Improving identification of patients who are likely to have palliative care needs in primary care in the UK

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Intellectual Property and Publication Statements

The candidate confirms that the work submitted is his own, except where work which has formed part of jointly authored publications has been included. The contribution of the candidate and the other authors to this work has been explicitly indicated below. The candidate confirms that appropriate credit has been given within the thesis where reference has been made to the work of authors.

The work in Chapter 2 of the thesis has appeared in publication as follows: Identification of patients with potential palliative care needs: a systematic review of screening tools in primary care. 2020. Yousuf ElMokhallalati, Stephen H Bradley, Emma Chapman, Lucy Ziegler, Fliss EM Murtagh, Miriam J Johnson, Michael I Bennett.

Study design, data collection, analysis and write-up were performed by Yousuf ElMokhallalati. The contribution of other authors was supervision of the study and feedback. Stephen H Bradley, Emma Chapman contributed as a second reviewer screening studies and assessing methodological quality and risk of bias.

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Thesis Structure

This thesis has been structured and submitted as an alternative style of doctoral thesis, incorporating published material. The thesis includes a total of four studies. Studies One, Two, and Three have been published in peer-reviewed journals, while Study Four will be submitted for publication in a peer-reviewed journal. An introductory chapter precedes the manuscripts, and a discussion chapter follows the presentation of the studies, binding the manuscripts into a coherent piece of work.

Studies One, Three, and Four are presented exactly as published or submitted, with minor formatting amendments to ensure the thesis is a cohesive whole (e.g., table numbers, reference formatting). Some findings from an abstract have been incorporated into Study Two, mainly adding additional findings about access to palliative care. In accordance with the guidance for an alternative style of doctoral thesis, each chapter contains its own list of references.

The alternative thesis style was chosen to maximise the research outputs generated from the PhD. This approach aligns with the Graduate Board at the University of Leeds, which encourages all postgraduate research students to publish and disseminate their PhD results.

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Abstract

Palliative care is essential for improving the quality of life for patients with advanced illnesses, yet timely identification and referral remain significant challenges, especially in primary care settings. This thesis aims to explore the process of identifying patients who may benefit from palliative care, focusing on existing screening tools, barriers to timely identification, and the potential benefits of electronic screening tools.

A systematic review (Study One) identified various screening tools used to identify patients with advanced progressive diseases likely to have palliative care needs. The review found significant variability in the effectiveness and usability of these tools, highlighting the need for more standardised approaches.

Observational studies (Studies Two and Three) used data from the National Survey of Bereaved People (VOICES) to examine factors associated with improved pain relief and end-of-life care experiences. The studies found that receiving specialist palliative care at home and having good continuity of primary care were associated with better outcomes.

A qualitative study (Study Four) explored barriers to the timely identification of patients with cancer in primary care and the potential benefits of electronic screening. Barriers identified included the absence of a systematic approach, resource limitations, and poor communication. The study also highlighted the positive impact of electronic screening tools in improving efficiency and standardisation.

Overall, the findings emphasise the importance of timely identification and referral to palliative care, particularly for patients with non-cancer illnesses who are often underrepresented in palliative care services. The research underscores the need for more inclusive and standardised approaches to ensure that all patients with palliative care needs receive appropriate and timely care.

Table of contents

Glossary

Abbreviation	**Definition**
ACP	Advance Care Planning
ADL	Activities of Daily Living
AOR	Adjusted Odds Ratio
ALS	Amyotrophic Lateral Sclerosis
BER	Balanced Error Rate
BSC	Best Supportive Care
CCG	Clinical Commissioning Group
CI	Confidence Interval
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CNN	Convolutional Neural Networks
COPD	Chronic Obstructive Pulmonary Disease
CPRD	Clinical Practice Research Datalink
CVA	Cerebrovascular Accident
DM	Diabetes Mellitus
DCP	Daily Care Professionals
DN	District Nurses
EAPC	European Association for Palliative Care
eFI	Electronic Frailty Index

EHR	Electronic Health Records
EOL	End-of-Life
GP	General Practitioner
GSF	Gold Standards Framework
GSF PIG	Gold Standard Framework Proactive Identification Guidance
HCP	Healthcare Professional
HRA	Heath Research Authority
ID	Intellectual Disability
IMD	Index of Multiple Deprivation
LACDP	Leadership Alliance for the Care of Dying People
MEDLINE	Medical Literature Analysis and Retrieval System Online
ML	Machine Learning
NECPAL	Necesidades Paliativas [Palliative Needs]
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NLP	Natural Language Processing
NPV	Negative Predictive Value
NOS	Newcastle–Ottawa Scale
ONS	Office for National Statistics
OR	Odds Ratio
PALLI	PALliative care: Learning to Identify people with intellectual disabilities

PC	Palliative Care
PPV	Positive Predictive Value
PRISMA-P	Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols
PROSPERO	International Prospective Register of Systematic Reviews
QOF	Quality and Outcomes Framework
RADPAC	RADboud indicators for PAlliative Care Needs
RCT	Randomised Controlled Trial
RNN	Recurrent Neural Networks
SE	Standard Error
SPC	Specialist Palliative Care
SPICT	Supportive and Palliative Care Indicators Tool
SPSS	Statistical Package for the Social Sciences
SQ	Surprise Question
SRA	Social Research Association
ST	Screening Tool
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology
UK	United Kingdom
UoL	University of Leeds
USA	United States of America
VOICES	Views of Informal Carers — Evaluation of Services
VIF	Variance Inflation Factor

WHO	World Health Organisation

Chapter 1: Introduction

1.1 Chapter Summary

This chapter introduces palliative care, focusing on its definition and goals. It reviews the historical development and expansion of palliative care beyond cancer to various life-limiting conditions. The role and challenges faced by primary care providers in delivering palliative care are discussed, including the timely identification of patients and the use of electronic health records for screening. The final section outlines the aims and objectives of the thesis and provides an overview of the research methods employed.

1.2 What is Palliative care

Palliative care is a multidisciplinary approach that aims to improve the quality of life for patients with advanced, progressive illnesses and their families. The World Health Organisation (WHO) defines palliative care as follows:

"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." (1)

The National Institute for Health and Care Excellence (NICE) in England provides a similar definition for palliative care:

"Palliative care is care given to improve the quality of life of patients who have a serious or life-limiting disease, such as cancer or dementia. The goal of palliative care is to prevent or treat as early as possible the symptoms of the disease, side effects caused by treatment, and psychological, social, and spiritual problems related to the disease or its treatment." (2)

The ultimate goal of palliative care is to optimise the quality of life for both patients and their families. It is designed to be comprehensive, addressing the individual as a whole rather than just focusing on the disease.

Historically, medical professionals have recognised the importance of relieving patient discomfort to improve overall well-being (3). The concept of modern palliative care emerged in response to the needs of patients with terminal cancer (4). In the late 1960s, Dame Cicely Saunders opened St. Christopher's Hospice in London, pioneering a holistic approach to end-of-life care that addressed physical, emotional, social, and spiritual pain (4-6).

Since its inception, the concept of palliative care has broadened and evolved. In 2002, the WHO redefined palliative care to include patients with various diseases beyond cancer and emphasised the importance of early intervention (1). Today, palliative care is considered appropriate for any advanced, progressive illness and can be provided alongside curative treatment (6).

In the UK, the first government-led End-of-Life Care Strategy was published in 2008 (7). Since then, numerous policies and initiatives have been implemented to ensure access to palliative care services for those in need. In 2014, the Leadership Alliance for the Care of Dying People (LACDP), a coalition of 21 national organisations in England, including NHS England, NICE and Public Health England, published national guidance in the 'One Chance to Get It Right' document (8). It identified five priorities for high-quality end-of-life care: recognition of dying, sensitive communication with patients and their families, patient involvement in decision-making, needs of families and others close to the dying person and individual plan of care (8). In 2022, the Health and Care Act was amended to mandate the provision of palliative care and end-of-life care services in all care settings for individuals of all ages (9). This legislative change represents a significant advancement in enhancing the availability and accessibility of palliative care in all settings.

Palliative care can be broadly classified into ‘generalist’ and ‘specialist’ based on the provider (10). Generalist palliative care is delivered by healthcare professionals who have acquired some clinical experience and basic knowledge of palliative care principles without undergoing specialised training in this area (e.g. the General Practitioner) (10-11). In contrast, specialist palliative care is usually provided by a multi-professional team of palliative care specialists who have undergone specialised training in this field to ensure that patients’ and families’ complex needs are met (10,12). Both types of palliative care are essential in providing comprehensive care for patients with advanced and life-limiting illnesses (10). Generalist palliative care can help to identify patients who may benefit from specialist palliative care, while specialist palliative care can provide more targeted and advanced interventions to manage complex symptoms and improve quality of life (12-13).

In recent years, there has been growing evidence to support the effectiveness of palliative care; however, the quality of this evidence remains limited. Numerous studies demonstrate an association between palliative care interventions and improvements in symptom burden (14-17). Patient and caregiver satisfaction is also an important measure of the success of palliative care. Research has shown that palliative care, mainly when introduced early, can lead to higher satisfaction among patients and caregivers due to its focus on individual needs, shared decision-making, and comprehensive care (16,18,19).

Additionally, palliative care has been found to reduce unnecessary hospitalisations and the use of intensive care units, thereby lowering healthcare costs (20,21). Moreover, studies indicate that patients who received palliative care were more likely to have had Advance Care Planning (ACP) discussions compared to those who received standard care (22). Also, there is a significant body of evidence suggesting that palliative care is strongly associated with improved quality of life for patients with various life-limiting conditions (17,23,24).

Despite positive findings, several limitations exist within the current body of research. One major issue is the heterogeneity of study designs, patient populations, and interventions, which complicates direct comparisons and generalisations (15,17). Many studies suffer from methodological flaws, including small sample sizes, potential biases, and a lack of blinding (15,17,24).

1.3 Access to palliative care

According to the World Health Organisation (WHO), approximately 54.8 million individuals globally need palliative care annually (1). It is estimated that in the UK, over 600,000 individuals are expected to die each year, and approximately 75% of them could benefit from palliative care (25,26). Moreover, it is forecasted that there will be a 25% increase in the demand for palliative care by 2040 in England (27). This projected rise can primarily be attributed to the growing elderly population and an increase in life-limiting illnesses (25,27). These expectations underline the urgency for healthcare systems to plan ahead by properly distributing resources and crafting strategies that can efficiently manage the expected growth in the need for palliative care services in the future.

While the UK ranks first in the quality of death index among 80 countries, indicating robust palliative care services and comprehensive national policies, there are still challenges to ensuring equitable access to palliative care for all individuals in need (28-30). Approximately one in four individuals with palliative care needs in the UK are not receiving the necessary support (29, 30). Inequities in access to palliative care are evident across various determinants such as age, diagnosis, ethnicity, geographical location, and level of care (31, 32).

Existing literature highlights an inequity in the provision of palliative care, with patients with non-cancer diagnoses being less likely to receive these services compared to their counterparts diagnosed with cancer (31-34). Several factors contribute to this difference. One significant factor is the unpredictable nature of disease trajectories in non-cancer illnesses, such as heart disease or chronic obstructive pulmonary disease (COPD) (35). The inherent uncertainty poses challenges for clinicians in determining the appropriate timing to initiate palliative care (35-36).

Moreover, the historical association of palliative care primarily with cancer care has resulted in lower awareness and utilisation among individuals with non-cancer illnesses (36, 37). Furthermore, research and policy efforts in palliative care have predominantly focused on cancer, inadvertently affecting the availability and quality of care for patients with non-cancer diagnoses (37-39). Potential gaps in education and training further compound this discrepancy, as healthcare providers may lack the necessary skills or feel less confident in addressing palliative care issues in non-cancer illnesses due to inadequate training (40).

Geographical disparities are significant; people in rural areas and regions with inadequate healthcare infrastructure have poorer access to palliative care providers and facilities, leading to delays and insufficient support (32,41). Socioeconomic, cultural, and ethnic differences also play a crucial role in access to palliative care. Individuals from lower socioeconomic backgrounds and certain ethnic groups may face the greatest inequities in accessing palliative care and experiencing favourable end-of-life outcomes (32-34). Barriers such as financial constraints, language barriers, cultural beliefs about death and illness, and general mistrust in the healthcare system contribute to these disparities (32,33,42). Additionally, age-related disparities exist, with older adults being less likely to receive support from palliative care services (32,33).

1.4 Provision of palliative care in primary care in the UK

In the UK, primary care providers play a vital role in providing palliative care, with around 45% of all deaths occurring under their care either at home or in care homes (39,43). They are fundamental in identifying patients who may benefit from palliative care, performing comprehensive assessments of patients' needs, providing support to both patients and their families, and liaising with specialist teams (44-46).

Primary care professionals are well-positioned to deliver effective palliative care to patients with advanced progressive disease (45,46). The long-standing relationships that GPs and DNs have with their patients make them well-placed to identify patients with palliative care needs at an earlier stage than tertiary services (47,48). When palliative care needs are identified early, primary care professionals can provide personalised and continuous care throughout the patient's journey (48,49). As care coordinators, general practitioners can collaborate with other healthcare professionals and facilitate referrals to specialist palliative care teams when necessary (44). Primary care providers are also equipped to address various aspects of palliative care, including symptom management, psychosocial support, and advance care planning (39,42). They have a holistic perspective, considering the physical, psychological, and social aspects of patients' well-being (48,49). By providing comprehensive and coordinated care, primary care professionals have the potential to ensure that patients receive the necessary support and interventions throughout their palliative care journey, which leads to improved patient outcomes and enhances the quality of life for those with advanced diseases (42).

Overall, primary care is in a unique position to provide high-quality palliative care. However, the delivery of palliative care in primary care settings in the UK faces several significant challenges (50). One of the main barriers to the provision of palliative care within primary care settings is the delay in identifying patients who may benefit from such services (46,51,52). Early identification of palliative care needs is crucial for optimal care provision (46,53). Without clear clinical guidelines or diagnostic criteria to guide their decision-making, healthcare providers cannot always identify when it is the right time to consider palliative care (46,51,52,53). This delay leads to unmet needs, increased hospitalisations, and negatively impacts patients' quality of life (13,14,20,21,46).

Moreover, the role of primary care staff in palliative care can sometimes be unclear, adding to the challenges (39,54). Although primary care practitioners are ideally placed to provide palliative care, they may experience uncertainty about their specific responsibilities and tasks, especially for patients still receiving active treatment from secondary care (54). Coordination of care is another significant challenge for primary care providers (50,54). While they are well-positioned to act as care coordinators, ensuring that all aspects of care are integrated can be difficult, particularly when multiple providers and care settings are involved (54).

The rising number of deaths at home or in care homes means primary care services need to provide a broad range of palliative and end-of-life care (43). This trend reflects many individuals' preference to spend their final days in familiar surroundings rather than a hospital (55, 56). However, providing appropriate palliative care at home or in care homes often requires intensive support and coordination, placing a considerable burden on primary care teams (44). This burden is further exacerbated by the ongoing shortage of GPs and budgetary restrictions (57,58).

Lack of training and skills among many primary care providers, particularly a deficiency in specialised palliative care training, also poses difficulties (50,53). Despite intentions to provide comprehensive care, they may lack the needed expertise to manage complex symptoms and emotional issues (53). Moreover, communication remains a significant challenge, especially when discussing end-of-life matters. Some practitioners may feel uncomfortable facilitating these conversations, leading to delayed or inadequate communication about care options and patient preferences (46, 54,55).

