These were compiled and organised into broader contexts and discourses. The entire analysis process was iterative, with preliminary findings being discussed with other co-authors, who are also the first author’s supervisors, throughout the process to ensure the robustness of the analysis. Assumptions of meaning of the texts and certain discourses were also discussed before finalising the findings.

2.4. Findings

Square brackets, [], were used to clarify obscure phrases within the policy texts. Underlining the text was enforced to add emphasis. Three interlinked discourses were identified: i) Shifting Agencies, ii) Formulaic Rightness, and iii) Visibility and Voices. These discourses are imbalanced in size and scope, reflecting the nature of ACP policy texts and the areas disproportionately discussed and emphasised by the Scottish Government. Each discourse is presented separately to facilitate the presentation of findings. The interlinkages between the discourses are discussed in the discussion section, with reference to the two research questions (see Table 1).

2.5. Discourse one: shifting agencies

The discourse of shifting agencies focuses on the representation of various stakeholders—PwD and HCPs—within the texts. These

Table 1
Discourses identified from the Scottish policy document.

Discourse	Extracts
Shifting Agencies	<p><i>‘Those individuals diagnosed early, and assigned a named [dementia] Link Worker, will continue to receive support using the 5 Pillars approach for the duration of their time living with dementia, or until such times as their needs change, and they require greater care coordination.’ – Scottish Government, 2017, p.11</i></p> <p><i>‘The [dementia practice] coordinator would have a critical role in supporting the person with dementia to die in their place of choice ...’ – Scottish Government, 2017, pp.16-17</i></p> <p><i>‘In order to achieve this [create an ACP], it is important for clinical teams to have sensitive, timely and focussed conversations with individuals living with dementia ...’ – Scottish Government, 2020, p.18</i></p>
Formulaic Rightness	<p><i>‘We think that the commitments outlined in this strategy will help ensure the right care and support at the right time and place for everyone ...’ – Scottish Government, 2017, pp.3-4</i></p> <p><i>‘This [House of Care] model details the components necessary to ensure collaborative care and support planning. This approach supports and enables people to articulate their own needs and decide their own priorities, through a process of joint decision making, goal setting and action planning.’ – Scottish Government, 2017, pp.17</i></p> <p><i>‘It is only by having such sensitive and compassionate conversations with people living with dementia and their loved ones, that they will get the care that is right for them when time becomes short [as a part of their ACP]’ – Scottish Government, 2020, p.18</i></p>
Voice and Visibility	<p><i>‘[the texts] includes direct input at every stage from people with dementia, their families and carers ...’ – Scottish Government, 2017, p.5</i></p> <p><i>‘We held a total of 14 individual virtual engagement events. -We spoke with over 100 attendees (organisations or individuals) in all.’ – Scottish Government, 2020, p.24</i></p>

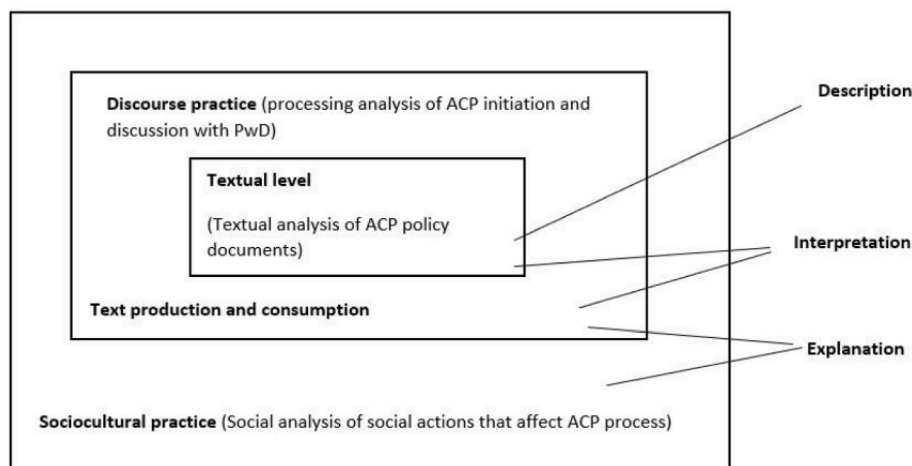


Fig. 2. Dimensions of discourse and discourse analysis.

stakeholders have varying degrees of agency over the ACP process. Within these documents, the Scottish Government's expected outcomes suggest that PwD are empowered to have a greater degree of agency and 'can take as full a part as possible in their own care planning' (11, p. 10), particularly during the early stages of dementia.

