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The clinical decision-making process involved in end of life care for people with dementia in primary care: A protocol paper

Cathryn Smith[1] | Paul Gill[2] | Jessica Baillie[1]

[1]School of Healthcare Sciences, Cardiff University, Cardiff, UK

[2]Department of Nursing, Midwifery and Health, Faculty of Life Sciences, Northumbria University, Newcastle upon Tyne, UK

Correspondence
Smith Cathryn, School of Healthcare Sciences, Cardiff University, Cardiff, UK.
Email: smithcl4@cardiff.ac.uk

Abstract

Aim: This article is a report of a study protocol designed to explore what factors inform healthcare professionals' clinical decision-making when providing end of life care for people with dementia in primary care.

Design: The proposed study will adopt a qualitative study design, utilizing an ethnographic approach.

Methods: A mixed sample group of registered healthcare professionals, including district nurses, specialist nurses and general practitioners, will be purposively sampled and recruited from one health board in Wales, which will cover three settings in primary care. A multi-method approach will be utilized to provide rich data, including non-participant observation, semi-structured interviews, and review of key documents. Data will be managed using NVivo 12 and analysed thematically. Ethics approval was gained in April 2022.

Discussion: Little is known about the end of life care decision-making process of healthcare professionals caring for people with dementia in primary care settings. This study will therefore address this pertinent gap. The study findings may also be transferable to healthcare professionals working in similar clinical settings across the UK.

Impact: It is anticipated that this study will inform the subsequent development of an intervention that can be used by healthcare professionals to support decision making and subsequently the provision of quality end of life care in primary care for people with dementia.

KEYWORDS
decision-making, decision-making, dementia, end-of-life care, ethnography, primary care, study protocol

1 | INTRODUCTION

The worldwide population is living longer and people are therefore living with age-related illnesses such as dementia, thus there

is considerable concern for the provision of future health and social care (World Health Organisation (WHO), 2017). World Health Organisation (WHO) (2017) states that in 2015 47 million people were affected by dementia worldwide, with a prediction that this

could rise to 75 million by 2030. Dementia is therefore one of the primary causes of mortality and morbidity internationally, making it high on the agenda in global healthcare education, policy, and research (World Health Organisation (WHO), 2017). Dementia is debilitating and life-limiting and palliative care can promote quality of life for people with dementia approaching end of life (World Health Organisation (WHO), 2017). The umbrella term dementia is used to describe a variety of progressive conditions that affect the brain, these include a diversity of symptoms associated with both memory and thinking skills. As dementia progresses, these symptoms become severe enough to affect everyday activities, resulting in multi-professional care from relatives, community nurses, general practitioners (GP), nurse specialists, care home staff and the wider multi-disciplinary team (MDT). Consequently, this will place an increased demand on the health service to address the increase of patients needing care who are diagnosed with dementia.

People with advanced dementia experience a range of symptoms, the disease process is complicated, and its progression is variable. This complexity, alongside the added complication that people with dementia also typically have additional comorbidities, means that there is no specialist best suited to provide care or have a clearly defined role at the end of life, thereby compromising continuity of care. People with dementia having to undergo burdensome interventions and changes in care at the end of life (EoL) have been discussed extensively in the literature, with numerous areas needing improvement to enhance decisions being made and the quality of care being received (Champion, 2017; Toscani et al., 2015). This alongside the relative lateness of diagnosing dementia, the loss of cognitive abilities associated with the disease, a reluctance to discuss death and dying post diagnosis, and the challenges associated with predicting an EoL trajectory, makes EoL decision-making vitally important to understand and ensure good quality of care (Champion, 2017; Toscani et al., 2015).

In response, this protocol describes a study that will investigate the decision-making process of healthcare professionals when providing end of life care (EoLC) for people with dementia in primary care.

2 | BACKGROUND

Palliative care has been well-established for providing support and care for people with terminal cancer, and it must be recognized that dementia is a condition that requires palliative care at some point in the course of the disease trajectory (World Health Organisation (WHO), 2017). There are numerous definitions of palliative care, which all encompass quality of life, family-centred care, support and treatment of pain and symptoms. EoLC is a significant component of palliative care involving care, support and treatment for people who are nearing the end of their life. Both palliative and EoLC involve key decision making by healthcare professionals, which involves the careful use of evidence-based literature, clinical expertise, and the patient's wishes to promote quality healthcare (Davies et al., 2016).