Furthermore, the COVID-19 pandemic has added an extra layer of complexity to these challenges (59). The crisis has led to a considerable increase in the number of people dying at home, which has further stretched the capacity of primary care services (59-61).

1.5 Timely identification of patients with potential palliative care needs in primary care

Early identification of patients who would benefit from palliative care is crucial for effective palliative care provision in primary care (1,64). Timely identification allows healthcare providers to start managing symptoms earlier, providing better support for emotional and psychological well-being, and enhancing the overall quality of life (17,19,23, 62,63).

Central to achieving early identification is the use of screening tools (65). Screening, as defined by the UK National Screening Committee, is "the process of identifying apparently healthy people who may have an increased chance of a disease or condition" (66). In palliative care, screening tools proactively identify patients earlier in their disease trajectory, often before significant deterioration occurs (65). These tools range from simple approaches, such as the Surprise Question ("Would you be surprised if this patient were to die within the next 12 months?"), to structured methods like the Supportive and Palliative Care Indicators Tool (SPICT) (50, 67). More recently, advanced electronic tools integrating artificial intelligence and electronic health records have emerged to standardise and improve patient identification (68).

Despite these advancements, the concept of "early identification" in palliative care remains ambiguous, lacking consensus on optimal timing and clear definitions (69). There is currently no clear, universally accepted definition of what constitutes "early" in this context. The timing that differentiates early identification from late identification is not explicitly established, and this can vary depending on numerous factors, including the specific illness, its trajectory, and the individual patient's circumstances (64,69,70). For example, the Gold Standards Framework (GSF) and the Quality and Outcomes Framework (QOF) in the UK suggest the introduction of a palliative care approach for patients with advanced progressive diseases from 12 months before anticipated death (71,72). In contrast, another perspective argues that early identification should coincide with the diagnosis of an advanced or life-limiting disease (73,74). Conditions such as advanced cancer or heart failure often manifest significant symptom burdens and quality of life issues at an early stage (23,25,74,75). In such instances, integrating palliative care early in the illness trajectory can help manage these symptoms alongside curative or life-prolonging treatments (73,74).

A number of tools have been developed in the UK to aid the identification of patients with potential palliative care needs in primary care, such as the Gold Standards Framework (GSF), the Supportive and Palliative Care Indicators Tool (SPICT), and the Surprise Question (SQ) (76-78). These tools often use a combination of clinical markers and Prognostication to identify potential palliative care candidates (78). Alongside these structured methods, clinical experience is crucial in identifying patients in need of palliative care (47,48,79). Additionally, patient requests can also initiate the consideration of palliative care services (80).

Despite the range of existing tools and strategies for identification, many patients are identified for palliative care at a very late stage in their disease trajectory, sometimes just days before their death (81). Late identification limits the time available for patients and families to fully benefit from palliative care, including symptom management, psychological support, advance care planning, and overall quality of life enhancement (17,19,23, 62,63). Additionally, this can result in end-of-life treatments that may not align with the patient's preferences, unnecessary hospital admissions, and increased strain on healthcare resources (20,21).

1.6 Challenges in timely identifying patients with potential palliative care needs in primary care

Timely identification of patients who could benefit from palliative care in primary care is challenging (81,82). One of the main difficulties is predicting prognosis, particularly in non-cancer diagnoses. The trajectories of non-cancer diseases can be unpredictable and highly variable, making it much more challenging for healthcare professionals to determine when the right time is to introduce palliative care (64,70). The lack of standardisation in determining when to transition a patient to palliative care poses a significant challenge in providing timely and appropriate care (83,84). This challenge primarily arises from the complexity and diversity of patient cases, varying disease trajectories, and individual responses to treatments, making it difficult to establish a universal set of criteria (82,84).

Staff shortages and inadequate training are also significant factors contributing to delayed or missed recognition of patients with potential palliative care needs (52,85). Clinicians are required to assess patients with complex needs and have sensitive discussions about prognosis and end-of-life decisions, which necessitate a particular set of competencies and specialised training (40,52,85). Consequently, many primary care practitioners may not feel equipped or confident to identify potential candidates for palliative care or navigate sensitive end-of-life conversations (40, 85).

Addressing these challenges necessitates a multi-faceted approach, including developing clear, evidence-based guidelines for palliative care initiation, investment in training and resource allocation within primary care settings, and establishing policies that facilitate sustainable financing for palliative care services in primary care (52,77,85,86). With these steps, we can improve the timely identification of patients who may benefit from a palliative care approach and, ultimately, enhance the quality of life for patients with advanced progressive diseases.

Furthermore, these challenges highlight the need for a more standardised and systematic approach to the early identification of patients who may benefit from a palliative care approach in primary care (77,85). Systematic automatic screening holds significant potential for enhancing the early identification of patients with palliative care needs in primary care settings (87-90). This technology-driven approach could improve current methods by standardising the identification process, minimising the potential for oversight, and enabling more timely intervention (89,90).

1.7 The use of electronic health records in patient screening and identification in primary care

Computerised records in general practice in the United Kingdom date back to the early 1970s, initially used for recalling appointments and tracking patients' medical histories (91). Over time, these records have become central to healthcare, aiding in research, quality improvement, and secure communication among staff members (91,92). In the last decade, electronic records have been used proactively to identify patients with potential healthcare needs, such as frailty and heart disease (87,93).

In the United Kingdom, tools like the Electronic Frailty Index and AnticiPal electronic tool utilise electronic health record data to assess health risks and needs (88, 93-95). The Electronic

Frailty Index uses patient data to determine the severity of frailty, while AnticiPal identifies patients with advanced illnesses who could benefit from palliative care (88, 95). Recently, there has been growing interest in incorporating artificial intelligence models into these tools, significantly enhancing their predictive capabilities (89,90). Artificial intelligence-enhanced electronic screening tools in primary care can potentially identify patients who may benefit from a palliative care approach (96,97). These tools use high-quality data to improve and address the limitations of current palliative care identification methods, enabling early identification and fostering timely support and referrals that align with patient needs and preferences (89,96,97). This approach could greatly benefit patients needing palliative care and improve the overall quality of primary care.

However, while electronic screening tools are becoming more prevalent in healthcare, their application and integration into routine practice in the United Kingdom remain limited (89,96). More research is needed to evaluate their usability, applicability, and limitations. Understanding these aspects is crucial for effectively integrating these tools into everyday clinical practice and maximising their benefits for patient care.

1.8 Summary of research problem

Despite the known benefits of palliative care, such as improved symptom control, enhanced patient and caregiver satisfaction, and improved quality of life, many patients who would benefit from such services are not identified until the late stages of their disease or, in some cases, not at all.

Identifying patients who could benefit from palliative care in primary care is a complex and critical challenge. One of the significant barriers to the timely initiation of palliative care is the challenge healthcare professionals face in accurately identifying patients who would significantly benefit from such interventions. In addition, the lack of standardised identification protocols and the complexities of disease progression create significant obstacles to accessing palliative care in a timely manner.

1.9 Aims and methodological approach

This thesis aims to gain a better understanding of current practices and barriers to the timely identification of patients with potential palliative care needs in primary care in England. The findings from this research could provide valuable insights for developing an automated screening tool in the future.

To address this aim, the research is structured around three interrelated objectives:

1. To identify and evaluate existing screening and identification tools used in primary care for patients with advanced progressive illnesses who may benefit from a palliative approach.
2. To analyse population-level data on end-of-life care and examine factors associated with the quality of care and symptom management at home.
3. To explore healthcare professionals' and patients' perspectives on the barriers to timely identification and the potential value of electronic tools in clinical practice.

To fulfil these objectives, mixed methods research design was employed, comprising a systematic review, two observational studies using national datasets, and a qualitative interview study. Each method was chosen for its suitability in addressing different aspects of the overall research question, and collectively they offer a well-rounded investigation of the topic.

The systematic review (Chapter 2) was conducted to synthesise available evidence on identification tools used in primary care. Systematic reviews are a recognised method for examining the scope and quality of existing literature and were used here to assess current practices, highlight limitations, and guide the direction of the following studies (98).

Chapters 3 and 4 present two observational studies using five years of national post-bereavement survey data from England. These studies aimed to: 1) determine the characteristics of good-quality end-of-life care for patients living at home; 2) examine the factors associated with good pain relief at home in the last three months of life for people with advanced progressive illness; and 3) examine the relationship between the extent of pain relief at home, the quality of end-of-life care, and receipt of specialist palliative care. These methods were chosen specifically to allow for the analysis of large, representative datasets that reflect real-world care experiences and to quantify patterns and associations that are not visible in smaller-scale or qualitative research.

Chapter 5 includes a qualitative study based on semi-structured interviews with healthcare professionals and patients with cancer. This method was chosen to explore in depth the barriers to timely identification and views on how digital tools might support earlier recognition of palliative care needs. Qualitative methods are particularly valuable in examining perspectives, challenges, and the practical realities of implementing new approaches (99).

Although these methods vary in approach, they are clearly connected. The systematic review summarises existing knowledge and identifies evidence gaps. The observational studies explore how care is currently being delivered and what factors associated with quality of end of life and symptom management. The qualitative study builds on these findings to understand why these issues persist and how practice might be improved. Together, these studies provide a structured and applied investigation of the challenges in identifying patients for palliative care in UK primary care and offer practical insights to inform service improvement and policy.

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Chapter 2: Identification of patients with potential palliative care needs: a systematic review of screening tools in primary care

Study One	
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2.1 Abstract

Background: Despite increasing evidence of the benefits of early access to palliative care, many patients do not receive palliative care in a timely manner. A systematic approach in primary care can facilitate earlier identification of patients with potential palliative care needs and prompt further assessment.

Aim: To identify existing screening tools for identification of patients with advanced progressive diseases who are likely to have palliative care needs in primary healthcare and evaluate their accuracy.

Design: Systematic review (PROSPERO registration number CRD42019111568).

Data sources: Cochrane, MEDLINE, Embase and CINAHL were searched from inception to March 2019

Results: From 4,127 unique articles screened, 25 reported the use or development of 10 screening tools. Most tools use prediction of death and/or deterioration as a proxy for the identification of people with potential palliative care needs. The tools are based on a wide range of general and disease-specific indicators. The accuracy of five tools was assessed in eight studies; these tools differed significantly in their ability to identify patients with potential palliative care needs, with sensitivity ranging from 3% to 94% and specificity ranging from 26% to 99%.

Conclusion: The ability of current screening tools to identify patients with advanced progressive diseases who are likely to have palliative care needs in primary care is limited. Further research is needed to identify standardised screening processes that are based not only on predicting mortality and deterioration but also on anticipating the palliative care needs and predicting the rate and course of functional decline. This would prompt a comprehensive assessment to identify and meet their needs on time.

2.2 Background

In Europe, 85% of people now die of chronic diseases such as cancer, heart disease, stroke and dementia.[1] Chronic diseases are characterised by slow progression, fluctuations in trajectory, long duration and uncertainty in prognoses.[2,3] During advanced stages of chronic life-limiting illnesses, patients usually suffer high levels of pain and other physical and psychological symptoms.[4,5] At this stage, patients with any progressive disease could benefit from palliative care.[6]

There is evidence from randomised controlled trials that earlier access to specialist palliative care can promote quality of life, reduce hospital length of stay and hospitalisations and even prolong survival.[7–13] However, current evidence shows that palliative care is often delivered late in the illness trajectory, and access to palliative care is inequitable.[14] In the United Kingdom, around 90,000 people with advanced progressive conditions who could benefit from palliative care are estimated not to be receiving such care every year.[15]

One of the key barriers to providing palliative care on time is the difficulty in identifying patients who could benefit from it.[16,17] Once the patient is identified as having potential palliative care needs, their needs can be assessed and addressed in a timely manner. However, not all patients with advanced progressive diseases have unmet palliative care needs. In addition, busy healthcare professionals cannot provide holistic assessment for all of these patients.[18] It has been suggested that a systematic method could facilitate earlier identification of a subset of patients with advanced progressive diseases who are likely to have unmet palliative care needs and hence benefit from palliative care needs assessment.[16,19]

Since most people with chronic diseases live at home in the last phase of their life, primary care teams are in the best position to identify patients with potential palliative care needs who could benefit from palliative care needs assessment.[20–22] Two systematic reviews have assessed the screening tools that can be used for the identification of patients who are likely to have unmet palliative care needs. However, neither of them examined the accuracy of the available tools.[16,19] This systematic review aimed to identify the existing screening tools for identification of patients with advanced progressive diseases who are likely to have unmet palliative care needs in primary care and synthesise the available evidence regarding their accuracy.

2.2.1 Review questions

- What screening tools have been used and studied to identify patients with advanced progressive diseases and potential palliative care needs in primary care?

- What are the main characteristics and differences between these screening tools?

- What is the accuracy of these screening tools?

2.3 Methods

A positivist approach was used to undertake this systematic review and narrative synthesis of the evidence. This research design was selected because the evidence incorporated a wide range of screening tools and included data from different study designs not suitable for a meta-analysis.[23] The details of the systematic review protocol are provided in PROSPERO (CRD42019111568). The systematic review was conducted and reported following Preferred Reporting Items for Systematic Reviews and Meta-Analyses protocols (PRISMA-P) guidelines.[24]

2.3.1 Criteria for considering studies for this review

Types of studies

We included articles that were published in peer-reviewed journals. Commentaries, abstracts, posters, letters to the editor, case reports, reviews and unpublished studies were excluded.

Types of participants

This review included studies examining adults (18 years or older). Studies that reported mixed populations of children and adults were included if data for adults were reported separately. Only studies which included primary care patients or assessed patients in primary care settings were included. Studies which were conducted in mixed settings were included as long as they included primary care patients.

Types of intervention

We included studies that mentioned the use or development of any screening tool to identify patients with advanced progressive diseases who are likely to have unmet palliative care needs in primary healthcare. Any type of screening tool (electronic or manual) was considered as long as it has been used to identify primary care patients with potential palliative care needs. We also included studies evaluating the ability of the current screening tools to identify patients who could have unmet palliative care needs.

Language

The search was restricted to articles reported in the English language.

2.3.2 Search strategy and study selection

We searched Cochrane Library, MEDLINE, Embase and CINAHL. A search strategy for MEDLINE is presented in Appendix A.1. Databases were searched from inception to the end of September 2018. The search was updated in March 2019 to include articles published after September 2018. We searched the reference lists of the included studies and the relevant review articles to make sure that all relevant articles were captured. The search strategies were created by one reviewer (YE) and peer-reviewed by a librarian and an information specialist, not otherwise associated with the project. The search results were imported into a reference management software package (EndNote X7) to remove duplicated references.

Abstracts of all identified studies were independently screened for inclusion by two reviewers. We obtained the full texts of all abstracts that met the inclusion criteria or where there was insufficient information in the abstract alone to determine eligibility. Final article selection was carried out after reading full papers by two reviewers. Disagreements related to screening were resolved through discussion, and where necessary, a third researcher was consulted.

2.3.3 Data extraction

The characteristics of the included studies and screening tools were extracted prior to synthesis. For studies assessing the accuracy of the screening tools, specificity, sensitivity, positive predictive value (PPV) and negative predictive value (NPV) were either extracted from the text or calculated from the reported data. Study authors were contacted to resolve any uncertainties, whenever possible. Data were extracted by one reviewer and double-checked for accuracy by a second reviewer.

