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Providing inclusive care and empowering people with dementia as a clinical pharmacist: a qualitative study of clinical pharmacist's experiences

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ABSTRACT

Objectives: Dementia is a growing global health concern, significantly impacting primary care settings, where the majority of care for people with dementia is provided. Underserved and vulnerable groups, who often face disparities in access to care are at greater risk of this strain. Clinical pharmacists are well-positioned to provide care but their potential contribution to enhancing person-centred and inclusive care for people with dementia is largely unexplored. The aims are to explore the views and experiences of primary care based clinical pharmacists in providing inclusive care to people with dementia in the community.

Method: We conducted 13 semi-structured interviews with primary care clinical pharmacists in England in 2023–2024, which were analysed using reflexive thematic analysis.

Results: Two overarching themes were developed from the interviews: 1) involving patients in decision-making, ensuring person-centered care and 2) the prevalence of health inequalities and the impact on patient care.

Conclusion: Taking a personalised and person-centred approach clinical pharmacists can engage with patients and carers in decision-making. This can empower people, particularly those from minoritised or disadvantaged groups, to take an active role in their care. This may help with medication adherence but also build trust, potentially leading to better quality and more equitable care. Personalised care should consider cultural beliefs and preferences to reduce misunderstandings or stigma and improve the overall experience for individuals, helping to reduce disparities.

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KEYWORDS

Clinical pharmacists; dementia; family carers; primary care; person-centred care

Introduction

Primary care is often the first point of contact to healthcare within national health systems for patients (Sundler et al., 2023). However, variation in access to healthcare services is widespread, and health inequalities disproportionately affect vulnerable or underserved groups, such as those from minority ethnic backgrounds (Gov.uk, 2022) or people with disabilities (WHO & World Bank, 2011). Barriers also exist to receiving person-centred care, particularly for people with dementia. Person-centred care is an approach that places the person in the centre of their own care (Rogers, 1961). The term provides a framework for individuals to be supported to contribute to their care through means of communication and shared decision making (Mitchell & Agnelli, 2015). Brookers (2003) outlined a person-centered dementia care approach should involve (Sundler et al., 2023) valuing and respecting both the person with dementia and carers (Gov.uk, 2022) recognising and addressing the unique needs of each person, (WHO & World

Bank, 2011) understanding the person's perspective and validating their experiences and (Rogers, 1961) creating an environment that promotes well-being and relationship building (Brooker, 2003). Some challenges to delivering this can include healthcare professionals' limited understanding of dementia and person-centered care, as well as difficulty meeting the needs of both patient and family carer, often overlooking family challenges (Marulappa et al., 2022). Supporting people with dementia requires a holistic approach, to provide support for cognitive and psychological symptoms, communication needs, behavioral symptoms and to address carer concerns (Doody et al., 2001). High-quality care, including regular monitoring, person-centered care, and integrated medical support, are essential to improve the quality of life for people with dementia (Ballard et al., 2018; Noel et al., 2017; Vickrey et al., 2006). Despite this, there is often suboptimal care for people with dementia, including high rates of sustained polypharmacy (Green et al., 2019) and inappropriate medication management for behaviours that challenge (Ballard et al., 2005).

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Population longevity, coupled with rising rates of multiple long-term conditions such as dementia, is placing unprecedented pressure on healthcare services, particularly primary care globally (Freund et al., 2015). This strain is likely to disproportionately affect underserved and vulnerable groups due to existing inequalities in access to care (Lueckmann et al., 2021). Integrating multidisciplinary teams in primary care dedicated to improving health and wellbeing, as well as tackling health inequalities, may enhance access to services (Fuller, 2022). In the UK, a relatively new role in the primary care multidisciplinary teams is the clinical pharmacist. Since the 1980s, pharmacists have increasingly provided direct patient care (Bradley et al., 2018) with their role in general practice becoming more clinically oriented (Baker et al., 2019; Khaira et al., 2020; Mann et al., 2018). Research in recent years has highlighted that clinical pharmacists can deliver a wide range of patient-oriented services and can reduce general practitioner workload and pressures (Alshehri et al., 2021; Maskrey et al., 2018). Clinical pharmacists are highly qualified medication experts who can carry out person-centred medication reviews for patients with chronic health conditions, and support with improving patient and health outcomes (N.H.S. England, n.d.). They are able to support with medication optimisation and increase the capacity of general practitioners to see patients (Claire et al., 2022).