Making decisions around EoLC can be more emotionally and clinically complex for clinicians with decisions needed around treatment options, plan of care and careful consideration around the overall benefit of these decisions to the patient (Anstey et al., 2016). The tension that surrounds decision making can lead to many healthcare professionals using heuristics, shortcuts, "rule of thumb" approach and can cause systematic mistakes, introducing errors and potentially biased judgements (Davies et al., 2016). Nevertheless, complex decision making in healthcare is inevitable, and in EoLC it plays a significant part in the care process and when initiating appropriate and timely care (General Medical Council 2010).

Primary care is defined as the service that provides access to care in the local community to help meet the health and wellbeing needs required for any individual (Public Health Wales, 2019–2020). It is the first point of contact with the National Health Service (NHS) for most people and is made up of numerous services such as district nursing teams and GPs surgeries (Public Health Wales, 2019–2020). Primary care is at the forefront for identifying, assessing, and planning care for people with dementia: most people living with dementia will be cared for in primary care (Amador et al., 2019). However, little is currently known about the decision-making process that takes place for people with dementia at the EoL in primary care alone, and consequently, evidence to guide quality EoLC for people with dementia in this setting is lacking. Yet, even with the shortage of specific guidance, decision-making in healthcare is inevitable. It is therefore important that healthcare professionals who are key decision makers should represent a clear identification of the EoL stage and ensure decisions are formed through a consensus with other professionals (Jox et al., 2010). When making clinical decisions on EoLC, healthcare professionals must consider a decision-making method that incorporates a variety of relevant factors that ultimately puts patient comfort as its primary objective. Consequently, further research needs to focus on understanding how and why healthcare professionals make their decisions and reasoning behind these decisions when caring for people with dementia at EoL in primary care.

A review of the literature established that existing, relevant research primarily explored the need for palliative care referrals, the influences on decision making, and the decisions made by health and social care professionals working across secondary care and long-term care facilities. Overall, the palliative care needs of people with dementia are under-estimated and under-treated on a global level, with patients experiencing barriers to care services and accessing care (Courtright et al., 2020). Much of the literature focused on advance care planning and health professionals' and families' perspectives of EoLC for people with dementia. Most qualitative studies concluded that there are many challenges and barriers that healthcare professionals face when providing EoLC (Courtright et al., 2020). While some studies have identified decision-making differences, little is known about the decision-making process that takes place for this patient group in primary and community care settings.

The following key themes were developed from the literature: education for healthcare professionals; support of the professional

role; organizational boundaries; decision making; and professionals' values and beliefs.

2.1 | Education for healthcare professionals

Numerous studies identified the need for additional education around EoLC for people with dementia for healthcare professionals to improve quality of care (Champion, 2017; Courtright et al., 2020; Koppitz et al., 2016; Riet Papp et al., 2015; Sinclair et al., 2019). Factors such as poor recognition and identification of deterioration, level of education, confidence, knowledge, and boundaries, ultimately affected professionals' decision making and were therefore associated with diverse and limited palliative referrals and EoLC. Champion (2017) and Courtright et al. (2020) found that appropriate education plays a vital part in healthcare professionals providing suitable EoLC, which is consistent with the wider literature (Anstey et al., 2016).

Riet Papp et al. (2015) conducted a multi-country (*n* = 6) experimental case vignette study with health and social care professionals (*n* = 84) across 13 long term care settings. The study indicated a clear divide, not only between countries, but in countries, showing different opinions about the point at which the palliative phase was identified. Some of the professionals considered that palliative care should commence in the early stages of dementia, whereas others considered the last days of life as the appropriate time to commence palliative care. Koppitz et al.'s (2016) Grounded Theory study also found that decision making was affected by the level of education of the nurse, this study was based in Switzerland were nurse education levels range from tertiary to second level education. Study results included the importance of education regarding nurses' abilities in observational assessment such as behavioural and symptom focused observations. Participants reported that seeking advice from colleagues who were educated to a higher level was pertinent to effective decision making, thus adding to the need for collective learning and the importance of education, where the transfer of knowledge can be disseminated (Koppitz et al., 2016).