2.3.4 Assessing the risk of bias

Two independent reviewers assessed the methodological quality and risk of bias in the studies that examined the accuracy of the screening tools. Disagreements were resolved first through discussion and then by involving a third reviewer for arbitration. For observational studies, we used the Newcastle–Ottawa Scale to assess the risk of bias.[25] The methodological quality of these studies was rated on a scale from 0 stars to 9 stars. Studies were classified into groups of low (less than 6 stars), moderate (7–8 stars) and high (9 stars) quality studies. The quality of randomised clinical trials (RCTs) was assessed using the Cochrane Collaboration’s tool for assessing the risk of bias.[26] This tool evaluates seven possible sources of bias. For each individual domain, studies were classified into low, unclear and high risk of bias.

2.3.5 Strategy for data synthesis

A narrative synthesis was used with information provided in the tables and text to describe and summarise the main findings and features of the included studies and the identified screening tools.

2.4 Results

2.4.1 Selection of studies

We identified 6,203 records through the database search and other sources (Figure 1). Of these, 2,076 duplicates were removed, leaving 4,127 publications for title and abstract screening. Fifty-seven articles remained following the review of title and abstract. An additional 32 articles were excluded following a full-text review, resulting in a total of 25 articles. Of these, only eight evaluated the accuracy of screening tools. No studies were excluded based on their quality assessment.

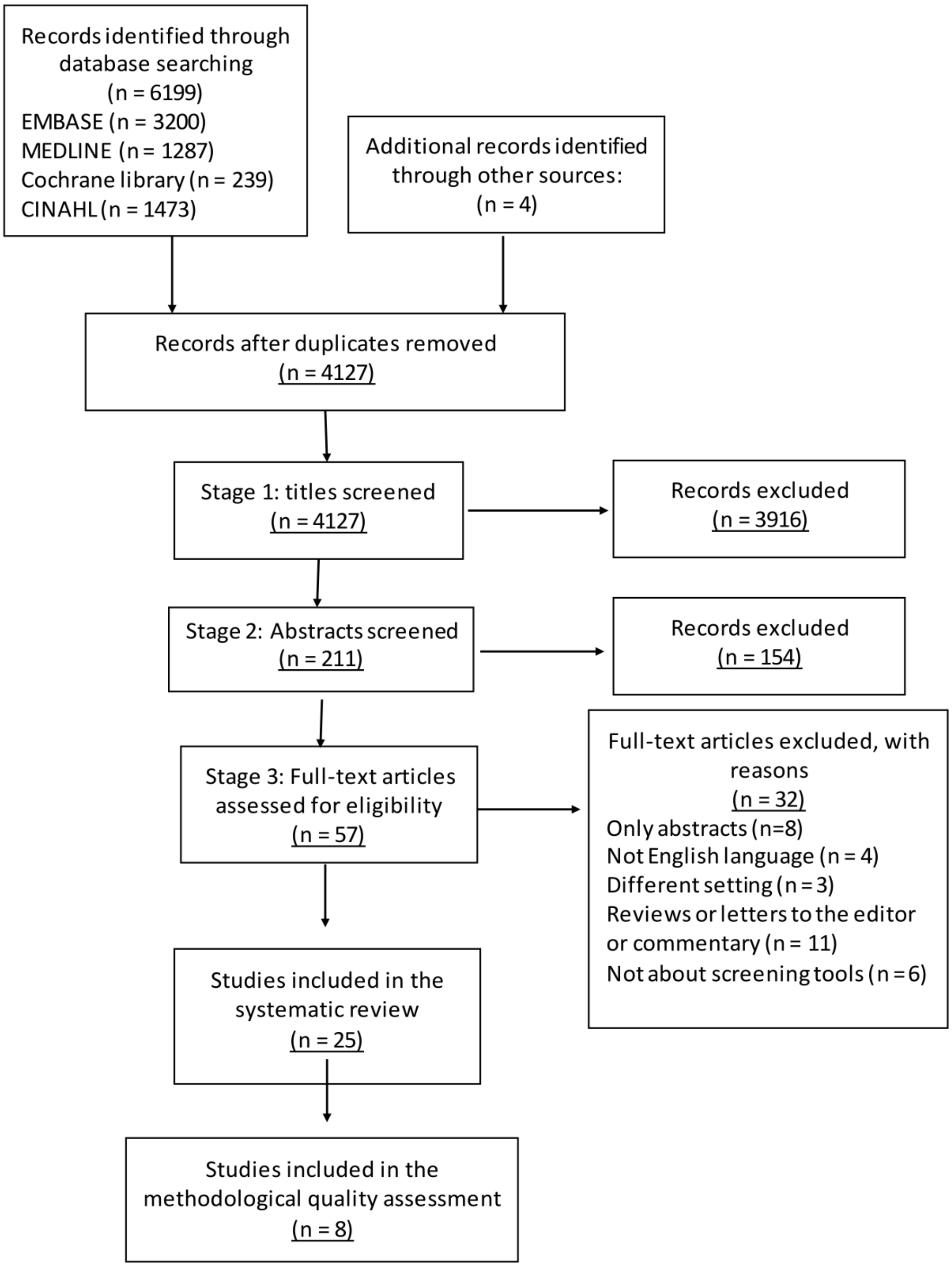

Figure 1. PRISMA flowchart of the study selection.

2.4.2 Characteristics of the included studies

The main characteristics of the 25 articles included in the review are outlined in Table 1.[20,21,27–49] Most studies were published within the last 5 years (2015–2019). Of those, 17 studies were carried out in the United Kingdom (7), the Netherlands (6) and Spain (4). Twelve studies were observational (prospective observational and cross-sectional), nine studies incorporated mixed methods, three studies were RCTs, and one was a service evaluation study. The majority of the studies included patients with a variety of both cancer and non-cancer conditions. A total of 17 studies were conducted exclusively in primary care settings, and the remaining studies were in mixed settings, including primary care.

2.4.3 Characteristics of the screening tools

Ten screening tools used to identify patients with advanced progressive diseases who are likely to have unmet palliative care needs were identified in this systematic review. Of these, nine were originally designed to identify patients with potential palliative care needs, and one was originally developed to identify patients with frailty (Table 2). Four tools were originally developed in the United Kingdom (Gold Standard Framework–Proactive Identification Guidance: GSF PIG, Supportive, and Palliative Care Indicators Tool: SPICT, AnticiPal electronic tool, and Electronic Frailty Index: eFI), three in the Netherlands (RADboud indicators for PAlliative Care Needs: RADPAC, PALliative care: Learning to Identify in people with intellectual disabilities: PALLI, and the double Surprise Question(SQ)), two in the United States (SQ and early identification tool for palliative care patients ‘Rainoe tool’), and one tool in Spain (Necesidades Paliativas [Palliative Needs]: NECPAL tool). Seven of the identified tools were paper-based screening tools, and three of them were electronic case-finding tools. The screening object for most of the identified tools was to identify patients who are at a high risk of deteriorating and dying and might benefit from palliative care. The time frame within which symptoms and clinical indicators are assessed varies across the screening tools. The PALLI tool assesses the health status over the last 3–6 months, but the time period for assessment is unspecified for the majority of the symptoms and clinical indicators in all other screening tools. Reviewing care, assessment of needs and initiating discussions about end-of-life needs are some examples of the recommended actions following the screening (Table 3).

Table 3 summarises the general and specific indicators of the screening tools for identification of people with potential palliative care needs in primary care. The SQ is part of all of the paper-based tools (except the RADPAC and the current versions of SPICT). Five tools (GSF PIG, SPICT, NECPAL, PALLI and AnticiPal) contain general indicators for decline and increasing needs, such as repeated unplanned hospital admissions, progressive weight loss and functional decline. Only NECPAL and PALLI contain indicators for psychological and cognitive decline. Six tools (GSF PIG, SPICT, NECPAL, RADPAC, PALLI and AnticiPal) contain additional disease-specific clinical indicators of decline for a number of medical conditions. In the paper-based tools, the number of items or questions varied significantly and ranged from 1 to 42. The remainder of this section describes the included tools used to identify patients who may benefit from palliative care in primary care.

1. The SQ, which was originally developed by Lynn, is the first tool that has been used for this purpose.[36,50] It is utilised as a part of some screening tools or used in isolation. The SQ asks whether the respondent would be surprised if the patient died within a specified time period (usually the next year). The SQ has been widely validated in different settings.[34,36,44] The proportion of patients identified by SQ as having potential palliative care needs across studies ranged from 1.6% to 79%. In those studies applied to patients with advanced progressive diseases, the percentage of patients identified by SQ as having potential palliative care needs ranged from 41% to 79%, whereas that applied SQ to more general populations reported percentages between 1.6% and 11.7%.[34,36,44]

2. The double SQ was developed by adding an additional question (SQ2) that asks whether the respondent would be surprised if the patient is still alive after 12 months when SQ1 is answered in the negative.[49] The purpose of adding the second SQ was to increase the

predictive value of SQ1. The validity of this tool has not been explored yet, although a pilot study concluded that the majority of GPs considered it a useful addition to SQ1.[49]

3. The GSF PIG was developed in the United Kingdom.[27,28] The tool, which is applicable across care settings, uses the SQ, along with general and disease-specific indicators of decline and increasing need. To the authors' knowledge, there is no underlying research about the development of GSF PIG, and no validation studies have been performed in primary care settings in the United Kingdom. The GSF PIG has been translated and adapted for the Italian context.[27] An Italian study used the GSF PIG in primary care and found that 0.67% of patients were identified as having a short life expectancy and needing palliative care. [27]

4. The SPICT was developed in the United Kingdom using a literature review, peer review and a prospective case-finding study.[32] It is a one-page tool which consists of a combination of general indicators of deteriorating health and disease-specific indicators. The SPICT had been translated and adapted to Japanese, German and Spanish settings.[20,29,31] These translated versions (in addition to the original English version) have been validated in a wide range of inpatient and outpatient clinical settings.[20,29,31,32,36] Various cutoff scores were used in different versions of SPICT (Table 3). Studies in Australia and Japan that used SPICT among old patients in primary care showed that between 5.1% and 17.3% of these patients could benefit from palliative care.[20,30,36]

5. Mason et al.[42] developed an electronic tool called AnticiPal based on the SPICT criteria. This electronic tool was developed initially through an iterative process of designing, implementation and testing. In a recent study to evaluate the utility of AnticiPal in Scotland, around 0.8% of 62,708 registered patients at eight GP practices were identified as having potential palliative care needs.[43]

6. The NECPAL tool was developed in Catalonia, Spain, based on SPICT and the GSF PIG tools.[35] This instrument, the NECPAL, is a checklist which combines the SQ with general clinical indicators of severity and progression (e.g. co-morbidity and resource use); and specific indicators for some medical conditions. NECPAL has been validated in a wide variety

of care settings.[15,33–35] Recent Spanish observational studies which conducted in multiple setting, including primary care settings, found that 1.5% of primary care patients and 73.7% of patients with advanced progressive diseases met the NECPAL criteria and could benefit from palliative care.[33,34]

7. The RADPAC tool was developed in the Netherlands through a three-step process comprising a literature search, focus group interviews and a Delphi study with GPs.[37] The RADPAC tool contains specific indicators for congestive heart failure, chronic obstructive pulmonary disease (COPD) and cancer, although it does not include the SQ or general clinical indicators that can be applied to all patients. A Dutch RCT on the effects of training GPs in early identification of patients who could benefit from palliative care using the RADPAC tool did not find any differences between the intervention and control groups in out-of-hours contacts, contacts with their GP, hospitalisations and place of death.[39] The study also revealed that only one in four patients who died had been identified as in need of palliative care.

8. The PALLI tool was designed to be used to identify people with intellectual disabilities who may benefit from palliative care.[40] The tool was developed in the Netherlands using a five-stage mixed methods design including retrospective survey, interviews, draft version, focus groups and finalisation for testing in practice. This tool, which consists of 39 questions, is composed of eight main themes such as physical decline, changes in characteristic behaviour, and increases in symptom burden. The PALLI tool has been validated for use among patients with intellectual disabilities in different settings, including primary care.[49] PALLI tool shows promising construct validity and feasibility. There is, however, less and mixed evidence for the predictive validity of this tool.[49]

9. Rainoe et al.[21] used computerised electronic records to identify the most common factors associated with death within the next year among hospitalised patients. A list of the identified factors (including age 75 and over and having diseases such as heart failure and COPD) was used to identify people who may benefit from palliative care. The electronic tool has been validated against clinical assessment in an observational study in the United States, which found that 5.6% of primary care patients could benefit from palliative care.[21]

10. Electronic Frailty Index (eFI) was developed in the United Kingdom to identify elderly patients in primary care who may be living with frailty.[47] The eFI uses a ‘cumulative deficit’ model to calculate a frailty score based on a range of deficits, which can be symptoms, signs, diseases and abnormal laboratory test values. The eFI has been used in two recent studies to identify people who are at an increased risk of mortality and may need palliative care.[47,48] Initially, Stow et al.[47] examined the ability of eFI to predict mortality by measuring it at a single time point, which found that 1.1% of individuals age 75 and over could benefit from palliative care. Stow et al.[48] conducted another study using eFI to examine if changes in frailty index can be used to predict mortality and the need for palliative care. The study identified a distinct frailty trajectory which can be used to identify people who are at a higher risk of dying within 12 months. This study found that 0.49% of people age 75 and over were identified as potential candidates for palliative care. The predictive validity of eFI to identify patients with potential palliative care needs has been evaluated in both studies.[47,48]

2.4.4 Accuracy of screening tools

Eight studies reported accuracy data for five screening instruments (SPICT, SQ, NECPAL, eFI and early identification tool for palliative care patients ‘Rainoe tool’).[21,34,36,44–48] Reference standards (i.e. the comparator against which the tool was compared) varied across these studies, including 3-month mortality, 12-month mortality, 24-month mortality and clinical assessment. One study was excluded as data were available only on positively screened patients.[27] Table 4 shows a summary of the sensitivity, specificity, PPV and NPV for the screening tools.

Across all screening tools and studies, only one study had a PPV of over 50% (83.8%). The NPV was high for most tools and varied from 99% to 69%. The sensitivity and specificity values varied considerably and ranged from 3.2% to 94% and 26.4% to 99%, respectively. Studies enrolling participants with advanced progressive diseases reported high sensitivity values; however, studies that targeted a general population of primary care (e.g. adults aged 70 and over) reported lower sensitivity values.