This suggestion is considered an important step, as previous research indicates that PwD often have their rights disregarded or overridden by their families and HCPs (Hansen et al., 2022; Thorogood et al., 2018). Consequently, such governmental proposals are seen as a proper way to address this issue and support PwD in asserting their right to create their ACPs. However, the analysis revealed that the discourse surrounding ACP in the texts is less empowering than expected. Rather than PwD, HCPs are somewhat positioned to instead facilitate the ACP process, specifically dementia link workers, dementia practice coordinators, and primary care teams positioned to have a greater degree of agency over the ACP process. For example, the dementia link workers are positioned to support PwD 'for the duration of their time living with dementia' (11, p. 11), whereas the dementia practice coordinators will support PwD 'to die in their place of choice ...' (11, p. 16–17).

The texts explicitly call for PwD to be in control of the ACP process and imply that dementia link workers and the dementia practice coordinators will simultaneously support PwD in this process. However, the texts do not specify who will initiate or support the ACP process, nor do they specify how the two roles will coordinate. This contrasts with the Scottish Government's commitment which aimed to ensure that PwD 'get timely access to good quality palliative and end of life care' (11, p. 16). The analysis suggests that the texts may not sufficiently support this statement, given that they do not specify how other HCPs and dementia link workers can work together with PwD to support the ACP process, which underpins access to good quality care.

In the 2020 publication, the proposed HCPs inferred to initiate an ACP with PwD shifted again, becoming even more explicit. This change might aim to mitigate feedback from stakeholders who all suggested that '... awareness of the post-diagnostic support (PDS) service and the one year entitlement was often low ...' (13, p.7), meaning that most PwD and families were neither aware of post-diagnostic support nor of the roles of dementia link workers and dementia practice coordinators. The texts further revealed a shift of responsibility regarding the ACP initiation process to clinical teams:

'... to achieve this [create an ACP], it is important for clinical teams to have sensitive, timely and focussed conversations with individuals living with dementia, their loved ones and those with Power of Attorney (where appropriate) about their care wishes ...' (13, p. 18)

The positioning of PwD and family members as recipients may therefore suggest a further disempowerment, contrasting with the Scottish Government's underlying human rights discourse.

Paradoxically, it positions PwD and their family as recipients of the ACP process. Disempowerment and shifting responsibility were further indicated when the Scottish Government proposed that primary care teams would be the key agents in initiating an ACP (The Scottish Government, 2020, p. 28).

This intention signalled readers to the 'COVID-19 Anticipatory Care Planning (ACP) guidance for people with dementia' document, which positions primary care teams as the key persons to conduct ACP with PwD. It is possible that this shift in responsibility to primary care teams was related to the increased workload during COVID-19, particularly in hospital settings. However, the texts did not justify why primary care teams were positioned to initiate an ACP with PwD, potentially causing further confusion regarding who is responsible for initiating ACPs.

The shifting responsibility did not improve within the latest documents. The Scottish Government continues to claim to enable PwD and their families to 'have equity of access to future care planning ...' (15, p. 51) and to 'uphold their right to participation in care needs assessment, future care planning ...' (16, p. 26). However, no explicit person(s) responsible for supporting the process has been stated, thereby continuing to make the ACP process unclear.

Moreover, the texts did not propose any guidance for the timeframe to initiate an ACP. This meant HCPs could interpret the timing to initiate an ACP with PwD differently, thus potentially leading to variable support for PwD that might not be in line with PwD's eagerness (or the lack thereof) to engage with their ACPs. Also missing from the text was an explanation of how and when an ACP should be revised. Consequently, these extracts indicated various HCPs who were inferred to have responsibility for the ACP process with unclear timing for engaging with PwD.

This discourse reveals inconsistent messages about who has agency over the ACP process and when to initiate and revise an ACP. This inconsistency could potentially lead to confusion among PwD, their family carers, and HCPs regarding who should initiate an ACP and when it should be initiated and revised.