To address mounting pressures and optimise outcomes for people with dementia, research into enhancing health and care services is essential. As clinical pharmacists have a prominent role in patient-facing duties, including roles in medication management, they could promote equal and sustainable care provision, enhancing person-centered care and inclusivity for underserved groups, including people with dementia. However, to our knowledge, there has been no research into how these patients are supported by clinical pharmacists within primary care.

Aims and objectives

To explore clinical pharmacists' experiences of supporting people with dementia to provide inclusive and personalised care when working in English primary care services.

Methods

Research design

Qualitative study using semi-structured interviews with clinical pharmacists working in primary care in England.

Recruitment and sample

To achieve a diverse participant sample, we used purposive sampling guided by the principle of information power (Malterud et al., 2016). This research focusses on a specific group (clinical pharmacists) within a specific health condition (dementia) and setting (primary care). Therefore, the aim is specific within a niche/narrow area, which aligning with the concept of information power suggests a smaller sample is needed. We estimated a sample of up to 15 participants (Malterud et al., 2016). This approach considered the study's objectives, participant characteristics, and analysis methodology (Malterud et al., 2016).

Participants were recruited through GP practices, NHS networks, the research team's contacts, and social media,

supplemented by snowballing methods (Goodman, 1961). Prior to interviewing we conducted a survey with clinical pharmacists in 2022–23, requesting participants to register interest in being interviewed. Recruitment materials were disseminated to clinical teams and shared through distribution lists. Interested individuals were encouraged to contact the researchers directly. Upon expression of interest, potential participants were provided with an information sheet and consent form.

Inclusion criteria

We recruited clinical pharmacists who worked in primary care (e.g. general practice, community teams, care homes) and were able to provide informed consent.

Exclusion criteria

Those who did not speak English.

Data collection

Interviews were guided by an interview schedule, collaboratively developed by the research team and the study's Patient and Public Involvement and Engagement (PPIE) panel. It was subsequently refined following a pilot interview. Topics included support for people with dementia as well as challenges and risks identified in dementia care. Please see [Supplementary Appendix 1](#) for the full interview schedule.

Interviews were conducted between December 2022 and March 2023 using telephone or video conferencing platforms. Informed written consent was obtained prior to each interview and reaffirmed at start and finish. One member of the research team (AW) conducted all interviews, which were audio-recorded and professionally transcribed verbatim. A second researcher (AB) checked transcripts against the original recordings. Interviews lasted between 30 and 60 min.

To ensure we were recruiting to our sampling strategy, participants provided demographic information. Participants received a £20 gift voucher as thanks.

Data analysis

Transcripts were imported into NVivo 14 (Lumivero, 2023) for reflexive thematic analysis (Braun & Clarke, 2021). The research team, comprising general practitioners, pharmacists, social care researchers, and social scientists with qualitative research expertise, collaboratively supported analysis. AB and ND independently initially coded two transcripts and met to discuss and agree on codes. Following this, the coding framework was shared with the rest of the team and refined. AB led the coding of the remaining transcripts, regularly consulting with ND and AW. Themes were collaboratively developed and refined through iterative discussion among all co-authors.

Ethical approval

Ethical approval was obtained from the Health Research Authority (HRA) and Health and Care Research Wales (23/LO/0054) and University College London Research Ethics Committee (3344/006).

Results

Sample characteristics

Thirteen clinical pharmacists participated in interviews, of these, ten completed the demographic questionnaire, summarised in Table 1. This sample was deemed sufficient working within the principles of information power, due to the richness of the data and as discussed about the narrow focus of this topic (Malterud et al., 2016). The clinical pharmacists were varied in their experiences of working directly with people with dementia, with some reporting regular contact and some explaining their contact was minimal, however we did not directly collect information on this.