2.4.5 Methodological quality of studies that reported accuracy data for screening tools

The assessment of the risk of bias is summarised in Appendix A.2 (RCTs), Appendix A.3 (a) (cohort studies) and Appendix A.3 (b) (case-control studies). On the basis of the Newcastle–Ottawa scale, three of the five cohort studies were judged to bear a moderate risk of bias (fair quality)[34,45,46] and one cohort was judged to have a high risk of bias (low quality) due to the lack of description of the follow-up and no adjustment for confounders.[21] Only one cohort study fulfilled most of the Newcastle–Ottawa scale criteria and had a low risk of bias (high quality).[44] The Newcastle–Ottawa scale assessment revealed that the two case-control studies were all of fair quality.[47,48] Based on the Cochrane risk of bias tool, the overall risk of bias for the included RCT was high because of unclear allocation concealment and differential drop-out rates between the two groups.[36]

Table 1. Characteristics of the included articles

Tool	Author, year	country	Setting	Study design	Study objectives	Population(s) tested in (final sample size)	Rating by	Per cent of Patients Identified by ST
SQ §	Barnes, 2008	UK	Primary care	Prospective observational study	To identify predictive factors of mortality of heart failure patients in primary care and to report the sensitivity and specificity of prognostic information from GPs.	Patients with heart failure >60 y (231)	GPs	41.1%
SQ §	Moroni, 2014	Italy	Primary care	Prospective cohort study	To determine the prognostic accuracy of GPs asking the SQ about their patients with advanced cancer.	Patients with advanced cancer(231)	GPs	54.6%
SQ §	Lakin, 2016	USA	Primary care	Retrospective observational study	To assess the SQ performance in primary care setting.	Patients screened for a high-risk care management program in primary care (1737)	GPs	6.6%
GSF PIG §	Clifford, 2016	UK	Primary care	Service evaluation	To describe the most recent developments and outline the potential of the updated version of GSF Gold Programme.	Primary care patients	-	-
GSF PIG (Italian version) §	Scaccabarozzi, 2018	Italy	Primary care and home palliative care units	Prospective observational study	To demonstrate the characteristics of patients with palliative care needs who were early identified by GPs and to explore their care process in home palliative care services.	Primary care patients (139,071)	GPs	0.67%
SPICT (German version) §	Afshar, 2018	Germany	Primary care	Mixed methods	To develop, refine, and evaluate SPICT (German version) for its application in primary care.	Primary care patients (case vignettes)	GPs	-
SPICT (Japanese version) §	Hamano, 2019	Japan	Primary care	Cross-sectional study	To identify the prevalence and characteristics of primary care patients being at risk of deteriorating and dying, as determined by SPICT.	Adults > 65 y (382)	GPs	17.3%
SPICT (Japanese version) §	Hamano, 2018	Japan	Primary care	Cross-sectional study	To explore the prevalence and characteristics of family practice patients who need a palliative care approach as determined using Supportive and palliative care Indicators Tool.	Adults > 65 y (87)	GPs	9.2%

SPICT §	Highet, 2013	UK	Primary care and hospital	Mixed methods	To refine and test SPICT tool to help multidisciplinary teams to identify patients at risk of deteriorating and dying in all care settings.	Patients with advanced organ failure.	Physician Nurse	-
SPICT (Spanish version) §	Fachado, 2018	Spain	Primary care and socio-sanitary services	Mixed methods	To translate, cross-culturally adapt to Spanish, and evaluate the Spanish version of the SPICT.	Patients with advanced progressive diseases (188)	Physician & nurse	-
SPICT (2012 version) & SQ §	Mitchell, 2018	Australia	Primary care	RCT	To test whether screening for likely death within 12 months using SPICT and SQ Is more effective than an intuition approach.	Adults > 70 y (4365)	GPs	11.7% (SQ) 5.1% (SPICT)
NECPAL & SQ §	Gómez-Batiste, 2017	Spain	Primary care, hospitals, social health centres and nursing homes	Prospective cohort study	To investigate the predictive validity of the NECPAL and SQ to determine 12- and 24-month mortality.	patients with advanced chronic conditions and limited life prognosis (1059)	GPs and nurse	79% (SQ) 73.7% (NECPAL)
NECPAL §	Gómez-Batiste, 2014	Spain	Primary care, hospitals, social health centres and nursing homes	Cross-sectional study.	To determine the prevalence of advanced chronically ill patients with limited life prognosis in need of palliative care using NECPAL tool	Primary care patients (51,595)	GPs and nurse	1.6% (SQ) 1.5% (NECPAL)
NECPAL §	Gómez-Batiste, 2013	Spain	Primary care, hospitals, social health centres and nursing homes	Mixed methods	To develop the NECPAL tool to identify patients in need of palliative care.	patients with advanced chronic diseases (1059)	GPs and nurse	-
RADPAC §	Thoonsen, 2016	The Netherlands	Primary care	Cross-sectional study after RCT	To examine whether trained GPs identified more patients in need of palliative care using RADPAC tool and provided multidisciplinary care more than untrained GPs.	Primary care patients (6278)	GPs	-
RADPAC §	Thoonsen, 2015	The Netherlands	Primary care	RCT	To train GPs in identifying patients in need of palliative care and in structuring anticipatory palliative care planning and study its effect on the quality of life.	Primary care patients	GPs	-
RADPAC §	Thoonsen, 2012	The Netherlands	Primary care	Mixed methods	To develop a tool for identification of patients with congestive heart failure, COPD and cancer who could benefit from proactive palliative care in primary care.	Primary care patients	GPs	-
PALLI §	Vrijmoeth, 2018$_b$	The Netherlands	Primary care, central residential settings and intellectual disability physician clinics.	Mixed methods	To evaluate feasibility, construct validity and predictive validity of PALLI.	Patients with intellectual disability who were more likely to be in need of palliative care (190)	GPs, intellectual disability physicians and daily care professionals	-
PALLI §	Vrijmoeth, 2018$_a$	The Netherlands	Primary care, central residential settings and intellectual disability physician clinics.	Mixed methods	To describe development of PALLI and to explore its applicability.	Patients with intellectual disability who were more likely to be in need	GPs, intellectual disability physicians and	-

						of palliative care (190)	daily care professionals	
The double SQ §	Weijers, 2018	The Netherlands	Primary care	Pilot RCT with caged vignettes	To pilot test whether adding SQ2 to SQ1 prompts GPs to plan for anticipatory palliative care.	Case vignettes (primary care patients)	GPs	-
Raincine tool ⌘	Raincine, 2007	USA	Primary care	Prospective observational study	To develop a methodology to identify patients who may benefit from palliative care and provide estimates of their prevalence in primary care.	Primary care patients (18308)	Electronic tool	4.6%
AnticiPal (updated version) ⌘	Mason, 2018	UK	Primary care	Mixed methods	To refine and evaluate the utility of an electronic ST to help primary care teams screen their patients for people who could benefit from palliative care.	Primary care patients (62708)	Electronic tool	0.61% -1.23% (0.8% for all practices)
AnticiPal ⌘	Mason, 2015	UK	Primary care	Mixed methods	To develop and test an electronic ST in primary care as a tool to improve patient identification for a palliative care approach.	Primary care patients (83229)	Electronic tool	0.6-1.7%
eFI ⌘	Stow, 2018$_{b}$	UK	Primary care	Longitudinal population-based study (case-control study)	To identify frailty trajectories that could indicate an increased risk of dying and the need to consider palliative care.	Adults > 75 y (26,298)	Electronic tool	1.1%
eFI ⌘	Stow, 2018$_{a}$	UK	Primary care	Prospective case-control study	To examine if changes in eFI could indicate where individuals are at increased risk of mortality and may require palliative care.	Adults > 75 y (13,149)	Electronic tool	0.49%

COPD* =** chronic obstructive pulmonary disease; ***GSF PIG* =** Gold Standard Framework Proactive Identification Guidance**;** ***SPICT= the Supportive & Palliative Care Indicators Tool; ***NECPAL=*** Necesidades Paliativas [Palliative Needs]; ***SQ=*** Surprise Question**;** ***eFI=*** Electronic Frailty Index***; GPs=*** *general practitioner;* ***PALLI=*** PALliative care: Learning to Identify in people with intellectual disabilities**;** ***palliative care*** = palliative care; ***ST=*** screening tool; ***RCT***= randomised control trial.

⌘ = Electronic tools; § **=** Paper-based screening tools.

Table 2. Summary of the main features of tools which were designed to identify patients with potential palliative care needs

Tool[a]	Screening objectives	languages	Target population	Setting (Primary care/GP, Hospital)	Type: paper-based /electronic tool	Completion time	Time frame of assessment	cut-off value	Actions are taken following screening
SPICT	To identify people who are at risk of deteriorating and dying and might benefit from palliative care.	English. Japanese, German, Spanish	All	Primary care/GP, hospital	Paper-based	SPICT™: A few minutes SPICT-DE: an average of 7.5 minutes. SPICT-ES™: an average of 4 minutes and 45 seconds	Unspecified for most variables.	**SPICT™ 2019 version), SPICT-DE and SPICT-ES:** no cut-off value. **SPICT-J:** SPICT + (≥2 general indicators or ≥1 clinical indicator) **SPICT-ES**: SPICT + (≥2 general indicators and ≥1 clinical indicator)	Review current care and care planning (e.g. review current treatment and consider referral for specialist assessment if symptoms are complex).
NECPAL	To Identify people who are at high risk of dying (who are likely in need of palliative care).	Spanish	All	Primary care/GP, hospital	Paper-based	NM (one page)	Unspecified for most variables.	NECPAL+ (SQ+, and "≥1 general indicator or ≥1 specific indicator")	Consider actions such as a holistic assessment, review of treatment and advance care planning.
RADPAC	To identify people who could benefit from palliative care based on their clinical indicators.	Dutch	Patients with COPD, congestive heart failure and cancer diagnoses	Primary care/GP	Paper-based	NM (one page)	Unspecified for most variables.	No cut-off point	Discuss with patient and their family to explore their problems and needs "proactive palliative care planning".
GSF PIG	To identify people who may be in their final stage of life who could benefit from an early palliative approach.	English, Italian	All	Primary care/GP, hospital	Paper-based	NM (one page)	Unspecified for most variables.	GSF PIG + (SQ +, ≥1 General indicator or ≥1 specific indicator)	Assess needs through advance care planning, discussions, and plan care tailored to patient choices.
PALLI	To identify patients with intellectual disability who may benefit from palliative care via screening deteriorating health,	Dutch	Patients with intellectual disabilities	Primary care/GP	Paper-based	Mean time of 10.5 minutes (physicians) and 10.1 minutes (daily care professionals)	Previous 3-6 months for all domains except fragility.	No cut-off point	Discuss with patients their health status and their need for palliative care in a multidisciplinary setting.

	indicative of a limited life expectancy.								
Surprise Question	To identify patients with poor prognosis who might benefit from palliative care.	English, Italian	All	Primary care/GP, hospital	Paper-based	NM (one question)	NA	SQ + (answer no to the 'surprise' question)	Initiate discussions about end-of-life needs and preferences.
The double SQ	To identify patients with poor prognosis who might benefit from palliative care.	Dutch, Slovak	All	Primary care/GP, hospital	Paper-based	NM (two questions)	NA	The double SQ + (a combination of SQ1: "no" and SQ2: "yes")	Prompt GPs to plan for anticipatory palliative care.
AnticiPal	To identify patients who potentially have deteriorating health due to one or more advanced illnesses and a likelihood of unmet supportive and palliative care needs.	English	All	Primary care/GP	Electronic	NA	Unspecified for most variables. Previous 18 months for Codes that indicate malignancy.	AnticiPal + (if one or more inclusion criteria are met, none of the exclusion criteria is met). The inclusion criteria: Type 1: Malignancy codes, e.g. pancreatic cancer. Type 2: Other single Read Codes at any time, e.g. Frailty. Type 3: Combinations of Read Codes, e.g. Difficulty swallowing and dementia.	Create a list of patients for review and care planning.
Racine tool	To identify people who are at high risk of death (who may benefit from palliative care.	English	All	Primary care/GP	Electronic	NA	NA	Patient is included if their electronic records contain at least one of the markers for high risk of death within the next year, e.g. age >75 or a diagnosis of congestive heart failure.	Create a preliminary screen to assist clinicians in early identification of patients in need of palliative care.

COPD = chronic obstructive pulmonary disease; ***GSF PIG =*** Gold Standard Framework Proactive Identification Guidance**; SPICT= the** Supportive & palliative care Indicators Tool; ***NECPAL=*** Necesidades Paliativas [Palliative Needs]; ***SQ=*** Surprise Question***; GPs=*** general *practitioner;* ***PALLI=*** palliative care: Learning to Identify in people with intellectual disabilities**; NM=** not mentioned**; NA=** not applicable; **+ =** positive.

[a] The most recent version of the tool

Table 3. Summary of the general and specific indicators of deteriorating health and increasing needs in the tools that were designed to identify patients with potential palliative care needs.

	GSF PIG	**SPICT**	**NECPAL**	**RADPAC**	**AnticiPal**	**PALLI**
Surprise Question (SQ)	Yes	No (SQ was part of some previous versions of SPICT but was removed from the recent versions of SPICT in different languages)	Yes	No	NA	Yes
Nutritional decline	Progressive weight loss (>10%) in the past six months Serum albumen <25g/l	Progressive weight loss or remaining underweight Low muscle mass	Weight loss > 10%	NM	NM	Weight loss
Functional decline	In bed or chair 50% of the day General physical and performance status decline (Barthel score) and decreasing activities Increasing dependence and need for support	In bed or chair >50% of the day Poor or deteriorating performance status Dependent and increasing need for support	- Karnofsky or Barthel score > 30% loss of two or more activities of the daily living Severe Dependence (Karnofsky <20)	NM	Codes that indicate housebound Codes that indicate very poor mobility	Spending more time in bed Less able to perform activities in the daily living (ADL) General physical decline
Cognitive decline	-	NM	Mini-mental/Pfeiffer Decline	NM	NM	Cognitive deterioration (e.g. remembers less, less oriented)
Symptom burden	Unstable, deteriorating, complex symptom burden	Persistent symptoms despite optimal treatment	Persistent symptoms (e.g. Pain, weakness, anorexia, dyspnoea, digestive)	NM	NM	Having more severe symptoms (progressive)
Psychosocial decline	NM	NM	Present of emotional stress (Detection of Emotional Distress Scale (DME) > 9)	NM	NM	Restless behaviour, depression, stress

			Severe Social Vulnerability (Social and family assessment)			
Multi-morbidity	Significant multi-morbidities.	NM	>2 chronic diseases	NM	Codes that indicate multiple organ failure and multimorbidity	Other serious chronic conditions (in addition to intellectual disability)
Urgent/unplanned admissions	Repeated unplanned hospital admissions	Unplanned hospital admission(s).	• > 2 urgent or not planned admittances in last 6 months	NM	NM	NM
Presence of an adverse event	Sentinel event, e.g. serious fall, bereavement, transfer to nursing home	NM	Geriatric syndromes **(at least two):** Falls, pressure ulcers, dysphagia, delirium, recurrent infections.	NM	NM	Recurrent infections
Others	Considered eligible for DS 1500 payment[a]					Geriatric home admission exam
Choice of no further active treatment/ no curative treatment available	Choice for no further active treatment	Chooses to reduce, stop or not have treatment (patient or family)	Limitations of therapeutic effort were mentioned by patient, family or the team	NM	NM	Any serious chronic conditions that cannot be treated or which continued treatment is not indicated.
Choosing or requiring palliative care	Asks for palliative care by patient	Asks for palliative care by patient or family	Asks for palliative care by patient, family or the team	NM	NM	NM
Additional specific clinical indicators for	Cancer, heart disease, COPD, kidney disease, liver disease, general neurological diseases, Parkinson's disease, motor neurone disease, multiple sclerosis, frailty, dementia, stroke.	Cancer, heart/ vascular disease, kidney disease, liver disease, neurological disease, respiratory disease, dementia/ frailty.	Cancer, COPD, chronic heart disease, chronic neurological disease (CVA, ALS, motor neurone disease, multiple sclerosis), dementia.	COPD, congestive heart failure and cancer.	Cancer, heart/ vascular disease, kidney disease, liver disease, dementia, frailty, stroke.	Intellectual disability and frailty.