2.6. Discourse two: formulaic rightness

This discourse represents visible and hidden assumptions within the texts that influence a more formulaic, singular way to engage with the ACP process. These assumptions reveal, once again, insufficient support for the ACP process for PwD. Instead, the ACP process is presented as formulaic in the texts, removing the consideration of how complexities around PwD's circumstances can shape the process.

Fairclough defines assumptions as 'the implicit meaning of the texts' (Fairclough, 2003) (p. 212). These are.

1. Existential assumptions (what exists).
2. Propositional assumptions (what is or can be or will be the case).
3. Value assumptions (what is good or desirable) (21, p. 55).

Under this discourse, existential assumptions within the texts convey that the 'right care' at the 'right time and place' for PwD exists. The policy implies that one of the successful policy outcomes is that more PwD 'are diagnosed early enough that they can take as full a part as possible in their own care planning' (11, p. 10).

This focus on early diagnosis of dementia seems sensible, given that PwD need an official diagnosis before they can access support from services. To support this, the Scottish Government signalled their commitment to the relevant strategy that will '... help ensure the right care and support at the right time and place for everyone ...' (11, p. 3-4).

However, the nature of 'right care' for PwD is not explicitly defined. It would be challenging for any reader to understand what this 'right care' might refer to, given that the concept of rightness is highly subjective. This existential formulaic rightness (the existence of a formula to give the right care at the right place and time) from HCPs' perspectives might differ from that of PwD. This is doubly problematic since the concept of right care, along with the goals of care, is even subjective among HCPs (Myers et al., 2022). Consequently, this creates a further challenge to the creation of an ACP and compounds the problems arising from the discourse of shifting agencies.

The texts contain propositional assumptions concerning the implicit nature of the ACP process as a finite, achievable process; that is, the 'right care' to initiate an ACP with PwD could be achieved with the proposed strategies within the texts. This assumption was followed by the proposal for HCPs to use the House of Care model, which the government proposed as the 'right' model to support the ACP process:

'This [House of Care] model details the components necessary to ensure collaborative care and support planning ...' (11, p. 17)

The statement above assumes that the House of Care model is legitimate since it comprises the 'necessary components' for initiating an ACP with PwD. Therefore, the model was chosen to achieve the 'collaborative, relational decision making and planning, which lies at the heart of person-centred care' (11, p. 17), which can be seen as relevant to the initiation and revision of ACP. However, this model and its justification are not fully discussed in the 2017 publication, nor does the publication expand upon how it should be implemented. It was not clear whether the proposal of this model stemmed from previous consultations or was suggested by the Scottish Government based on what they considered strong evidence. The lack of elaboration on the model's application and its absence from subsequent publications raises more questions about the model's validity and relevancy in the ACP process, as well as regarding why the model was proposed initially.

The House of Care model also does not fully encapsulate the iterative nature of ACP. This is evident in the central texts of the House of Care model, which proposes a 'timely focused conversation to plan- 'What matters to you' (11, p. 17). This indicates that the authors of this model perceive an ACP discussion as a finite, singular action, which contradicts academic literature establishing that ACP is largely an iterative process (Sedini et al., 2022; Van Rickstal et al., 2022). Consequently, although the proposed House of Care Model may be useful for framing comprehensive support for PwD, it may not sufficiently guide HCPs and PwD in revising their ACPs.

While the policy texts refer to the importance of the time it takes to create an ACP in several places, the timing for revision of ACP is not explicitly stated. The authors of the policy documents assume that HCPs and PwD can pinpoint the 'right time' to initiate and revise an ACP themselves, thereby further reducing the chance for PwD to effectively create their ACPs since such timing is, again, largely subjective.