Two overarching themes were developed from the interviews: (1) the prevalence of health inequalities and the impact on patient care and (2) involving patients in decision-making, ensuring person-centered care.

The prevalence of health inequalities and the impact on patient care

Engaging with non-English speakers

Clinical pharmacists reported that engaging individuals from minority ethnic backgrounds presented challenges, especially when language barriers hindered effective communication. Once engagement was achieved, these barriers continued to pose challenges in delivering services to individuals where English was not their first language:

I think certainly within [minority ethnic backgrounds] they're probably a bit harder to reach so maybe if there were things translated into their language or awareness for them. If we could highlight a bit of awareness of the help that is out there because I think, you'd probably say some of these communities feel a bit marginalised sometimes if they can't access things. [CP03]

Table 1. Demographic characteristics (completed by 10 of 13 participants).

		Clinical pharmacist
Age	18–35	3
	36–45	1
	46–55	4
	56–65	1
	Not answered	1
Gender	Female	7
	Male	3
Ethnic group	White – English	5
	Other White	1
	Indian	2
	Arab	1
	Pakistani	1
Education	Degree level	4
	Master's level	5
	Post-graduate Diploma	1
Professional grade ^a	Band 6	4
	Band 7	1
	Band 8	5
	Less than 1 year	1
Years working as clinical pharmacist	2–3 Years	1
	More than 5 years	8
Years experience in primary care	Less than 1 year	1
	2–3 Years	3
	4–5 Years	1
	More than 5 years	5
Work location by region	London	3
	South West England	1
	Yorkshire and Humber	2
	South East England	1
	North West England	3

^aThe 'Agenda for Change' is the main pay system for NHS staff, which includes nine pay bands across different professional grades. Staff can move up the bands by gaining relevant skills and experience. Available at: <https://www.healthcareers.nhs.uk/working-health/working-nhs/nhs-pay-and-benefits/agenda-change-pay-rates>.

While many clinical pharmacists reported using LanguageLine ((LanguageLine Solutions, 2024) an online interpreting and translation service)) to support patients, there were still challenges. Reliance on an interpreter could hinder the development of rapport and empathetic communication of the clinical pharmacist:

We've got to involve a LanguageLine service and a translating service [...] and so then there's a third party involved [...] but I think, that's a hindrance because I want to show empathy to these patients and the language shouldn't be the bit that comes in the way of us forming a rapport and a relationship moving forward as their clinician. [CP11]

Some participants mentioned the benefits of having a family member there who knows the patient well and can provide interpretation:

We had an elderly patient the other day who was Italian, in his 80s, with dementia, cannot speak a word of English [...] you have to make sure that the daughter is there [...] at least, you can try and provide good care to them and to him. But it is a barrier, yes, when you come across it. [CP01]

Challenges for those from low socioeconomic status

Challenges extend beyond language barriers. Even with patients who could speak English, obstacles persisted in effectively delivering information, such as prescribing medication and the associated instructions for adherence. Variations in literacy levels and communication skills hindered patients' understanding, particularly those from low socioeconomic status backgrounds, who often faced difficulties in reading and comprehending information:

When I initially started, I basically assumed that everybody was reading or could read [...] I noticed that the demographics is very different from where I live to where I actually work. And the number of patients they couldn't read. [CP10]

Clinical pharmacists identified highly deprived regions in England as having the greatest challenges and a higher concentration of individuals with long-term health conditions:

In the village where I work, it's probably one of the most deprived in England [...] It's just a high prevalence of, like, hypertension, diabetes, coronary heart disease, [...] chronic pain, stuff like that. Yes, it's not a very healthy cohort of patients. [CP04]

Clinical pharmacists highlighted the need for personalised care, which involves getting to know patients on an individual level, understanding their unique situations and backgrounds, and tailoring services to meet their specific needs. This includes factors such as the affordability of meals and the appropriateness of prescribed medications:

A lot of medication you need to take with food. So, if they are not eating, the medication is not being absorbed [...] especially in the wintertime, I have had patients say 'well I can either heat the house or I can have two meals.' And it is then thinking outside the box – how do I change the medication [...] so that they don't need to eat? [CP10]

Stigma as an added layer of complication to health inequalities and providing care to underserved groups

Some participants considered that minority ethnic communities often encounter significant stigma and misconceptions surrounding mental illness, hindering acceptance and support

following a diagnosis. This included accessing and receiving support from the clinical pharmacy service:

You're dealing with cultures who traditionally don't exist in mental health, you know, mental health doesn't exist in their cultures, or it's not spoken about, and there's a lot of stigma. But then you're also dealing with the acceptance of the patients that, they're getting old or they're having trouble with their memory, so it's an added layer of complication to get them to understand that. [CP03]

Some participants thought that such stigma may deter families from seeking support for early signs of cognitive impairment, delaying timely diagnosis and medication initiation. This contributes to social isolation and exacerbates existing health inequalities:

I think culturally people don't want to get their family members officially diagnosed with things like dementia. Because I think culturally there's stigmas and I would say especially in the Indian, Asian culture, that if you've got dementia, you're stupid or something is wrong with you. They don't see it as a disease basically and they see any kind of mental issue as a problem. [CP11]

Involving patients in decision making, ensuring person-centred care

Communication and understanding

Participants described regularly engaging in discussions with both the person with dementia and their family members to ensure shared decision-making in the individual's best interests. This collaborative approach included exploring the person with dementia's perspective on their medication, making their input a central component, empowering them to participate in the decision-making process:

What I tend to do is see what the patient wants first, so what their expectations are and what they want from their medication. So, a lot of them don't want to take too many tablets; I work with the patient to see what tablets we can stop, or which ones we need to continue and why. [CP07]

Participants recognised the importance of involving the person with dementia, and not just addressing family, to promote participation and empowerment and maintain person-centred care:

I just think having the patient there would just transform everything. Because also, it makes the patient feel like everyone's there for them, they care. It makes the carer feel satisfied as well because just having those conversations with patients and carers, with these vulnerable patients, they do feel forgotten sometimes when you're having chats with them. [CP11]

Some participants often opted to engage with carers instead of patients, especially when communication with the patient was challenging:

I'm trying to explore the views of that person, if they can speak for themselves, and to involve next of kin or someone that they trust or knows them well, just to ensure what we're doing with and to a person is what they would consent to or perhaps would have consented to if they could. [CP02]

Factors such as limited experience, lack of confidence, or little knowledge of communication strategies for people with dementia were also cited as potential reasons for engaging with the carer:

I think because we tend to speak a lot to the carers there tends to be general reluctance to speak directly to dementia patients. I think it might be because we struggle as to how we would deal with that conversation. [CP13]

A negotiation with patients and families around medication changes

Some participants reported patient's worry about coming off medication they had been taking for a long time, even though it may have been worsening their cognitive impairment. They felt this could lead to patient risk including polypharmacy and prolonged medication use beyond the National Institute for Health and Care Excellence (NICE) guidelines, which could have detrimental impact on health and the individual's safety:

They're [antipsychotic medication] one of those that are started when there's an acute presentation of agitation, when a patient might have a UTI, or they've moved between a care setting. And then they're [antipsychotic medication] used beyond the six weeks licence period. You get that resistance from the families to say, 'This has made them better. We don't want to stop it.' Versus, it's made them better in the short-term, but in the long-term it's putting them at higher risk of falls, a higher risk to their heart and it's inappropriate to use them beyond the six weeks. [CP05]

Similar challenges arose when deprescribing medications initiated by doctors from both primary and secondary care. In these instances, patients or their carers often expressed reluctance to discontinue treatment when suggested by a clinical pharmacist and preferred a doctor to deprescribe. This may be due to lack of familiarity with the new role rather than due to the individual themselves:

Because we're relatively new having pharmacists in general practice, some patients still have that kind of 'why are you making these changes when it's been my doctor that started them?' So again, establishing those relationships. [CP05]

Along with prescribing challenges, there were challenges related to medication adherence. Healthcare professionals often needed to negotiate changes in medication regimens, involving carers and empowering patients to make informed decisions:

I would explore as to why they don't like taking that medication, sometimes people's perceptions of taking medication are different to what your perceptions are and then I feel it's very much a negotiation. So, I get if it's the size of the tablet then we look at if we can maybe change it to a different kind of tablet, maybe we could cut it in half. [CP13]

Discussion

The aims of this study were to gain a deeper understanding of how clinical pharmacists support diverse patient groups with dementia. Two main themes were developed, around the impact of health inequalities and personalised care, empowering patients and those with dementia.

A key theme generated from the interviews was the role clinical pharmacists can play in providing personalised care, involving both the patient and carers in decisions around their health, such as medication changes. Important skills centred around listening, communication, and negotiation in delivering person-centred care. Involving individuals to engage in conversations and decisions about their care may help to empower people with dementia and families, which is particularly

important for minority groups or those who have previously been disempowered and marginalised. Empowerment and engagement in conversation, may help to develop trust, leading to higher levels of adherence and more equitable care (Hickmann et al., 2022). While participants recognised the importance of direct patient involvement, many opted to communicate with carers or family members instead. This was potentially influenced by factors such as a lack of confidence or experience in interacting with people with dementia. Research has highlighted the importance of including both the person with dementia and carer in consultations and promoting person-centred care. The quality of the relationship between the person with dementia and their carer, underpinned by trust, is crucial, and clinician understanding of the factors that support or disrupt this dynamic is essential (Tuijt et al., 2021). It is important for clinical pharmacists to adeptly balance the communication needs of both the patient and carer to optimise care (Dooley et al., 2015). Awareness of the uniqueness of each member of the 'triad' of healthcare professional, carer and patient is important, and efforts made to understand how differing relationships can impact care provision. Families may be divided or there may be culturally specific needs meaning carers and patients may have their own values and considerations (NICE, 2018).

Developing guidelines for clinical pharmacists and healthcare professionals on navigating the dynamics between patients and carers, while also fostering patient autonomy, would be valuable. These guidelines should emphasise person-centred care, as evidence suggests that such an approach enhances the quality of life for individuals with dementia (Ballard et al., 2018). Barnett et al. (2016) proposed a person-centred framework for deprescribing and managing polypharmacy in older adults, which integrates both the patient's and clinician's priorities. This approach facilitates effective communication and shared decision-making during medication reviews (Barnett et al., 2016). Together with guidance and frameworks, training on communication involving negotiation skills and person-centred care for people with dementia, supported by use of interactional techniques or visual aids to support comprehension might be beneficial (Collins et al., 2022).

Negotiation within medication reviews with clinical pharmacists was noted by participants. This has been demonstrated in recent research of medication reviews, which report a change in the decision-making process from being about and for the patient, to involving the patient in a dialogue to reach agreement about medication changes (Swinglehurst et al., 2023). Patients value relationships with clinicians who are good listeners and feel they can negotiate choices in a supportive environment (Sumpton et al., 2021). These are skills that should be developed with all healthcare professionals, to enhance patient satisfaction and delivery of personalised care.

The significant impact of health inequalities on patient care was highlighted throughout the interviews. Certain groups, often facing barriers such as stigma or language challenges, experienced disproportionate difficulties in benefiting from clinical pharmacy services. These deep-rooted societal inequities which have long hindered care provision, now extend to and pose significant challenges to accessing the clinical pharmacy service. However, it was also simply expressed through some pharmacists only addressing and communicating with carers and neglecting the voice of the person with dementia themselves, created an inequality in itself for people with dementia to be able to communicate their needs and concerns.