COPD = chronic obstructive pulmonary disease ***GSF PIG =*** Gold Standard Framework Proactive Identification Guidance**; SPICT= the** Supportive & Palliative Care Indicators Tool; ***NECPAL=*** Necesidades Paliativas [Palliative Needs]; ***SQ=*** Surprise Question***; PALLI=*** PALliative care: Learning to Identify in people with intellectual disabilities**; NM=** not mentioned; ***NA=*** not applicable.

[a] DS 1500 is a Form for patients who are terminally ill who are not expected to live for more than six months to rapidly access benefits in the UK.

Table 4: Summary of the sensitivity, specificity, positive predictive value, negative predictive value for the screening tools.

Reference	Length of Follow-Up	Comparison	Tool	Cut-off value	Reference standard	Final sample(n)	Age, mean or median (SE, SD, range)	Sensitivity	specificity	PPV	NPV
Mitchell, 2018	12 months	Intuition	SPICT (2012 version)	SPICT + (SQ+ with ≥2 general indicators or ≥1 clinical indicator)	12-month Mortality	1525	79.1, mean (SD 6.9)	34.0%	95.8%	20.5%	97.9%
			SQ	SQ + (answer no to the 'surprise' question)	12-month Mortality			33.7%	95.6%	14.0%	98.4%
Gómez-Batiste 2017	24 months	No	NECPAL	NECPAL+ (SQ+, and "≥1 general indicators or ≥1 specific indicators")	12-months mortality	1059	81.3, mean (SD 11.8)	91.3%	32.9%	33.5 %	91.0%
					24-months mortality			87.5%	35.0%	45.8 %	81.7%
			SQ	SQ + (answer no to the 'surprise' question)	12-months mortality			93.7%	26.4%	32.0 %	91.9%
					24-months mortality			91.4%	28.7 %	44.6%	84.2%
Raincine, 2007	6-month (the length of the study)	No	Raincine tool	Patient is included if their electronic records contain at least one of the markers for high risk of death within the next year, e.g. age >75 or a diagnosis of congestive heart failure.	Clinical assessment	18308	-	94.0%	97.0%	36.0%	99.0%
Barnes, 2008	12 months	No	SQ	SQ + (answer no to the 'surprise' question)	12-months mortality	231	77, median (range 71-82)	79.0%	61.0%	11.6%	97.8%
Moroni, 2014	12-months	No	SQ	SQ + (answer no to the 'surprise' question)	12-months mortality	231	70.2 mean (SE 0.9)	69.3%	83.6	83.8	69.0%
Lakin, 2016	12-months	No	SQ	SQ + (answer no to the 'surprise' question)	12-months mortality	1737	65, mean	20.5%	94.4%	20.2%	94.5%
Stow, 2018$_b$	12 months	No	eFI	People with rapidly rising frailty (initial increase of 0.022 eFI per month before slowing from a baseline eFI of 0.21)	12-months mortality	26,298	For cases: 85.14, mean (SD 5.98) For control: 85.65, mean(SD 5.98)	3.2%	99.1%	19.8%	93.3%

Stow, 2018[a]	3 months	No	eFI	eFI Cut value > 0.19	3-months mortality	7890	For cases: 85.1, mean(SD 6.0) For control: 85.6, mean(SD 6.0)	76.0 %	53.0%	11.0%	97.0%

SPICT= the Supportive & Palliative Care Indicators Tool; ***NECPAL=*** Necesidades Paliativas [Palliative Needs]; ***SQ=*** Surprise Question***; eFI =*** electronic Frailty Index; ***SE=*** standard error; ***SD=*** standard deviation; ***PPV=*** positive predictive value; ***NPV=*** negative predictive value; **+ =** positive.

2.5 Discussion

2.5.1 Main findings

We identified 10 screening tools for identification of patients with advanced progressive diseases who are likely to have unmet palliative care needs in primary care, which varied in content and accuracy, and in general, the validation studies were of low quality and with a high risk of bias.

Most of the identified tools use either prediction of death or deterioration or both as proxies for the identification of people who are likely to have unmet palliative care needs. Patients with advanced progressive diseases experience different trajectories of decline and usually have varying needs at different phases in the illness trajectory.[51,52] Therefore, the identification process should not be based solely on predicting mortality or survival, but it should also focus on anticipating their needs whenever they occur, and predicting the rate and course of functional decline in order to trigger holistic assessment and make a proactive palliative care plan.

The proportion of patients identified with potential palliative care needs across studies ranged from 0.49% to 79%. The accuracy of five tools (of which data were available in eight studies) showed sensitivity ranging from 3.2% to 94%, and specificity ranging from 26.4% to 99%. The wide variation in the accuracy of the screening tools may be caused by both variations in diagnostic groups and disease trajectory during the last year of life.

2.5.2 Strengths and weaknesses/limitations of the study

This is the first systematic review to assess the evidence on accuracy of screening tools for identification of patients with advanced progressive diseases who are likely to have unmet palliative care needs in primary care. We used a broad search strategy to identify all potentially relevant studies by searching Cochrane Library, MEDLINE, Embase and CINAHL, and the quality of the validation studies was assessed by two reviewers independently with disagreements resolved by a third reviewer.

Our findings are limited by several issues. First, our search strategy was designed to capture all of the relevant papers, but given the nature of this topic, it is possible that some papers may have been missed. Although we conducted a comprehensive and broad search of the literature, we only included English language studies. We did not also include unpublished results or studies from the grey literature, which may have introduced publication bias. However, the methodological quality of grey literature is usually lower than the quality of published studies literature.[53,54] Second, there is no current consensus about a reference standard against which the accuracy of a screening tool could be assessed. All studies used mortality as a reference standard, with the exception of one study that used clinical judgement to determine whether the identified patient could benefit from palliative care.[21] This is a major flaw in the evidence, in that we know palliative care needs do not relate particularly closely to time to death, especially for some illnesses such as organ failures. Data were universally missing on how many patients identified (or missed) by the screening tools actually had palliative care needs and so we cannot be certain of the true clinical value of these tools.

2.5.3 What this study adds

Improving identification of patients who are likely to have unmet palliative care needs is a crucial step to overcome inequity in access to palliative care and to ensure that patients receive the right care at the right time to meet their needs and preferences.[55,16] Identification does not mean referral to specialist palliative care services is necessarily needed, but rather, it should trigger a comprehensive and holistic assessment of palliative care needs of the identified patients and their families.[17,50]

Although some of the identified tools recommended some actions to be taken after the screening process, there is no clear or appropriate care pathway for people with advanced progressive diseases who have been identified as having potential palliative care needs. Based on the findings from this review, we created a conceptual graph to describe the process of patient identification and assessment of palliative care needs (Figure 2). The first step in the process is using a screening tool to aid the identification of patients with advanced progressive diseases whose health is deteriorating and hence benefit from palliative care needs assessment. The screening tool should be based not solely on predicting mortality and deterioration but also on anticipating the needs whenever they occur and predicting the rate and course of functional decline. The identified patients who have potential palliative care needs could then be targeted for assessment to identify their unmet palliative care needs. The outcomes of the assessment can help to determine the level of care required and may prompt an introduction of a palliative care approach ‘generalist palliative care’ or referral to a specialist palliative care service.

Primary care teams play a vital role in caring for people with advanced chronic diseases.[56] One of the main challenges for them is to identify which of their patients might have unmet palliative care needs.[57,58] Implementing a systematic tool could help the primary care team to identify patients with advanced progressive diseases and their potential palliative care needs. However, issues such as high workload and decreased resources and capacity in primary care can be barriers to implementing such a screening tool.[42] Therefore, we recommend the use of an electronic tool to systematically and automatically identify patients who might have unmet palliative care needs and trigger the use of a needs assessment tool. Although some electronic screening tools have been used, such as AnticiPal and Rainoe tools, their validity is unclear as they used the risk of deteriorating and dying as a proxy for the identification of people with potential palliative care needs.[21,43,56]

The design of the future automated tools should be based on predicting functional decline and increasing needs, as well as predicting mortality. Future studies of these tools should apply adequate reference standards, such as palliative care interviews, to examine whether the screening tools accurately identify patients with potential palliative care needs.[50,59] The implementation and use of these tools within current clinical practice software require minimal resources and very little training and capacity, which allow them to be used in busy primary care practices.[18,60] Implementation of validated and standardised screening tools would transform the identification process in primary care and improve timely access to palliative care for people with advanced progressive diseases and potential palliative care needs.

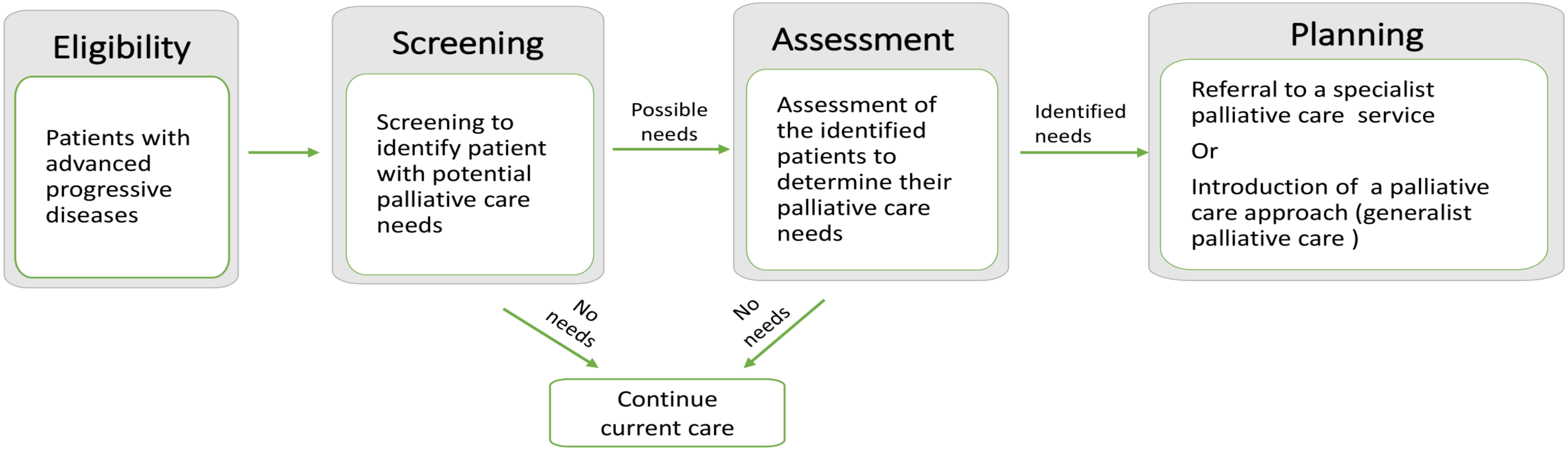

Figure 2. The process of patient identification and assessment of palliative care needs.

2.5.4 Conclusion

This systematic review identified 25 studies that reported the use or development of screening tools to identify patients who are likely to have unmet palliative care needs. The evaluation of these tools was limited because of a lack of a valid comparator and so their true clinical utility is unknown. Further research is needed to identify standardised screening processes that are based not solely on predicting mortality and deterioration but also on anticipating a person's needs whenever they occur and predicting the rate and course of functional decline in order to trigger the use of a needs assessment tool to identify and address their unmet needs at the right time.

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Chapter 3: The Quality of End-of-Life Care and its Association with Utilisation of Community-Based Specialist Palliative Care Services: A 5-Year Analysis of Nationwide Mortality Follow-Back Survey Data in England

Study Two	
Journal:	British Journal of General Practice
Submission status:	Published in April 2023
Reference:	ElMokhallalati Y, Chapman E, Relton SD, Bennett MI, Ziegler L. Characteristics of good home-based end-of-life care: analysis of 5-year data from a nationwide mortality follow-back survey in England. British Journal of General Practice. 2023 Jun 1;73(731):e443-50.

3.1 Abstract

Background: Recently, there has been an emphasis on providing good-quality end-of-life care; however, little is known about it and its determinants for patients living at home.

Aim: To determine what characterises good-quality end-of-life care for patients living at home.

Design and setting: An observational study using 5-year data from the National Survey of Bereaved People (Views of Informal Carers — Evaluation of Services [VOICES]) in England.

Method: Analysis was based on data for 63 598 decedents, who were cared for at home in the last 3 months of life. Data were drawn from 110 311 completed mortality follow-up surveys of a stratified sample of 246 763 deaths registered in England between 2011 and 2015. Logistic regression analyses were used to identify independent variables associated with the overall quality of end-of-life care and the outcome of end-of-life care.

Results: Patients who received good continuity of primary care (adjusted odds ratio [AOR] 2.03; 95% confidence interval [CI]=2.01 to 2.06) and palliative care support (AOR 1.86;95%CI = 1.84 to 1.89) experienced better overall quality of end-of-life care than those who did not, as perceived by relatives. Decedents who died from cancer (AOR 1.05; 95% CI=1.03 to 1.06) or outside of hospital were more likely to receive good end-of-life care, as perceived by relatives. Being older—compared with those aged under 65—was associated with better care, with AOR 1.06 (95% CI=1.04 to 1.08) for ages 65–84 and 1.42 (95% CI=1.40 to 1.45) for those aged 85 and over. Being female (AOR 1.16; 95% CI=1.15 to 1.17), and White (AOR 1.09; 95% CI=1.06 to 1.12) were also associated with better overall end-of-life care, as perceived by relatives. Living in a more socio-economically deprived area was associated with lower odds of receiving good end-of-life care (AOR 0.94; 95% CI=0.93 to 0.95), compared with those in the least socio-economically deprived areas.

Conclusion: Better quality of end-of-life care was associated with good continuity of primary care, specialist palliative care support, and death outside of hospital. Disparities still exist for those from minority ethnic groups and those living in areas of socio-economic deprivation. Future commissioning and initiatives must consider these variables to provide a more equitable service.

3.2 Introduction

End-of-life care aims to meet the physical, psychological, social, spiritual, and practical needs of terminally ill patients and their caregivers (1). For many, being well cared for and having the choice to die in their preferred place are their priorities as they approach the end-of-life; however, not all people achieve their preferences (2-4). In the UK, around 50% of people die in their usual place of residence (5).

Inadequate community services and support, poor service coordination, the high burden on informal caregivers, and difficulties in symptom control often lead to frequent, unnecessary hospital admissions(6-8). These issues commonly prevent patients from achieving their end-of-life preferences(3, 9). Evidence from the National Survey of Bereaved People (VOICES) in England supports this, revealing that pain is least well controlled at home compared to acute care facilities or hospices in the last few months of life (10). These challenges highlight the critical need for improved community-based services and better coordination of care to support patients' end-of-life preferences effectively.

Palliative care is designed to improve symptoms and quality of life for patients with advanced progressive disease and their caregivers (11). There is growing evidence suggesting that palliative care offers significant benefits, particularly in quality of life and symptom management (12, 13). Systematic reviews and studies support the effectiveness of palliative care in reducing symptoms such as pain, breathlessness, and psychological distress, which are common among patients with advanced illnesses (14-18). Despite its benefits, the impact of palliative care on other outcomes, such as survival and psychological symptoms, is less clear (12, 19, 20).