2.2 | Support of the professional role

Support for professionals making clinical decisions is vital, as decisions around care, treatment and medication at the EoL can be clinically complex and emotionally distressing. When considering dementia and its disease trajectory, it is important to use the fundamental human rights of decision making and draw on a proactive, collaborative approach, as the situation is diverse and challenging due to the disease trajectory (Sinclair et al., 2019). Qualitative research from Sinclair et al. (2019) focused on supportive decision making for people with dementia and not specifically on EoLC. The results clearly portrayed the importance of

a 'supportive toolbox' that included both generic and specialist skills to support professionals in making decisions. Despite this, participants reported having access to different education sessions and resources, suggesting the need for a more readily available approach to education or being aware of relevant services available to help (Sinclair et al., 2019). It was also reported that there is little supportive guidance and knowledge of pathways to care, and the need for easy access to training for all professionals (Champion, 2017; Koppitz et al., 2016).

2.3 | Organizational boundaries

Numerous studies indicated variability in the organizational boundaries in health and social care and how this affects professionals' decision making and care provision. There seems to be constraints around system structures and the need to objectively measure patients' functioning and need for care (Sutherland, 2020). Sutherland (2020) conducted a qualitative interpretive descriptive study exploring EoL decisions that nurses make for residents in their care with dementia. The study found discrepancies in nurses' ideologies and professional accountability that therefore resulted in role distinctions and constraints around decision making, which is consistent with findings from the wider literature. Three qualitative studies reported organization structures such as a lack of formal policies that led to a disconnection of services, which then complicated decision making (Lamahewa et al., 2018; Sutherland, 2020; Sutherland et al., 2019). While Courtright et al. (2020) reported on the impact of organizational factors on the care and decision making for people with dementia at EoL, this study was conducted in secondary care and therefore may not represent the difficulties in primary and community care identified by Lamahewa et al. (2018) and Sutherland (2020). Constraints are apparent around system structures and the need to objectively measure patients' functioning and need for appropriate care.

2.4 | Decision making

Five studies discussed decision making related to EoLC for people with dementia (Champion, 2017; Courtright et al., 2020; Sinclair et al., 2019; Sutherland et al., 2019; Toscani et al., 2015). A cohort study by Toscani et al. (2015) found that an array of decisions was made about the use of medication, hydration and admission to hospital. Yet interestingly, there were no decisions made specifically to the initiation of EoLC coinciding with the findings from Champion's (2017) study where registered nurses were low in confidence in decision making on palliative care. Interestingly decisions made around EoL and palliative care were also affected by patients' families. If family members had resisted palliative care, then the decision was made not to refer to or initiate palliative care (Sinclair et al., 2019).

2.5 | Values and beliefs of professionals involved in EoLC

Several studies indicated the role that values and beliefs of healthcare professionals has on decision making (Riet Papp et al., 2015; Sutherland, 2020; Sutherland et al., 2019). In the literature there seemed to be tension between rational and emotional decision making. Sutherland et al.'s (2019) study emphasized the conflicting tension between values and care priorities relating to EoLC decision making, which ultimately reinforced role boundaries in long term care facilities. It was found that values and beliefs of professionals seemed to be outweighed by organizational pressures, and some participants viewed decision making as a rational responsibility lacking any form of emotions (Sutherland et al., 2019). Lamahewa et al. (2018) found that conflict emerged when personal values and ethos differed from clinical guidelines and regulations. This conflict occurred both internally and externally to the organization and occurred between professionals and family members when values and beliefs differed, leading to difficult decision making. Rigid routines and guidelines hindered and/or stopped professionals' autonomy and values on decision making (Lamahewa et al., 2018).