In addition, the House of Care model was proposed by the authors to be used for individuals with long-term conditions. This proposal does not fully consider the unique characteristics and symptomatology of

dementia, particularly the fluctuating mental capacity of PwD and the variability of diagnoses and death trajectories (Tan et al., 2019; Vinay et al., 2023), making its application to PwD less relevant. Moreover, Silver (2018) discussed the impracticality of the House of Care Model, given that only 3% of people living with chronic conditions have a care plan. This might be partly explained by the House of Care model and its associated guidance not explicitly stating who will be responsible for the ACP discussion (Ian, 2018). This critique is similar to the first discourse of shifting agencies. Therefore, while the House of Care Model could be useful as a framework to support PwD, the limited evidence suggests it may not fully support a more flexible and iterative approach to ACP. Other alternative models may be more appropriate to support PwD and warrant further exploration.

Finally, three explicit value assumptions were identified. The first value assumption was that PwD would want their 'loved ones' to be involved in the ACP process, as shown through the use of sensitizing words supporting this assumption:

'It is only by having such sensitive and compassionate conversations with people living with dementia and their loved ones, that they will get the care that is right for them when time becomes short [as a part of their ACP]' (13, p. 18)

This assumption does not apply to all PwD given that not every PwD fits such a set of assumptions, namely some do not have 'loved ones' or, if they do, may prefer not to discuss their ACP with their family. Consequently, the texts fail to propose a tangible strategy to support PwD who deviate from these underlying assumptions due to this lack of oversight surrounding PwD's circumstances.

The second value assumption suggested that the ACP process was 'sensitive' and could only be achieved through 'compassionate conversations'. This notion aligns with existing literature indicating that HCPs perceive ACP as a sensitive topic of discussion since the process often addresses sensitive topics (Harrison Denning et al., 2019; Phenwan et al., 2020). The text reinforces this perception, alerting HCPs to these potential sensitivities, potentially leading HCPs to avoid initiating and revising ACPs with PwD when HCPs feel uncomfortable holding or initiating such conversations (Keijzer-van Laarhoven et al., 2020).

Beyond assumptions concerning what is 'right' for PwD and the ACP process, implicit value assumptions regarding PwD's characteristics were also identified. The Scottish Government claims to support the ACP process with PwD irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death ... (11, p. 17).

The authors appeared to position themselves as inclusive in supporting PwD, regardless of their personal characteristics. However, their implicit value assumption regarding biomedical thinking around dementia care becomes apparent when they subsequently described PwD as 'frail and elderly' with 'a range of conditions' (11, p. 17). This suggests an assumption by the authors that PwD occupy the older age range and often have other conditions, which is not always accurate given the diverse age range, diagnoses, and symptoms among PwD (Tan et al., 2019).

Value assumptions about PwD are subtly hinted at throughout the texts, as evidenced by the varying terminology used to describe dementia, which is related to biomedical or other approaches. The most frequently used terms across all documents were 'people with dementia' and 'people living with dementia', considered the politically correct term to use at the time. However, other terms more closely associated with the disease were also used, namely 'such people' or 'people in this category', indicating a repositioning of the emphasis toward the diagnosis of PwD and the biomedical aspect of dementia. If the emphasis is placed on the condition (and its associated clinical staging), this may lead to overlooking or even neglecting the person behind the diagnosis, contradicting the implied concept of person centred care.

Regarding the last value assumption of the terminology around ACP, the Scottish Government announced a change from the official term 'Anticipatory Care Planning' to 'Future Care Planning', as the initial term was not well understood by the public (Smith et al., 2023). This

change was based on the rationale that it should promote the 'thinking ahead approach' and enable any individual to discuss their ACP, though the actual process to achieve this goal remains unspecified. There is still no indication of public awareness regarding this newly coined term, which has not been adopted elsewhere in the world, leaving its acceptability and comprehensibility still in question.

The identified assumptions surrounding both the ACP process and PwD's characteristics appear to have influenced ACP policies. Unsurprisingly, these emotive and value-laden assumptions are less conducive to a person-centred ACP process. That is because the timing for initiating ACP remains unspecified, and the revision aspect of ACP continues to be neglected. Consequently, parallel to the discourse of shifting agencies, this discourse of a singular formulaic approach to the ACP process further contributes to the arbitrary support PwD receive from HCPs.

2.7. Discourse three: visibility and voices

This discourse investigates the visibility and voices of PwD and other stakeholders within the texts, as well as the limitations in the policy-creation process that affect their input. The analysis suggests that, in the past, the policy-creation process seemed to obscure PwD's input despite the claims of inclusivity and equality during the policy-development process. However, there has been a gradual improvement in the recent publications.