The variability in results and methodological limitations of existing studies highlight the need for more rigorous research with standardised methodologies and diverse patient populations(12, 15, 16). Access to palliative care remains inconsistent, which impacts the quality of end-of-life care. Improving access to palliative services is essential for enhancing care quality (21-23). Understanding the factors that influence end-of-life care, including access to palliative services, is crucial for achieving better patient outcomes. In recent years, increasing emphasis has been placed on evaluating the quality of current end-of-life provision to understand and improve care and outcomes for patients approaching the end-of-life (24-26). However, previous studies assessing end-of-life care and its determinants have several limitations. Most previous studies used only health-claims data, administrative data, or small-survey data or have typically focused on a limited population, such as patients with cancer or patients aged ≥65 years (27-30). Very few studies assessed the quality of end-of-life care for patients living at home (28).

The primary aim of this study is to identify factors associated with better quality end-of-life (EOL) care for patients with advanced disease who were cared for at home in the last three months of life, including the role of palliative care. The secondary aim is to examine factors associated with access to home-based specialist palliative care.

3.3 Methods

3.2.1 Data sources and study population selection

This population-based secondary data analysis used individual-level data from an annual population-based mortality follow-back survey and a national register of deaths. The National Survey of Bereaved People (VOICES) was a nationally representative survey of deaths in England, conducted annually between 2011 and 2015 to describe end-of-life care for adults in England (31). The survey used informants (usually a relative or friend of the deceased) who were bereaved as proxies for views of decedents in their last 3 months of life. Patient demographics (for example, age, sex, and cause of death) were obtained from the Office for National Statistics (ONS) death registration database, which was linked at patient level with the survey data by ONS. Data were weighted to correct for sampling and response biases, and to account for underrepresentation of certain groups. More information about the National Survey of Bereaved People (VOICES) and its methodology has been reported elsewhere (32). As the primary outcome of the study reported here was the quality of end-of-life care for patients with advanced disease, who were cared for at home at the end-of-life, the sample was limited to decedents who died a non-sudden death and lived at home within 3 months of death. This study was reported using Strengthening the Reporting of Observational Studies in Epidemiology

(STROBE) guidelines (33).

3.2.2 Outcome measures

The primary outcome was the overall quality of end-of-life care, as reported by proxy. Survey responders rated the decedent’s overall quality of end-of-life (last 3 months) as outstanding, excellent, good, fair, or poor. Secondary outcomes included the following end-of-life care quality indicators as perceived by relatives: • sufficient family support (‘yes, as much as we needed’, ‘yes, but not as much as we needed’, or ‘no’); • recording preferred place of death (‘yes’ or ‘no’); and • patients’ involvement in decision-making as much as they wanted (‘yes’ or ‘no’).

3.2.3 Covariates

Data on decedents, including age at death, sex, geographical region, place of death, and level of socio-economic deprivation, were obtained from the ONS death registration database. The level of socio-economic deprivation was measured using the Index of Multiple Deprivation (IMD) 2010 deciles (1 = most socio-economically deprived, 10 = least socio-economically deprived), based on the deceased’s postcode (34). The VOICES survey provided self-reported data on ethnicity, length of illness before death, continuity of primary care, receiving specialist palliative care at home, and responder relationship to decedents (35). Ethnicity was categorised into White, Asian, Black, Arab, other, and mixed ethnic background.

Specialist palliative care at home proxy measure

The VOICES survey contained questions about services that were provided to decedents at home in their last 3 months of life. Responders were asked whether the decedent received care from specialist palliative care services at home. These services were defined as: hospice home-care nurse or specialist, hospice-at-home service, or Macmillan or Marie Curie nurse (Marie Curie and Macmillan Cancer Support are UK charities — the former offers specialist palliative care services for patients with a terminal illness, the latter offers specialist palliative care services for patients with cancer).

Continuity of primary care

Continuity of care can be defined as ‘the extent to which a person experiences an ongoing relationship with a clinical team or member of a clinical team’(36). In the study presented here, the ability to see a preferred GP was used to measure continuity of primary care. The VOICES survey asked how often decedents saw their preferred GP in the last 3 months of life. Decedents were considered to have good continuity of care if they saw their preferred GP always, almost always, or a lot of the time (37).

3.2.4 Statistical analysis

Logistic regression analysis was conducted to examine the association between various factors and the outcomes of interest. The primary model focused on identifying the characteristics of decedents that were independently associated with receiving home-based specialist palliative care. For this model, the outcome measure was whether the decedent received home-based specialist palliative care.

Subsequent logistic regression models included receiving home-based specialist palliative care as an independent variable to determine its impact on other outcomes. The covariates included in these models were:

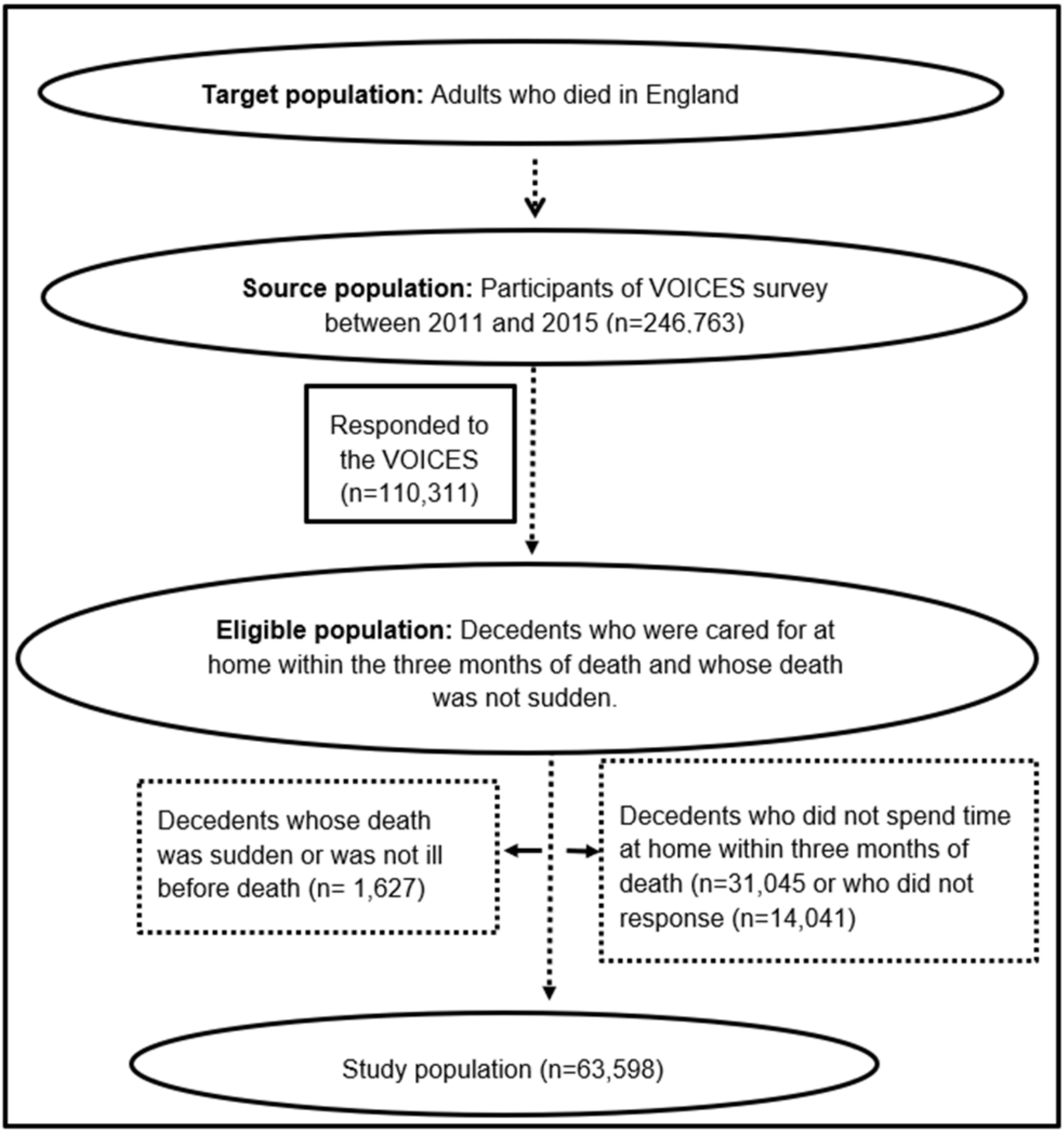
- Age
- Sex
- Relationship of the respondent
- Cause of death
- Duration of illness
- Place of death
- Socio-economic deprivation level
- Ethnicity
- Continuity of primary care

Complete-case analysis was utilised due to the minimal amount of missing data. To manage potential collinearity among variables, covariates were entered into a multivariable model if their univariate P-values were less than 0.1. A backward stepwise likelihood ratio test was employed to refine the model, retaining only those variables that significantly improved model fit.

For the final logistic regression model diagnostics, potential multicollinearity was assessed using variance inflation factors. P-values less than 0.05 were considered statistically significant. The analyses were adjusted using published weights for the VOICES survey to account for selection and response bias (38).

All statistical analyses were performed using IBM SPSS Statistics (version 24.0).

Flow chart showing inclusion and exclusion (with reasons for exclusion) of patients for the study



3.4 Results

Over the course of the 5-year survey, 110 311 of 246 763 people who were bereaved responded to the survey (45% response rate); of these, 63 598 were included in the study (Figure 1). Data were missing for the following variables: ethnicity (n = 3425, 5.4%), continuity of primary care (n = 1368, 2.2%), relationship to decedents (n = 994, 1.6%), and length of illness (n = 713, 1.1%).

The majority of decedents in the study reported here were ≥75 years old (65.1%), half (50.2%) were female, and 27.6% lived in the most socio-economically deprived areas. Of the sample, 59.2% of the decedents died of non-cancer conditions, just fewer than half (47.8%) were ill for >1 year before death, and 56.9% died in hospital (Table 1).

3.3.1 Characteristics of decedents receiving home-based specialist palliative care

In our study, 28% of decedents received specialist palliative care at home. Approximately 60% of cancer decedents received specialist palliative care, compared to less than 10% of those with non-cancer conditions (Table 3). Patients with haematological cancers had the lowest rate of specialist palliative care at 36.9%, whereas those with head and neck cancers experienced the highest rate at 69.2%. From the regression model, we found that patients with cancer(adjusted odds ratio [AOR] 11.66; 95% confidence interval [CI] = 11.45 to 11.86) and those with good continuity of primary care were significantly more likely to receive home-based specialist palliative care support (AOR = 1.48; 95% CI = 1.46 to 1.50) (Table 4). Older age and living in the most socio-economically deprived areas were associated with reduced access to home-based specialist palliative care services ($p < 0.001$). In the univariate regression analysis, ethnicity did not meet the inclusion threshold for the multivariable model, as its p-value was 0.24, which is above the pre-specified limit of 0.1. Consequently, it was not included in the subsequent multivariable analysis.

3.3.2 Primary outcome: overall quality of end-of-life care, as perceived by relatives

Table 4 shows the multivariable analysis of the factors associated with the overall quality of end-of-life care, as perceived by relatives.

Better overall quality of end-of-life care was associated with receiving good continuity of primary care (AOR 2.03; 95% CI = 2.01 to 2.06) and home-based specialist palliative care support at home

(AOR 1.86; 95% CI = 1.84 to 1.89) compared with those who did not. Better overall quality of end-of-life care, as perceived by relatives, was also associated with a longer duration of illness, being older, female, having a spouse as a responder, living in the least socio-economically deprived areas, being of White ethnicity, dying from cancer (versus non-cancer), and dying outside hospital (particularly at home or in a hospice) (Table 2).

3.3.3 Secondary outcomes: other quality of end-of-life indicators

Data regarding the secondary outcomes are presented in Table 5.

- **Receiving sufficient family support, as perceived by relatives**

Relatives of decedents who received specialist palliative care at home and experienced good continuity of primary care had greater odds of receiving sufficient support at the end-of-life than those who did not. Being a relative of decedents, the decedent being aged≥65 years, female, or living in the least socio-economically deprived areas were also associated with sufficient family support, as perceived by relatives. Partners and spouses were also more likely to receive good family support in comparison with others.

- **Recording preferred place of death**

Receiving specialist palliative care at home and experiencing good continuity of primary care were statistically significantly associated with greater odds of recording a preferred place of death. Decedents who died in hospital, were from minority ethnic groups, or whose cause of death was non-cancer were less likely to have recorded a preferred place of death.

- **Patients' involvement in decision-making as much as they wanted**

Decedents were more likely to be involved in decision-making at the end-of-life, as perceived by relatives if the decedent received good continuity of primary care or received home-based specialist palliative care; non-White decedents and those living in the most socio-economically deprived areas were less likely to be involved. Compared with decedents who died in hospital, those who died in care homes were less likely to be involved in decision-making, as perceived by relatives.

Table 1. Sociodemographic and clinical characteristics of decedents (n = 63 598) in the last 3 months of life	
Characteristics[a]	n (%)[b]
Age, years, mean (SD)	79.0 (12.11)
Age of deceased at death in years	
18-64	7,817 (16.0)
65-74	11,308 (18.9)
75-84	20,140 (31.0)
85 +	24,333 (34.1)
Sex	
Male	31,264 (49.8)
Female	32,334 (50.2)
Ethnicity	
white	58,526(96.8)
mixed	144 (0.3)
Asian	952 (1.8)
black	441 (0.9)
others	110 (0.2)
Socio-economic Deprivation level[C]	
High (IMD deciles 1-3)	20,810 (27.6)

Intermediate (IMD deciles 4-7)	26,946 (42.0)
low (IMD deciles 8-10)	15,842 (30.4)
Length of illness prior to death, year	
< 1	33,415 (52.2)
> 1	29,470 (47.8)
Cause of death	
Non-cancer	36,887 (59.2)
Cancer	26,711 (40.8)
Relationship of respondent	
Spouse or partner	20,184 (33.7)
other	42,420 (66.3)
Place of death	
Hospital	35,127 (56.9)
Home	17,791 (27.4)
Hospice	6,027 (8.9)
Care home	4,653 (6.4)
Receiving home-based specialist palliative care support	
Yes	18,107 (28.2)
No	45,491 (71.8)
NHS areas	
North	20,744 (33.2)
Midlands and East	20,738 (32.7)
South	16,367 (24.3)
London	5,749 (9.8)

SD standard deviation, *IMD* Index of Multiple Deprivation

[a] Data were missing for the following variables: ethnicity (n=3425, 5.4%), continuity of primary care (n=1368, 2.2%), relationship of responder to decedents (n=994, 1.6%), and length of illness (n=713, 1.1%).