The review of the literature established that existing, relevant research primarily explored the need for palliative care referrals, key factors that informed decision making, and the decisions made by health and social care professionals working across secondary care and long-term care facilities. Only three studies were found to have conducted part of their research in primary care, and in all three, the number of participants representing primary care only ranged from 30–80 with one study not stipulating the number of primary care participants included. Furthermore, only two studies were conducted in the UK, and even though most of studies were conducted in countries with a similar healthcare system to the UK, there remains some potential differences in related social and cultural issues, health structures and organizations.

Furthermore, much of the published literature around healthcare professionals' EoLC decision making for people with dementia utilized a single method of data collection. The use of multiple methods, including observation, may therefore offer additional insights into participants' views and actions (Hammersley & Atkinson, 2019). Although some of the studies included in the literature review identified variations in the clinical decision-making process, little is currently known about the decision-making process that takes place for this patient group in primary care alone. Thus, there is a significant gap in the research with regard to decision-making of healthcare professionals on EoLC for people with dementia in primary care.

3 | THE STUDY

3.1 | Aims

The study aim is to explore what factors inform healthcare professionals' clinical decision-making when providing EoLC to people with dementia in primary care.

The study will look to answer this by:

1. Observing healthcare professionals' recognition of deterioration in people with dementia and establishing their clinical decision-making in EoLC;
2. Establishing if there are any facilitators and/or barriers associated with recognizing the deterioration of people with dementia at EoL;
3. Ascertaining the factors that influence clinical decision-making about preferred place of care (should that place of care change during this time); and.
4. Generating evidence to support the development of an intervention that can subsequently be tested in primary care to inform the clinical decision-making process in EoLC for people with dementia.

3.2 | Design and methodology

To meet the aim and objectives, this qualitative study will adopt an ethnographic approach. Ethnography uses reasoning and judgement to uncover meaning, describing the focussed actions of people in various situations to achieve an understanding and pattern of human behaviour (Hammersley & Atkinson, 2019). In healthcare research, ethnography can be used to explore service delivery and interactions in real-world settings. While classic ethnographies are typically conducted in a single site for an extended period of time, applied ethnography enables the inclusion of multiple sites over a shorter time period (Savage, 2006). Applied ethnography will therefore be undertaken in this proposed study to meet the aim and objectives, adopting established methods of ethnographic data collection and analysis in a shorter timeframe across several sites. Notably, no ethnographic studies were identified in the literature review relating to this topic.

A constructivist paradigm will be adopted in the study. Constructivism attests that reality is socially constructed, therefore making it relative to a specific context (Mann & MacLeod, 2015). Constructivism suggests that individuals create meaning through interactions, thereby constructivist research aims to comprehend the 'how' and 'why' of events and to understand how individuals make sense of these events (Mann & MacLeod, 2015). Therefore, a constructivist approach will be adopted to explore the factors that influence decision making in the social context of primary care.

3.3 | Setting, sampling and recruitment

The study will be undertaken in one NHS health board in Wales, in three settings in primary care: one rural, one urban and one metropolitan. These three settings have been chosen to establish a broader, comprehensive insight into the different socio-demographics. It is important to establish equity in care delivery, by understanding the impact that geographic access has on service

delivery, development and planning can help initiate equality in care for people with dementia at EoL. Geographical location also influences palliative care and place of death. A systematic review, which included studies from 13 countries with over 1.5 million patients, found that healthcare service variability influenced place of death due to service location alongside other factors such as socio-demographics and support from social care (Gao et al., 2018). This therefore challenges the conventional belief that every healthcare professional equally provides unequivocal treatment; yet from previous research it is clear to see that this is not always possible, and factors such as demographics have an overall effect on primary health care services.

The phenomenon of interest in this study is EoLC decision making, therefore, all healthcare professionals who are actively working in primary care in the study sites and have experience in providing EoLC in the community to people with dementia at EoL will be eligible to participate. A purposive sample of healthcare professionals will be recruited to ensure that the participants can meaningfully represent the target population (Patton, 2015). Participants will be identified and recruited into the study by the senior nurse in primary care and GP Neighbouring Care Network lead (NCN). Both the senior nurse and the GP NCN lead will be gatekeepers, supporting the identification of eligible participants. Participants will be recruited from different health professional backgrounds, including community nurses, GPs, palliative care nurses and community mental health nurses, to reflect the key professionals involved in EoLC decision making outlined in the inclusion and exclusion criteria (Table 1).