Communicating with patients whose first language was not English presented challenges. Communication and meeting patient needs effectively is an important prerequisite for successful patient outcomes and healthcare access (Hadziabdic et al., 2011). The use of third-party services such as LanguageLine (LanguageLine Solutions, 2024) may provide a solution, but some participants did not discuss these services, suggesting a potential lack of awareness about them. A recent study of NHS clinicians found 95.6% of clinicians agreed cultural and language differences impact patient care, with 71.8% being aware of the LanguageLine and actively using it with patients (Irimia et al., 2024). Despite this, building rapport and expressing empathy were reported to be hindered by third-party interpretation. Involving carers who speak the patient's language can be a potential solution. However, this approach is not universally applicable or appropriate as many people do not receive support from family members or friends. In situations where family may not be available, this can result in reduced comprehension, poorer medication adherence and worsening prognosis for the patient (Crane, 1997).

This study builds on the current evidence base of healthcare professionals' experiences regarding delivering care, including dementia care, for patients from minority ethnic groups. Our findings mirror other studies in observing that certain health conditions, such as dementia, carry a stigma within minority ethnic communities that prevent or delay seeking support from primary care teams (Linney et al., 2020; Nielsen et al., 2021). This reduced access to healthcare professionals, including clinical pharmacists, can increase health disparities and negative outcomes. Another study revealed significant disparities in dementia care between minority ethnic and white British patients. Black African and Black Caribbean people with dementia were more likely to experience psychotic symptoms and less likely to receive antidepressant treatment compared to their White counterparts. South Asian patients exhibited higher rates of depressive symptoms, while all ethnic minority groups demonstrated increased odds of polypharmacy (Tsamakis et al., 2021). To overcome these challenges, clinical pharmacists and healthcare professionals alike need to develop a greater awareness and understanding of the barriers faced by ethnic minority groups and how to overcome them. This could potentially equip clinicians with the tools necessary to effectively access and deliver good care and medication support (Levkovich et al., 2021).

Clinical pharmacists are medication specialists who are able to support with medication optimisation for diverse groups of patients who have chronic health conditions (N. H. S. England, n.d.). Beyond medication review, their role extends to patient and carer education, multidisciplinary team collaboration, and proactive management of drug-related problems (Burnand et al., 2025). However, our study reveals critical needs to enhance their ability to effectively support diverse patient groups with dementia, particularly in the areas of specialised communication techniques and culturally sensitive care training. Training should include practical strategies for communicating with patients with cognitive impairment and cultural competency training should address the specific cultural practices that may influence dementia care in different minority ethnic groups.

Strengths and limitations

To our knowledge, this is the first study to review clinical pharmacists' experience of supporting people with dementia,

considering this from an inequalities lens, and addressing barriers and potential solutions when delivering dementia care. Although our sample is small, it contained a wide range of participants with varied experience in dementia care which gathered a broad range of perspectives, and as our aim was narrow and the quality of the data was high, the concepts of information power would suggest our sample is sufficient (Malterud et al., 2016). The semi-structured nature of interviews allowed flexibility and encouraged reflection by the clinical pharmacists on delivering inclusive and personalised care. The study is however limited by participation of pharmacists only working in England, and, although we sampled a diverse range, findings may not be transferable to other countries or other parts of the UK and different healthcare systems worldwide.

Conclusions

This study aimed to understand the experiences of clinical pharmacists in supporting people with dementia and considering inequalities in care. Key themes of inclusive and personalised care and patient empowerment were developed. However, significant health inequalities, particularly affecting minority ethnic groups, were evident in hindering efficient and equitable care provision. Clinical pharmacists need to be confident in their negotiation and communication skills to enable them to be able to effectively tailor their approach to the individual's needs, family situation, culture, literacy and background. A focus on personalised care can help to close the gap in health-related inequalities. Addressing health inequalities and enhancing cultural competence within the healthcare system are crucial steps towards improving care for everyone. Research and policy should focus on developing practical strategies and guidance to overcome these challenges and enhance the role of clinical pharmacists in supporting diverse populations.

Disclosure statement

No potential conflict of interest was reported by the authors.

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Data availability statement

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

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