[b] Unless otherwise specified, all percentages were weighted by sampling weight and non-response weight

[c] Measured by IMD deciles in England (1 most socio-economically deprived, 10 least socio-economically deprived)

Table 2 | Frequency and per cent of cancer and non-cancer decedents who received home-based specialist palliative care in the last three months of life

	N (%)[a]	Receiving home-based specialist palliative care	
		Yes	No
Cancer (overall)	26,711 (40.8)	15,269 (57.9)	11,442 (42.1)
Head and neck	498(2.0)	337 (69.2)	161 (30.8)
Oesophageal	1,332 (5.0)	848 (64.6)	484 (35.4)
Stomach	756 (2.9)	464 (61.6)	292 (38.4)
Colorectal	2771 (10.3)	1733 (62.9)	1038 (37.1)
Liver	774 (2.9)	440 (56.2)	334 (43.8)
Pancreas	1588 (5.8)	992 (63.2)	596 (36.8)
Lung	5223 (19.9)	3101 (59.9)	2122 (40.1)
breast	1808 (7.0)	1148 (65.3)	660 (34.7)

Female genital and reproductive organs	1248 (4.7)	819 (66.5)	429 (33.5)
Prostate	2,024 (7.1)	1155 (57.3)	869 (42.7)
kidney	682 (2.6)	404 (60.7)	278 (39.3)
Bladder	849 (3.0)	432 (51.7)	417 (48.3)
Brain and CNS	886(3.6)	580 (66.8)	306 (33.2)
Haematological	1611 (5.9)	596 (36.9)	1015 (63.1)
Unknown/ others	4661 (17.3)	2220 (48.1)	2441 (51.9)
Non-cancer (overall)	36887 (59.2)	2838 (7.8)	34049 (92.2)
Cardiovascular disease	10703 (29.6)	776 (7.0)	9927 (93.0)
Lung and respiratory disease	9784 (26.1)	764 (8.1)	9020 (91.9)
Neurological	4507 (12.5)	492 (11.2)	4015 (88.8)
DM	489 (1.3)	63 (12.4)	426 (87.6)
Liver	815 (2.9)	68 (7.0)	747 (93.0)
Renal	394 (1.1)	35 (9.1)	359 (90.9)
Dementia	4184 (10.3)	280 (6.9)	3904 (93.1)
Others non-cancer	6011 (16.2)	360 (6.2)	5651 (93.8)

[a] Unless otherwise specified, all percentages were weighted by sampling weight and non-response weight

Table 3| Logistic regression of factors associated with receiving home-based specialist care in the last three months of life

Decedent characteristic	**AOR^a**	**95% CI**
Sex		
Male	Reference	-
Female	1.03*	1.02-1.05
Index of multiple deprivation - Quintile		<0.001
1 (most socio-economically deprived)	Reference	-
2	1.07**	1.04-1.10
3	1.10**	0.08-1.13
4	1.18**	1.15-1.22
5 (least socio-economically deprived)	1.20**	1.18-1.23
Length of illness prior to death (year)		
<1	Reference	-
> 1	1.51**	1.49-1.54
Age of deceased at death (years)		<0.001
18-64	Reference	-
65-74	0.92**	0.90-0.94
75-84	0.68**	0.66-0.69

85+	0.46**	0.45-0.47
Continuity of primary care		
Good	1.48**	1.46-1.50
Poor	Reference	-
Relationship of respondent		
other	Reference	-
Spouse or partner	1.26**	1.24-1.28
Cause of death		
Non-cancer	Reference	-
Cancer	11.66**	11.45-11.86

[a] AORs from multivariable logistic regression model.

*P value <0.001

**P value <0.05

*** P value = 0.05

AOR=adjusted odds ratio. IMD=Index of Multiple Deprivation.

Table 4 | Logistic regression of factors associated with overall quality of end- of-life care

Decedent characteristic	AOR[a]	95% CI
Age of deceased at death in years**		
65-84 versus <65	1.06**	1.04 -1.08
85+ versus <65	1.42**	1.40 – 1.45
Sex (female v male)	1.16**	1.15 1.17
Relationship of respondent (spouse/partner v other)	1.57**	1.55-1.59
Cause of death (cancer v non-cancer)	1.05**	1.03-1.06
Duration of illness (>1year v <1 year)	1.07**	1.06-1.09
Place of death**		
Hospice versus hospital	1.78**	1.74-1.81
Care home versus hospital	1.10**	1.08 – 1.13
Home versus hospital	1.73**	1.71-1.75
Socio-economic Deprivation level[b] **		
High level (IMD deciles 1-3) versus low level of deprivation (IMD deciles 8-10)	0.94**	0.93- 0.95

Intermediate level (IMD deciles 4-7) versus low level (IMD deciles 8-10)	0.98 ***	0.95 – 1.00
Receiving home-based specialist palliative care (yes v no)	1.86**	1.84 - 1.89
Ethnicity (white v non-white)	1.09**	1.06 -1.12
Continuity of primary care (good v poor)	2.03**	2.01-2.06

OR odds ratio, *CI* confidence interval, *IMD* Index of Multiple Deprivation

[a] Adjusted ORs from multivariable logistic regression model

[b] Measured by IMD deciles in England (1 most socio-economically deprived, 10 least socio-economically deprived)

*P value <0.001

** P value <0.05

*** P value = 0.05

Table 5 | Logistic regression of factors associated with quality of end-of-life care indicators

	Quality of end-of-life care indicators					
	Receiving sufficient family support		Having a recorded preference for place of death		Patients' involvement in decision-making as much as they wanted	
Decedent characteristic variables	AOR[a]	95% CI	AOR[a]	95% CI	AOR[a]	95% CI
Age of deceased at death in years						
65-84 versus <65	1.35**	1.33-1.38	1.06**	1.04-1.08	1.22**	1.19-1.25
85+ versus <65	2.14**	2.09-2.18	1.17**	1.13-1.20	1.80**	1.74-1.86
Sex (female v male)	1.21**	1.20-1.23	0.95*	0.94-0.97	1.01	0.99-1.03
Relationship of respondent (spouse/partner v other)	1.68**	1.66-1.71	1.07**	1.05-1.09	1.25**	1.22-1.28
Cause of death (cancer v non-cancer)	0.83**	0.82-0.85	1.99**	1.95-2.03	1.01	0.99-1.04
Duration of illness (>1year v <1 year)	1.05**	1.04-1.07	1.26**	1.24-1.28	1.17**	1.15-1.19
Place of death**						
Hospice versus hospital	1.12**	1.09-1.14	2.38**	2.32-2.45	1.32**	1.27-1.37
Care home versus hospital	1.05**	1.02-1.08	1.62**	1.56-1.57	0.76**	0.74-0.79
Home versus hospital	1.76**	1.73-1.79	5.06	4.96-5.16	1.90**	1.85-1.95

Socio-economic Deprivation level[b]						
High level (IMD deciles 1-3) versus low level of deprivation (IMD deciles 8-10)	0.92**	0.91-0.94	1.01	0.99-1.04	0.90**	0.88-0.92
Intermediate level (IMD deciles 4-7) versus low level level of deprivation (IMD deciles 8-10)	0.96**	0.95-0.98	1.00	0.98-1.02	1.01	0.98-1.03
Receiving home-based specialist palliative care (yes versus no)	2.81**	2.76-2.86	2.53**	2.48-2.68	1.70**	1.65-1.75
Ethnicity (white v non-white)	1.00	0.97-1.03	1.52**	1.44-1.60	1.44**	1.36-1.51
Continuity of primary care (good v poor)	1.92**	1.89-1.94	1.36**	1.34-1.38	1.71**	1.68-1.75

AOR adjusted odds ratio, CI confidence interval, IMD Index of Multiple Deprivation

[a] Adjusted ORs from multivariable logistic regression model

[b] Measured by IMD deciles in England (1 most socio-economically deprived, 10 least socio-economically deprived)

*P value <0.001

** P value <0.05

*** P value = 0.05

3.5 Discussion

3.4.1 Summary

Determinants of good-quality care for patients living at home during their last 3 months of life are not well understood.

In this analysis, good continuity of primary care, receiving specialist palliative care at home, being older, and dying in a hospice or at home were all identified as being independently associated with indicators of better-quality end-of-life care, as perceived by relatives. Living in the most socio-economically deprived areas and being from minority ethnic groups were statistically significantly associated with decreased odds of receiving good end-of-life care.

2.4.2 Strengths and limitations of the study and the VOICES dataset

A key strength of this study is its large sample size (63,598 decedents) and the use of five-year data from the VOICES survey, a nationally representative bereavement survey in England, linked to death records. This enabled a robust evaluation of the reported quality of end-of-life care and its associated factors for patients with advanced disease. The study benefits from the use of multivariable modelling and a complete-case analysis approach to address missing data.

However, as an observational cross-sectional study, the findings are based on associations and do not allow for conclusions about causality or directionality. The study was also limited to decedents who received care at home in the last three months of life, excluding those in hospitals or institutions, which may restrict generalisability. Furthermore, the data were collected between 2011 and 2015—prior to the COVID-19 pandemic—which has since changed many aspects of end-of-life and primary care (39,40). As such, findings may not fully reflect current care contexts.

In addition, place of death and achieving the preferred place of death have been widely used as indicators for end-of-life care quality (41, 42). However, as a patient’s condition changes, the expressed preferred place of death and care may not be the most suitable to achieve optimal care and symptom management; as such, the authors considered that recording a preferred place of death (even if that is not achieved) was a marker for having a degree of advance care planning in place, and used it as one of the indicators for end-of-life care quality (4, 42-44).

While the VOICES (Views of Informal Carers – Evaluation of Services) survey offers valuable population-level insight, it has notable methodological limitations. The reliance on bereaved relatives as proxy respondents may introduce recall or subjective bias, especially in the assessment of pain and psychological symptoms (45- 47).

Another limitation is the underrepresentation of ethnic minority groups and individuals from socioeconomically deprived areas (38). Ethnicity data are self-reported and were not included in the weighting process due to the absence of ethnicity information in death registration data (38). This restricts exploration of inequalities and may reduce the generalisability of findings for marginalised groups (48).

Interpretation of certain variables—such as "continuity of care" and "involvement in decision-making"—may vary across respondents. In this study, continuity of care was measured by the frequency of seeing a preferred GP in the last three months of life, consistent with some prior national surveys and studies (49-51). However, this indicator may not capture the broader concept of continuity, which includes relational, informational, and management aspects (52,53).

In this study, weighted data were used to adjust for sampling design and non-response, supporting nationally representative estimates (38). However, the weights do not account for all potential biases—such as illness severity, health literacy, or caregiver support—which may influence both care experiences and survey completion (54). Additionally, ethnicity was not included in the weighting, as it is not recorded on death certificates, limiting representativeness for ethnic minority and socioeconomically disadvantaged groups (38).

Despite these challenges, the VOICES dataset remains one of the most comprehensive national sources of end-of-life care data in England. Its breadth and scale allow for meaningful population-level analyses and insight into care delivery patterns. When interpreted with caution, VOICES continues to inform practice and policy in palliative care. Findings from this study—particularly those linking continuity of primary care and access to specialist palliative services with perceived quality of end-of-life care—remain relevant and aligned with existing evidence. Future research should prioritise inclusion of underrepresented populations and explore the use of longitudinal and mixed-methods designs to capture diverse and evolving experiences of end-of-life care.

2.4.3 Comparison with existing literature

Our findings that home-based specialist palliative care and good continuity of primary care are associated with improved quality of end-of-life care align well with existing academic research. The ability to see a preferred GP consistently during the last three months of life was associated with better-quality end-of-life care, as perceived by relatives. This reinforces the evidence that good continuity of primary care enhances patient outcomes (29, 55-59). The importance of the GP in supporting the family is also evident. Our study's logistic regression analysis showed that good continuity of primary care was significantly associated with receiving sufficient family support. This is consistent with current evidence, which indicates that perceived continuity of care is linked to higher emotional functioning among both patients with advanced cancer and their relatives (30). Additionally, continuity of care has been shown to ensure a “satisfying” dying experience for carers (60). A national GP survey in the UK about end-of-life care in the community found that continuity of care was often compromised by resource constraints, workload, and staffing issues (61). This highlights systemic challenges that need addressing to improve care continuity.

Our study demonstrated that specialist palliative care is associated with higher quality end-of-life care, which aligns with current evidence (62). Research by Chan and colleagues showed that palliative care significantly improves patient and caregiver satisfaction among those with progressive neurological diseases (17). High levels of satisfaction are key indicators of successful palliative care, as they reflect how well the care meets the needs of patients and their families (17). Keane and colleagues also found that supportive care interventions, including palliative care, lead to higher satisfaction due to their holistic approach (63). The data presented here mirror previously described inequities in the quality of end-of-life care, showing that there are disadvantages for those of lower socioeconomic status and from minority ethnic groups (21, 64, 65).

Our findings also highlight significant disparities in palliative care access and the quality of end-of-life care. Patients with non-cancer diagnoses and those from more socio-economically deprived areas are less likely to receive palliative care, suggesting that these disparities could lead to inefficiencies and uneven care burdens across the system, as shown in current studies (66-70). Addressing these disparities is crucial for ensuring equitable care for all patients through targeted interventions.

2.4.4 Implications for research and practice

The association between good continuity of primary care and palliative care with positive outcomes at the end-of-life has been identified. However, significant disparities in access to palliative care, particularly among patients with non-cancer diagnoses and those from more socio-economically deprived areas, highlight the need for targeted research to address these inequalities. Future research should prioritise the development of standardised screening tools to identify patients who could benefit from palliative care. The current lack of such tools results in inconsistent and delayed referrals, particularly in primary care (71, 72). Implementing systematic and standardised tools can ensure timely and appropriate palliative care referrals, thus improving patient outcomes and overall quality of care (73).

The key role of GPs in supporting both the patient and family at the end-of-life is clear; however, the question of how the primary care service might provide good continuity of care to more people is not so easily answered. Continuity of care and how best to provide it is an area of interest to many GPs and policymakers — as discussed in a recent editorial article —

but current constraints of workload, staffing issues, and limited time may mean that the priority is for patients to be seen, rather than by whom they are seen (61, 74). A recent qualitative study by the authors confirms that patients at the end-of-life and their carers find it distressing to have to explain their situation repeatedly to primary care staff, including receptionists (75). The results presented here show that being White versus non-White increased the odds of having a recorded preferred place of death and being involved in decision-making. The reasons for this disparity are not explained by the data analysed and merit future investigation. The National Cancer Patient Experience Survey shows consistently lower satisfaction and a less positive experience of care, overall, for patients from a minority ethnic group, and data from a UK study of bereaved families of Black Caribbean patients perceived that GPs could have done more to manage their loved ones' symptoms (76, 77). These underline the importance of recording ethnicity and other demographics in future research and data collection to help researchers and commissioners better understand the experience of marginalised groups, and work towards codeveloping tailored support for sensitive conversations and interventions.

The COVID-19 pandemic has resulted in unprecedented pressure on community health services, increased the number of deaths in the community, and exacerbated inequalities in end-of-life care that have intensified the need for improvements in palliative care access, provision, and recognition (39, 40). In England, the Health and Care Act 2022 includes a new legal duty to provide palliative care and end-of-life care services in every part of England for people of all ages in all settings (78). This is an important step in providing high-quality integrated care for people approaching the end-of-life, particularly in community settings, which can be achieved by using and implementing individual-level outcome measures in clinical practice, expanding the specialist workforce, providing training for the primary care workforce, and increasing community support for patients at the end-of-life (39,40,78). Good continuity of primary care, specialist palliative care support, and death outside of hospital were associated with better quality of end-of-life care as perceived by relatives. However, as inequalities between ethnic and socioeconomic groups still exist in end-of-life care, future commissioning and initiatives must consider these variables to provide equitable and high-quality end-of-life care in the community setting.

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Chapter 4: Specialist palliative care support is associated with improved pain relief at home during the last 3 months of life in patients with advanced disease: analysis of 5-year data from the national survey of bereaved people (VOICES)

Study Three	
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4.1 Abstract

Background: Studies have shown that more than half of patients with advanced progressive diseases approaching the end-of-life report pain and that pain relief for these patients is poorest at home compared to other care settings such as acute care facilities and hospice. Although home is the most common preferred place of death, the majority of deaths occur outside the home. Specialist palliative care is associated with improved quality of life, but systematic reviews of RCTs have failed to show a consistent association with better pain relief. The aim of this study was to examine the factors associated with good pain relief at home in the last 3 months of life for people with advanced progressive disease.