The theory behind information power was utilized to determine the sample size transparently. Information power emphasizes the importance of methodological principles to estimate sample size, the more information power the sample holds the lower number of participants are needed (Malterud et al., 2015). For this study, the sample of participants will be experts in their field of care, clinical decision-making on EoL is made continuously in the MDT meetings and therefore the sample size need not be large to facilitate data saturation (Malterud et al., 2015). It is therefore anticipated that a sample size of 10 healthcare professionals (GPs $n = 2$; specialist nurses $n = 2$; community nurses $n = 6$) will be recruited from each study site, therefore 30 participants will be recruited in total.

3.4 | Data collection

The triangulation of methods and data is important in ethnographic research, the multi-method approach can provide an understanding of organizations and compare what people do and say in a particular setting, ultimately adopting an iterative approach during data collection as one method can illuminate another (Hammersley & Atkinson, 2019). Therefore, three data collection methods will be used in this study: non-participant observation of MDT meetings, semi-structured interviews and document analysis, which will involve the extraction of local and national policies, frameworks, and guidelines on decision making around EoLC for people with dementia. The lead author will conduct all data collection across the three sites.

3.4.1 | Non-participant observation

Using observation in healthcare research enables better understanding of the practices and processes in a particular setting by engaging with participants in their own environment (Jones & Smith, 2017). Participants will be observed in practice during specific multi-disciplinary meetings relating to care needs for patients at EoL, such as palliative care meetings and virtual ward round meetings. The clinical decision-making process will be observed, including discussions between healthcare professionals. The observations are anticipated to last around 30–90 min, the length of the meeting, and post-observation questioning will be used for further clarity if appropriate with participants who have consented to be observed. Brief fieldnotes will be documented during the observations, which will be expanded and written in full after the observation has taken place.

3.4.2 | Semi-structured interviews

Interviewing participants is particularly important in generating data and information about events and can help to confirm data generated through observations (Hammersley & Atkinson, 2019). Semi-structured interviews will be undertaken

TABLE 1 Inclusion and exclusion criteria.

Inclusion	Exclusion
Registered health care professionals	Allied health professionals, such as dietitians, physiotherapist, occupational therapists
Health Professionals with primary care experience of over one year to ensure adequate exposure to EoLC in this setting	Professionals with no or less that one year primary care experience
Health Professionals with EoLC experience of one year and over	Professionals with no or less than one year EoLC experience
General practitioners with EoLC experience	Student health care professionals
Registered nurses of all banding	

with healthcare professionals who have been observed. Ethnographic interviews that are semi-structured in nature include questions that are mostly open ended, allowing flexibility and conversations to take place that seeks clarification (Hammersley & Atkinson, 2019). A topic guide (Table 2) will be used in the interviews, facilitating further exploration of the research question, ensuring flexibility and allowing for probing to ensure individual contextualization. The topic guide (Table 2) was developed following the literature review and in relation to the aim and objectives of this research.

Following the development of the topic guide and prior to the interviews taking place a pilot interview will be conducted, this will help provide a sense of appropriateness and feasibility of the topic guide, pace of interview and to make any necessary adjustments to the questions (DeJonckheere & Vaughn, 2019). Interviews will be conducted by one researcher and are anticipated to last up to 45 min. Interviews will be conducted either virtually or face to face, dependent on participant choice, and will be audio recorded with participants' consent. For interviews conducted virtually, a separate audio recording device will be used to record audio and not the platform itself. Microsoft Teams has been chosen as this is compatible with NHS devices. Online interviewing can be flexible and convenient, providing the opportunity to overcome barriers associated with face-to-face interviews such as financial constraints and geographical dispersion (Gray et al., 2020). Crucially, online interviewing can have comparable interaction to face-to-face interviews (Gray et al., 2020). Researchers can collect data in a multimodal way, and therefore if required, online interviewing will be used as a sole method or alongside face-to-face interviewing in this study.