In the 2017 and 2020 publications, the Scottish Government stated that the whole policy document and its strategies had received '... direct input at every stage from people with dementia, their families and carers ...' (11, p. 5). This positioning around inclusion and equality during the policy-creation process is further pursued in the 2020 publication given that the Scottish Government '... [virtually] spoke with over 100 attendees (organisations or individuals) in all ...' (13, p. 24). This claim of inclusion might relate to the underlying human rights discourse and the rhetoric of equality contained in the texts, as well as the co-creation of the policy and throughout the engagement process (The Scottish Government, 2017, 2020, p. 29, p. 28). However, there is little evidence to support this claim: the voices of key persons —PwD, family carers, and HCPs— appear to be largely absent.

In the 2017 publication, there were no quotes or evident feedback from PwD, family carers, or HCPs. Instead, the texts created were a summary of proposed strategies that were drawn upon from the 'collaboration' process with relevant stakeholders. Within this, the generalised use of language may inadvertently hide the direct voice of PwD and their families since their participation is alluded to but never fully evidenced. The way in which the texts 'plus input from PwD and families' were structured also revealed hidden intentions from the Scottish Government that positioned PwD and families as auxiliaries for HCPs. As a result, it is unclear how PwD and their families are prioritised in the policies.

In the 2020 publication, the policy texts were developed during the UK lockdown and the consultation process was conducted virtually, which influenced the policies created. The continued absence of input from PwD highlights ongoing inequalities in text production and distribution. The 2020 publication utilised anonymised quotes from participants to support the government's proposed commitments and subsequent actions, with 29 quotes used throughout the text. However, regarding ACP policy, there is no sectoral or experiential evidence within the section, as none of the 29 quotes was used to support the government's statements in that area. This may suggest a lack of input from stakeholders, raising questions about the legitimacy of the ACP policy enacted by the government. The voices of HCPs, especially dementia link workers and primary care teams, were also missing, further silencing key persons involved in the initiation of ACPs.

There was no mention of how PwD would be involved in ACP creation in the future or how the proposed strategy enabled PwD '... to articulate their own needs and decide their own priorities' (11, p. 17). This is problematic since PwD require additional support for the

discussion and engagement process due to symptoms of forgetfulness and fluctuating mental capacity associated with dementia (Phenwan et al., 2021; Sixsmith et al., 2021). It was not clear how the government proposed to address this articulation of 'their own needs' and empower PwD's participation in the initiation of ACP. Furthermore, the term 'need' has variable definitions, depending on whether the authors approach it from a biological, societal, economic, or even philosophical perspective (Asadi-Lari et al., 2003). This is problematic as PwD's needs (or changing needs) also relate to the likelihood of the initiation and revision of their ACPs. Given that the texts do not indicate which definition is used, the Scottish Government's perspective regarding the 'needs' of PwD may therefore differ from PwD's own perspectives, potentially leading to mismatched expectations between these stakeholders.

Further, these online engagements exacerbated the issue of digital exclusion, affecting people who do not use technology or are unable to use it, particularly PwD. This is incongruous given that the impact of digital exclusion had been acknowledged as a priority in the Scottish Government dementia policy (The Scottish Government, 2020, p. 28). The policy-creation process did not include 'everyone' as claimed, thereby distancing the text policies from the claim of equality which underpins the person-centred care discourse. As these examples demonstrate, the construction of policy content in this manner might not be transferable or agreeable to wider audiences, particularly for marginalised populations such as PwD or family carers without internet access, PwD who have difficulty participating due to the advanced stage of dementia, or those who did not or were unable to participate in the events.

The texts do not outline how individuals or organisations can be involved in the policy engagement and creation process. Annex B disclosed a long list of participating organisations and participants ('100 attendees'). On closer inspection, the degree of participation from each stakeholder sector was unequal. For example, only one university was involved in the engagement process, and six out of fourteen NHS health boards were involved. While it is reasonable to include relevant stakeholders in such a consultation process, it is not clear within the texts why these particular organisations were involved despite others not being involved given that the input from these non-participating organisations might differ.