3.4.3 | Documents

Documentary analysis will involve the extraction of local and national policies, frameworks, and guidelines on decision making around EoLC for people with dementia. There are many examples of the benefits of using documentary analysis in ethnographic studies such as accessibility, being a reliable source of data and being easy to manage (Hammersley & Atkinson, 2019).

3.5 | Data analysis

The data will be analysed thematically, where interview transcripts, fieldnotes and documents will be read, key patterns identified, which will be grouped into themes and categories (Braun & Clarke, 2021). Braun and Clarke's (2021) reflexive thematic analysis can be used with different methodologies, including ethnographic research, such as the study by Roudsari et al. (2015) and Ihlebeak (2020). In line with the constructivist paradigm, the research team will develop concepts to make sense of the data collected, recognizing that these are socially produced by the research team (Braun & Clarke, 2006). Understanding the concepts will help identify features and patterns of action, this will also involve the focus on official and general informal rules that guide decision making in healthcare. The data will be individually read many times to become familiar with any patterns, connections and similarities. In ethnographic analysis organization of the data is the first stage, generating ideas and conceptualizing these. A relationship between all the data collected from all methods will be sought by the development of categories that will encapsulate sections of the data relevant to the research aim and objectives (Hammersley & Atkinson, 2019).

TABLE 2 topic guide.

Main questions	Probes	Clarifying questions
Can you please share your experience of making decisions on end-of-life care EoLC for people with dementia?	Clarify why you find it easy/difficult? Clarify what strategies you use?	
Do you use any aids or support that help in making EoLC decisions?	Clarify what support is available? Clarify why you use additional aids? Clarify what works best for you?	Can you please clarify what you mean by …?
Are there any factors that influence your decision making on EoLC for those people with dementia?	Clarify what these factors are? Clarify how they influence your decision making?	Can you please expand on …? Can you please give some examples of …?
Can you share your experience of recognizing deterioration in people with dementia approaching end of life?	Clarify how you established this?	
What do you feel are the challenges to EoLC services for people with dementia?	How do you feel their access is limited by … not limited by …	

Audio recordings of interviews and observations will be transcribed verbatim. Themes and categories will be generated and organized, adopting an iterative approach. The data will be managed using NVivo 12, all three different methods will generate data that will be looked at individually drawing on the identification of codes. Coding the data will involve repeatedly re-reading the data to develop meaning (Braun & Clarke, 2021). Once this is completed the clarification of the meaning of themes and categories will be explored. Data generated from the three different methods will be treated equally, themes will be created from all data collected ensuring the process brings all data together thematically. The data will be analysed primarily by the lead author, but the co-authors will also support with the coding element of data analysis to promote the quality of the study (Busetto et al., 2020).

3.6 | Rigour

To promote the trustworthiness of the study, Guba and Lincoln's (1989) framework will be utilized. Credibility will be developed through prolonged engagement with participants from the participating NHS organization, providing supporting information on the study. To achieve dependability, a clear audit trail for data collection will be documented ensuring a logical, traceable process. Records will be maintained and supervisor involvement in data analysis will be adopted to inform theme and theory development and limit the potential for lone researcher bias. Transferability to other settings will be aided by providing rich descriptions of the findings. Lastly confirmability will be established when the three previous standards have been achieved, this will also include the use of triangulation of methods and participants to ensure rich data.

Reflexivity will be addressed through awareness of the researcher's role in the study. It is important to question the way of doing and become aware of how interpretation can be influenced by assumptions, enabling the research to be open to change and adaptive in response to the reflexive process (Hammersley & Atkinson, 2019). A reflective journal will be maintained throughout the research process to facilitate a reflexive approach.

3.7 | Ethical considerations

The study will be undertaken in accordance with the Health Research Authority (HRA) UK Policy Framework for Health and Social Care Research (Health Research Authority (HRA), 2017), alongside the research governance policies of the host University. Ethics approval was obtained from the host university in April 2022.