In addition, the representation of PwD is somewhat ambiguous; only six of the one hundred participants came from non-professional backgrounds. As such, due to the sectoral imbalance, the reliance on professionalism, and the invisibility of PwD and non-professional participants, the claims of involvement and equality are not fully established.

This sectoral imbalance was further evident when the Scottish government stated their intent to continue using the existing guidelines to support the current ACP process, which is led by HCPs:

'We will continue to implement the COVID-19 Dementia Anticipatory Care Guide to help those living with dementia, and their families.' (13, p. 18)

This commitment expands the previous statement which signposts the readers to additional documents aimed at the primary care team and that '... complements and enhances existing ACP guidance and was developed in collaboration with The Life Changes Trust, Alzheimer Scotland and Healthcare Improvement Scotland ...' (13, p. 18).

These extracts do not reveal any contributions from PwD and their families, as they remain absent in the ACP policy section. Instead, additional stakeholders and organisations are introduced: Healthcare Improvement Scotland, the two national dementia workforce programmes, The Life Changes Trust, and Alzheimer Scotland. Further examination shows that Healthcare Improvement Scotland was involved in the policy-making process for both the 2017 and 2020 publications, and was one of the powerful, visible stakeholders in being named in both policy documents. Their involvement included the creation of the 'My Anticipatory Care Plan' document, which is an endorsed document to be

used as a tool by the Government for discussing and documenting ACP (The Scottish Government, 2020, p. 28). Consequently, instead of empowering PwD and enabling their input, the structural representation within the texts somehow retains the power to invoke change within these social and organisational actors while not clearly defining the role of PwD and their families in the process.

Nevertheless, the voice and visibility of PwD and their families are markedly visible in the 2023 and 2024 publications. Both publications include a dedicated section outlining the policy co-production process with the lived experience panel group and the strategy advisory group (The Scottish Government, 2023, 2024, p. 92). The lived experiences of PwD are also included in the 2023 publication, thus making PwD explicitly visible. However, in terms of ACP policies, it remains unclear how—or if—PwD contributed to that particular section or not, making the relevance and practicality of ACP debatable.

3. Discussion

This study addressed two research questions. First, to reveal the discourses present in Scottish dementia policies that influence the initiation and revision of ACPs for PwD. Second, to examine how the voices of PwD, family carers, and HCPs influence dementia policy regarding the ACP process.

For the first research question, findings suggested that the Scottish dementia policies have indeed improved over the years, with increased input and participation from PwD and family carers in the latest dementia policy-creation process, making these policies more inclusive (The Scottish Government, 2020, 2023, 2024, p. 28, p. 92). However, the current ACP policy still does not adequately support the initiation and revision of ACPs with and for PwD. Consequently, PwD may not receive adequate, equitable support to empower their human rights and ensure equality of opportunity in initiating and revising their ACPs, as proposed by the Scottish Government.

This insufficient support stems from inconsistent messaging within the discourses and approaches concerning the initiation and revision of ACPs with PwD, compounded by the discourse of shifting ACP agency and assumptions around the ACP process. Despite the Scottish Government's positioning of dementia policies within a human rights framework, the analysis revealed a vacillation between the human rights approach, equality, person-centred care, and a biomedical approach. This vacillation undermines the foundation of the policies, thus potentially creating an unclear message for readers. The ambiguity surrounding agency and the question of who should act as key persons to initiate an ACP, or how various stakeholders can collaborate in the best interests of the PwD, further complicates the policies. The policies reveal an unclear delegation of responsibilities, making it difficult to establish 'who' is responsible for initiating ACPs.

Another finding which challenges the person centred care discourse was that the ACP policies tended to fit certain characteristics of PwD. The assumptions within the texts often portray PwD as 'old and frail', living with supportive families ('loved ones') who advocate for them, along with the assumption that PwD have limited capability to negotiate ACPs themselves. These assumptions contradict both equality and person centred care discourses, as some PwD can advocate for themselves and are capable of negotiating their ACPs (sometimes with support). These problematic discourses and vacillation are not unique to Scottish dementia policies, as PwD are often constructed within policy texts as either a dichotomous or homogenous group, or simply as a disease stage (Hansen et al., 2022). Hansen et al. (2022) highlighted similar issues in their analysis of 21 dementia policy documents, where PwD were often labelled with dichotomised words stemming from the biomedical aspect of dementia symptoms, tending to position PwD as 'someone to be acted upon' by other people who were not affected by or living with dementia. As presented by Hansen et al., (2022, p. 135), examples of the words associated with PwD are:

'progressive', 'symptoms', 'disabled', 'dependent', and 'decline' or

contrastingly, 'independent', 'confident', 'contribute', and 'participate'

These words reveal the contrasting perception of PwD as: i) recipients of care who have less agency over their care and actions (due to their symptoms and cognitive decline over time) and ii) autonomous agents who can live independently, make their own decisions, and can contribute to wider society (Hansen et al., 2022). Although Hansen et al.'s analysis focused on the discourse of dementia friendliness within policy documents, their findings resonate, to some extent, with the current study, particularly with the two discourses of 'shifting agencies' and 'formulaic rightness'. These contrasting perceptions of PwD do not fully capture the nuances and complexity of PwD's situations and capabilities, as a PwD can be an independent person who can participate and express their future needs coherently or with relational support despite fluctuating mental capacity or decreasing cognition (Bamford et al., 2021; Hennelly et al., 2021).

These limiting perceptions of PwD and their positioning in the policy texts are also evident from the analysis. While the Scottish Government appeared to position PwD as autonomous individuals within a human rights discourse, this intention has not been efficiently translated into practice within the texts. New ACP policies must address the relational needs of PwD and their families to ensure the heterogeneity and diversity within the population of PwD are recognised and their varied circumstances addressed.

A further finding is that ACP policies tend to neglect the importance of ACP revision. In all publications, the focus seems to be on the initiation of ACP but not on its revision. However, the literature has consistently indicated that ACP is an iterative process, requiring ongoing discussion and re-examination from individuals (Bally et al., 2020; Phenwan et al., 2020; Wendrich-van Dael et al., 2020). This is even more important for PwD due to their fluctuating mental capacity and the increasing need for family input (Phenwan et al., 2020; Van Rickstal et al., 2022). This lack of nuance in the policy texts may further contribute to the failure of ACP and associated implementation for PwD.

Regarding the second research question, the discourse of visibility and voices has revealed that the voices of PwD, family carers, and HCPs in dementia policies were largely obscured in the past but have been made more visible lately. However, the representation of these stakeholders within the texts is not entirely discernible; their contributions, if any, are at best diluted and generalised in both publications. As such, this diminished visibility and input from dementia care stakeholders might contribute to the variable support PwD receive from HCPs, as the current policies do not provide sufficient guidance for HCPs.

For PwD, this relates to the slogan advocated by most dementia organisations: 'no research about us, without us' (Shannon et al., 2021). This slogan ensures that any dementia policies created are inclusive and incorporate actual inputs from PwD that are relevant to them. To achieve such inclusivity, it is essential to provide additional support to enable PwD to engage meaningfully in the policy-making process, given their dementia symptoms, such as forgetfulness and anxiety (Phenwan et al., 2021).

The lack of support around the coordination of care between dementia link workers, dementia coordinators, and other HCPs within the policies is equally concerning, as this can lead to the lack of integrated care for PwD (Bamford et al., 2021). Specifically, no mechanism in dementia policies facilitates revision of the care and support received by PwD at a given point in time (Bamford et al., 2021). Consequently, it can be deduced that there is also little attention supporting the revision of ACP for PwD. Bamford et al. (2021) further highlighted the need for customised support for PwD due to their different symptoms and progression. This recommendation aims to ensure that PwD's current needs and emerging future needs are addressed accordingly (Bamford et al., 2021). Unfortunately, this suggestion is not apparent in existing dementia policies in the UK and other developed countries, indicating a need for further attention (Vinay et al., 2023).

3.1. Implications for future research

Findings from the study suggest that the discourses within the dementia policy can significantly influence HCPs' attitudes and practices, and subsequently, the support for the ACP process that PwD receive due to how HCPs are positioned. Specifically, the discourse around shifting ACP agencies has proven problematic for HCPs in efficiently supporting the ACP process. These findings highlight the need for improved dementia policies that address three areas.