Written informed consent will be taken by the researcher following a comprehensive explanation of the study to eligible participants. The consent process will not be a one-off event but will run throughout the data collection process. A Participant Information Sheet (PIS), written in accordance with Health Research Authority (HRA) (2017) guidance, will be provided to all eligible participants. If data need to be collected electronically, electronic consent forms will be used where participants will initial all statements and sign using an electronic signature. If participants are unable to provide an electronic signature acceptable for this research then a paper copy will be used. All participants will also be aware that they can withdraw at any time without prejudice, which is stipulated in the PIS and consent form.

Anonymity and confidentiality will be maintained throughout the research. Discussions from interviews will be anonymized following the interview and all participants will be given a pseudonym. All information gathered will be kept confidential in accordance with the Data Protection Act (UK 2018).

3.8 | Patient and public involvement

Patient and public involvement (PPI) has informed the design of the study and will continue throughout the research. PPI in research is fundamental to research design, ethical conduct, and dissemination of the results (Bagley et al., 2016), advocating the voice of the people affected by a condition. A stakeholder advisory group (including people with dementia, a carer and a healthcare professional) has been established and meets to discuss the study progress, including the study aim and objectives, PIS and consent form. Effective PPI can promote high-quality research, ultimately benefitting healthcare services, patients and the public (Bagley et al., 2016). In dementia research, there is a growing appreciation of the need for meaningful PPI. While there may be challenges associated with this, involving people in research who are living with dementia allows for the recognition of their viewpoints and perspectives that can influence the design and delivery of the research protocol (Miah et al., 2019).

4 | DISCUSSION

This protocol has outlined a proposed ethnographic study encompassing a multiple method approach of non-participant observation, interviews and documentary analysis. Participants will include community nurses, specialist nurses and GP's from three areas in one health board in Wales. It is anticipated that the findings will help inform the subsequent development of an intervention that can be used by healthcare professionals to support the provision of quality EoLC in primary care for people with dementia. The study findings will be reported according to COREQ guidance (Tong et al., 2007). These findings will potentially be applicable to other similar healthcare professionals working in similar areas across the UK. The results will also have the potential to inform the development of EoLC decision making in similar NHS organizations throughout the UK.

4.1 | Limitations

The proposed study will be a single site study with a small number of participants included in the sample group, therefore the findings cannot be assumed to be representative of a wider population outside of primary care.

5 | CONCLUSION

This protocol has summarized the rationale and design of an ethnographic study to explore factors that inform healthcare professionals' clinical decision-making when providing EoLC to people with dementia in primary care. While there is a plethora of research related to dementia and EoL, there are relatively few studies that focus on primary care and decision making. Therefore, the proposed study will provide an insight into the decision-making process associated with EoLC for people with dementia who reside in primary care. As the prevalence rate of dementia is rising and with most people being subsequently cared for in primary care, it is necessary to ensure that decision-making process is adequate and consistent, to support healthcare professionals in providing high quality end of life care.

AUTHOR CONTRIBUTIONS

CS, PG, JB: Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; CS, PG, JB: Involved in drafting the manuscript or revising it critically for important intellectual content; CS, PG, JB: Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; CS, PG, JB: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*):

1. substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
2. drafting the article or revising it critically for important intellectual content.

CONFLICT OF INTEREST
No conflict of interest has been declared by the authors.

PEER REVIEW
The peer review history for this article is available at https://publons.com/publon/10.1111/jan.15587.

DATA AVAILABILITY STATEMENT
Data sharing is not applicable to this article as no new data were created or analyzed in this study.

PROTOCOL REGISTRATION
Open Science Framework. Link: https://doi.org/10.17605/OSF.IO/VHBXW.

PATIENT AND PUBLIC CONTRIBUTION
A patient and public involvement (PPI) group was set up at the commencement of this study, five PPI representatives have assisted with helping to shape the research proposal and design. Particular emphasis was placed on the research question, aims and objectives, all members also contributed to the participant information sheets and consent forms to ensure comprehensibility. All members will continue to play a vital part throughout the development of the study.

ORCID
Cathryn Smith 🔟 https://orcid.org/0000-0002-9430-0308
Paul Gill 🔟 https://orcid.org/0000-0003-4056-3230
Jessica Baillie 🔟 https://orcid.org/0000-0002-4592-7286

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