First, a consistent approach and recommendation for initiating and revising an ACP with PwD is required. That is, the key persons who have the agency to initiate and revise the ACP should be explicitly identified to ensure that PwD and their families receive the support they need. In this context, these key persons are not specified HCPs but rather those who have established trusting relationships with PwD (such as family carers or certain HCPs) (Phenwan et al., 2020) and should be indicated as such.

Second, the notion of revising ACPs within the policies is still lacking. More information for PwD, their families, and HCPs regarding the ACP discussion process and documentation is needed to ensure that PwD can participate in the creation of their ACPs throughout the dementia trajectory.

Third, current policies in the UK, including Scotland, do not fully consider the variations in PwD's needs due to different symptomatology, symptoms progression and manifestations of dementia which can vary hugely from those living with young-onset dementia to vascular dementia, Alzheimer's and mixed-type dementia (Vinay et al., 2023). Therefore, revised ACP policies must account for the different symptoms of dementia, especially for those who might need support in documenting their ACP and those living with young-onset dementia whose needs differ from other groups of PwD (Tan et al., 2019; Van Rickstal et al., 2022). PwD's participation in the policy-making process must be explicit and evident to ensure that future policies reflect their needs, particularly for PwD who do not fit the homogenous dementia stereotype identified in the policy. To achieve this, additional input—PwD's voices with different diagnoses—is still needed and could be achieved via a co-design approach with PwD and their families (Keogh et al., 2021).

3.2. Strengths and limitations

To our knowledge, this is the first CDA study that has explored discourses relating to the ACP process within Scottish dementia policies. The analysis yields additional insight and understanding on how the identified discourses around ACP have restricted the HCPs' support on the initiation and revision of ACP with PwD. Moreover, the first author situated himself as an outsider during the policy analysis. As such, his outsider positionality gave a new perspective that might have been overlooked by insiders such as the policymakers themselves or contributors who worked in the dementia field (Hayfield et al., 2015).

3.3. This study poses two limitations

First, the first author uses English as a second language; he analysed the policy texts with this pre-existing background. This might limit certain aspects of the analysis and interpretation of the texts, particularly at the semantic-level of analysis of the CDA. There may be words with different yet subtle meanings that are overlooked, which could reveal the authors' hidden ideologies and stances around ACP initiation and revision. This was mitigated by discussions with other research team members, all of whom are English native speakers (see the data analysis section). Further, CDA could potentially be used to further the researcher's own ideological agenda (Mullet, 2018), rather than focusing on the analysis. For this study, this meant the first author could overly focus on how the dementia policies negatively influence the ACP process. This limitation was addressed through team reflexivity during the

analysis process, along with a detailed description of the process to ensure that the final analysis is robust.

Second, this study only examined particular aspects of the four latest dementia policy documents in Scotland related to ACPs; regional and local policy documents were not included in the analysis. Consequently, there could be potential misinterpretations due to a lack of contextual or localised information. Therefore, additional analysis of dementia documents from other nations in the UK or other countries might provide a more comprehensive perspective on the dementia policy landscape, thereby leading to further insights into the discourses that will facilitate the ACP process.

4. Conclusions

The three discourses in this study identified that: 1) empowerment to initiate and revise ACPs shifted across different stakeholder groups such that no specific group 'owned' the process, thereby making it difficult to isolate who 'should' initiate or revise an ACP; 2) the policies indicate a singular formula to proceed which belies the complexity of the process; and 3) the visibility and voice of PwD and their family carers were not clearly evidenced, suggesting that policy may overlook relevant aspects of the process for PwD. These policy shortcomings may help explain the variability in HCP support for initiating and revising ACPs. They also highlight an inherent disempowerment regarding the participation of PwD and their family carers in the process. Consequently, a review of ACP policies for PwD is required to improve the ownership, relevance, and visibility of PwD within the process.

CRedit authorship contribution statement

Tharin Phenwan: Writing – review & editing, Writing – original draft, Visualization, Validation, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Judith Sixsmith:** Writing – review & editing, Formal analysis. **Linda McSwiggan:** Writing – review & editing, Formal analysis. **Deans Buchanan:** Writing – review & editing, Formal analysis.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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