Methods: Data were obtained from the National Bereavement Survey in England, a cross-sectional post-bereavement survey of a stratified random sample of 246,763 deaths which were registered in England from 2011 to 2015. From 110,311 completed surveys (45% response rate), the analysis was based on individual-level data from 43,509 decedents who were cared for at home before death.

Results: Decedents who experienced good pain relief at home before death were significantly more likely to have received specialist palliative care (adjusted OR = 2.67; 95% CI, 2.62 to 2.72) and to have a recorded preferred place of death (adjusted OR = 1.87; 95% CI, 1.84 to 1.90) compared to those who did not. Good pain relief was more likely to be reported by a spouse or partner of the decedents compared to reports from their son or daughter (adjusted OR = 1.50, 95% CI, 1.47 to 1.53).

Conclusion: This study indicates that patients at home who are approaching the end-of-life experience substantially better pain relief if they receive specialist palliative care and their preferred place of death is recorded regardless of their disease aetiology.

4.2 Introduction

Pain is a highly prevalent and debilitating problem among people with advanced progressive disease [1, 2]. Studies have shown that more than 50% of patients with advanced cancer and non-cancer diseases reported pain, and the prevalence may increase as they approach the end-of-life [2–4]. Managing pain in people approaching the end-of-life is a major concern for healthcare professionals and a global public health priority [5, 6]. Despite the increased availability of strong opioids, many patients still do not receive adequate analgesia for their pain [7]. Even in the UK, access to and duration of opioid treatment is limited for patients before they die, and people aged 60 years or older are less likely to receive opioids compared to younger patients [8, 9]. Numerous studies have consistently shown a mismatch between expressed preferences for place of death and actual place of death, with most people preferring to die at home but the majority dying in hospital [10, 11]. Issues such as carer burden or difficulties in controlling pain and other symptoms at home make the majority of deaths occur outside the home [12, 13]. This is supported by evidence from the National Survey of Bereaved People (VOICES) in England, which showed that pain relief is the poorest for people who received end-of-life care at home compared to those dying in acute care facilities or hospice [14]. Only 19% of respondents reported pain to be completely relieved in people who were cared for at their own home in comparison with 64% in hospices, 43% in care homes and 40% in hospital [15]. UK policy supports the need for improved quality of care for people dying at home, particularly relief from pain [16–18]. Although specialist palliative care (compared to usual care) is associated with improved quality of life, there is inconclusive evidence from meta-analyses about the effect on reducing pain and symptom burden [19–25]. Pain relief in older adults and those with non-cancer disease may be harder to obtain because these patients have limited access to specialist palliative care services compared to younger patients and those diagnosed with cancer [14, 26–29]. We aimed to examine the factors associated with good pain relief at home in the last 3 months of life for people with advanced progressive illness. Specifically, we sought to examine the relationship between the extent of pain relief at home and receiving specialist palliative care.

4.3 Methods

4.3.1 Population and data source

The National Survey of Bereaved People (VOICES, Views of Informal Carers - Evaluation of Services) is a nationally representative cross-sectional survey which was conducted in England annually for 5 years, 2011–2015, to collect information about the quality of end-of-life care, particularly in the last 3 months of life [30]. The survey was commissioned by NHS England and administered by the Office for National Statistics (ONS). The survey's results are based on a relative's or friend's perspective on the quality of end-of-life care provided to the decedent. Previous analyses of VOICES data have been used to inform national policy on end-of-life care service and assess and evaluate the quality of end-of-life care in different settings (home, hospital, care homes and hospices) [31]. Every year, a stratified sample of around 49,000 adults was selected from deaths which are registered in England. The VOICES questionnaire was sent by post to the person who registered the death of the decedent, who is normally a family member or a close friend. Respondents were contacted once between 4 and 11 months after death (two further reminder questionnaires were sent if there was no response). The sampling weight and non-response weight were created by the ONS for each year. The sampling weight and non-response weight were then combined by taking the product of the two. We used the combined weight to adjust for sampling and non-response biases. Further information on VOICES methodology is available from the ONS [30].

4.3.2 Sampling

We obtained data from five annual VOICES surveys conducted between 2011 and 2015. During this period, 246,763 people were invited to participate, of whom 110,311 (45%) returned a completed questionnaire. Because the VOICES survey does not contain information about palliative care in settings other than home, we examined factors associated with good pain relief at home in the last 3 months of life for people with advanced progressive illness. In addition, the main outcome was the success of pain relief at home, which was applied only to decedents who had pain at home in the last 3 months of life. The following exclusion criteria were applied:

1. Decedent who died suddenly or was not ill prior to death.
2. Decedent who did not spend any time at home in the last 3 months of life.
3. Decedent who did not have any pain at home in the last 3 months of life.

4.3.3 Independent variables

Respondent characteristics included age, gender and relation to the decedent (spouse/partner, son/daughter, other). Decedent characteristics included age, gender, cause of death (cancer or non-cancer), index of multiple deprivation (IMD) quintiles (1 = most socio-economically deprived, 5 = least socio-economically deprived), and duration of illness before the decedent died. We developed variables for service characteristics labelled receiving specialist palliative care at home in the last 3 months of life (yes or no), recorded preference for place of death (yes or no) and urgent care provided out of hours (once or twice, three times or more, not at all).

4.3.3.1 Specialist palliative care proxy measure

Respondents were asked about the decedent, ‘when he/ she was home in the last three months of life, did he/she get any help from any of the services: hospice home care nurse or specialist, hospice at home service, Macmillan nurse or Marie Curie nurse? (Macmillan and Marie Curie are UK-based charities that fund clinical nurse specialists in palliative care who deal with patients with cancer and non-cancer diagnoses). If respondents answered ‘yes’ to any of the three questions, it was assumed that their relative had received specialist palliative care in the last 3 months of their life, defined as professionals or services whose core activity is providing palliative care. If responders answered ‘no’ to all three questions, it was considered for the purposes of this research that their relative had not received specialist palliative care in the last 3 months of their life.

4.3.3.1 Recorded preference for place of death

The survey asks about the decedent: ‘Did she/he ever say where she/he would like to die?’ If responders answered ‘yes’, they were asked about the preferred place of death. After that, they were asked, ‘Did the healthcare staff have a record of this?’ Having a preference recorded for place of death in the medical records was used as a positive indicator for this variable.

4.3.4 Outcomes

The primary outcome was the extent of pain relief at home. We collapsed the response categories included in the survey for ease of interpretation into (1) good pain relief (pain relieved completely, all of the time and completely, some of the time) and (2) poor pain relief (pain relieved partially, not at all).

4.3.5 Statistical analysis

Based on individual-level survey data, numbers and percentages (both unweighted and weighted) were calculated to summarise decedent and respondent characteristics. Logistic regression models were used to examine the association between decedent and respondent characteristics and good pain relief. All variables that had a p-value less than 0.1 univariately (to account for potential collinearity) were included in an initial multivariable model. As the aim of the analysis was to identify factors associated with good pain relief, rather than develop the most parsimonious model, variables were retained in the final multivariable model if they improved the fit of the model based on the likelihood-ratio test (using backward selection $p < 0.05$). In the final multivariable logistic regression model, we assessed potential multicollinearity using the variance inflation factor (VIF). Statistical software IBM SPSS statistics version 24 was used for data management and analysis. We used the published weights for the VOICES survey in the analysis to account for the study design and to adjust for non-response bias [30].

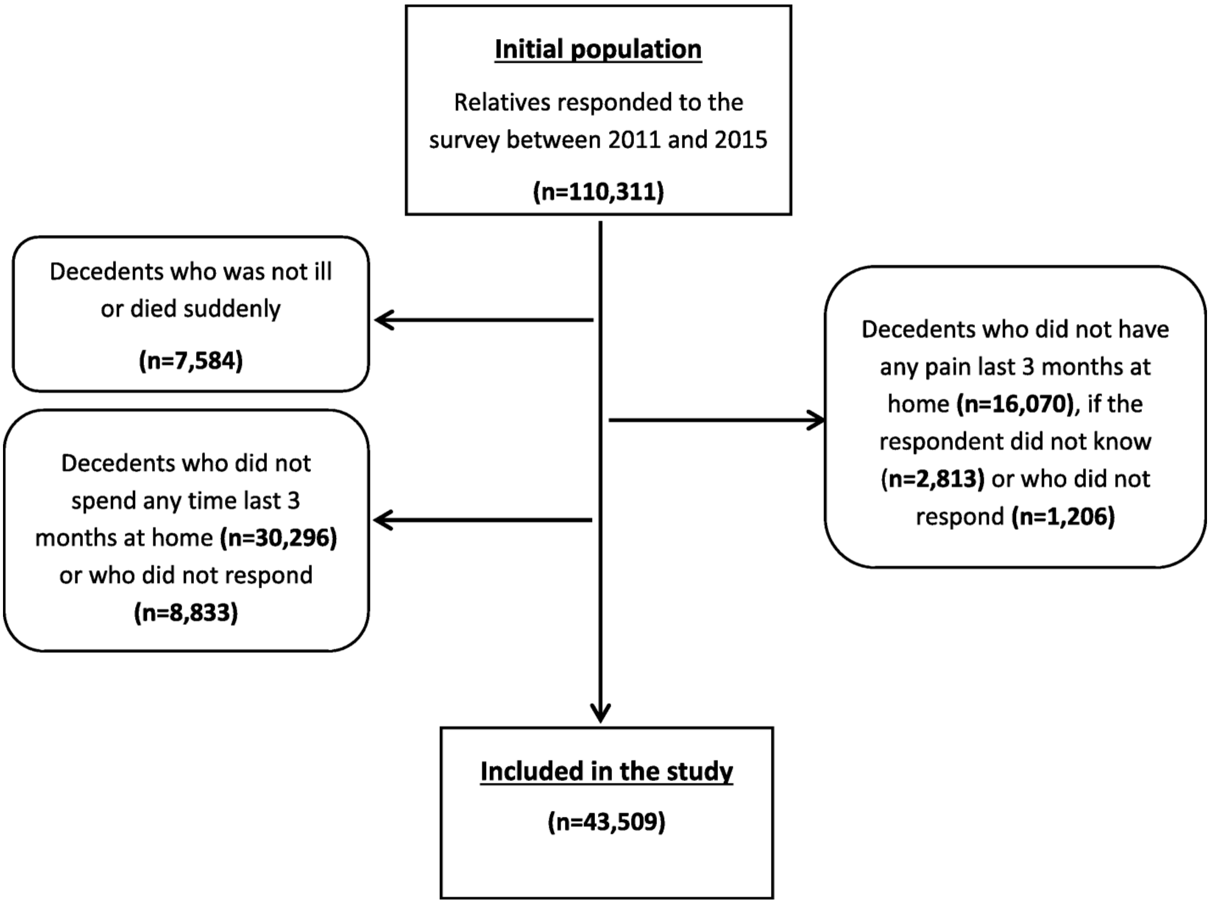

Fig 1 | Flow chart showing records included in this study as well as reasons for exclusion.

4.4 Results

Of the 110,311 respondents to the VOICES questionnaire from 2011 to 2015, 66,802 (60.6%) respondents did not meet the inclusion criteria and were excluded (Fig. 1). Therefore, 43,509 (39.3%) of respondents were included in our analysis. Around 51.6% of decedents were female, and 59.8% of survey respondents were female (Table 1). Decedents aged 75 and older account for 60.9% of the study population. Over half of the decedents (52.1%) were ill for more than a year prior to death, and 51.2% of deaths were from non-cancer disease. Data were missing for the following variables: How long had she or he been ill prior to death (484, 1.1%), respondent age (531, 1.2%), respondent's relationship to decedent (733, 1.6%) and respondent sex (2298, 5.1%). Care and service characteristics by cause of death are shown in Table 2. Overall, 35.7% of decedents received specialist palliative care at home, and 24.6% had a recorded preference for place of death. About 78.7% of decedents had at least one out-of-hours service contact in the last 3 months of life. Cancer decedents were more likely to receive specialist palliative care support at home (66.2% vs 9.9%), have a recorded preference for place of death (36.6% vs 13.1%), and contact out-of-hours service in the last 3 months of life (81.6% vs 75.9%) compared to non-cancer decedents. Pain relief by cause of death is presented in Table 3. Overall, just under half of the decedents in our study experienced good pain relief (47.8%). For decedents with non-cancer disease, around 39.6% had good pain relief compared to 56.4% of cancer decedents ($p < 0.001$). Table 3 also compares pain relief by service characteristics. This shows that 66.2% of decedents who received specialist palliative care services at home experienced good pain relief compared to 37.5% of those who did not ($p < 0.001$). Among patients who had a recorded preference for place of death, 66.0% had good pain relief in comparison with only 41.7% of decedents who did not ($p < 0.001$). Good pain relief stratified by cause of death and service characteristics is illustrated in Fig. 2. Univariately, all characteristics were significantly associated ($p < 0.001$) with good pain relief at home (Table 4) and remained in the final multivariable model. The multivariable model revealed a significantly higher chance of experiencing good pain relief among those who received specialist palliative care at home (adjusted OR = 2.67; 95% CI, 2.62 to 2.72) and who had a recorded preference for place of death (adjusted OR = 1.87; 95% CI, 1.84 to 1.90) in comparison with those who did not, keeping all other characteristics constant (Table 4). In addition, compared to decedents who did not contact out-of-hours services, decedents who contacted out-of-hours services three times or more were more likely to have good pain relief (adjusted OR = 1.05; 95% CI, 1.03 to 1.07), while decedents with one or two out-of-hours service contacts experienced worse pain relief (adjusted OR = 0.89; 95% CI, 0.87 to 0.91). The results also showed that women had 3% higher odds of good pain relief than compared to men (adjusted OR = 1.03; 95% CI, 1.01 to 1.04), keeping all other characteristics constant. In addition, shorter duration of illness was associated with a reduced probability of experiencing good pain relief in comparison with decedents with illness for more than a year; that is, the odds of good pain relief were 9% lower for decedents who were ill between 1 month and 6 months prior to death in comparison with decedents with illness for more than a year. Moreover, decedents who died of cancer were more likely to experience good pain relief (adjusted OR = 1.08; 95% CI, 1.06 to 1.10) compared to non-cancer decedents, keeping all other characteristics constant. Decedents aged 75 and older were more likely to experience good pain relief compared to younger decedents. For example, the odds of experiencing good pain relief were 46% higher among decedents aged 85 and older compared to younger decedents aged 74 or younger. Socio-economic deprivation (IMD) was significantly associated with good pain relief but in a nonlinear pattern. For example, compared to the most socio-economically deprived quintile, decedents who lived in the second least socio-economically deprived quintile had significantly higher odds of good pain relief, while those in the least socio-economically deprived quintile had no difference in their odds of good pain relief. The respondent’s relationship with decedents was also significantly associated with good pain relief. Good pain relief was more likely to be reported by a spouse or partner of the decedent compared to a son or daughter of the decedent (adjusted OR = 1.50, 95% CI, 1.47 to 1.53), keeping all other characteristics constant. Multicollinearity did not appear to be present, based on an evaluation using the variance inflation factor (VIF). All VIF scores are less than 1.7. These scores are well below the cutoff values of between 5 and 10, in which collinearity may be problematic [32].

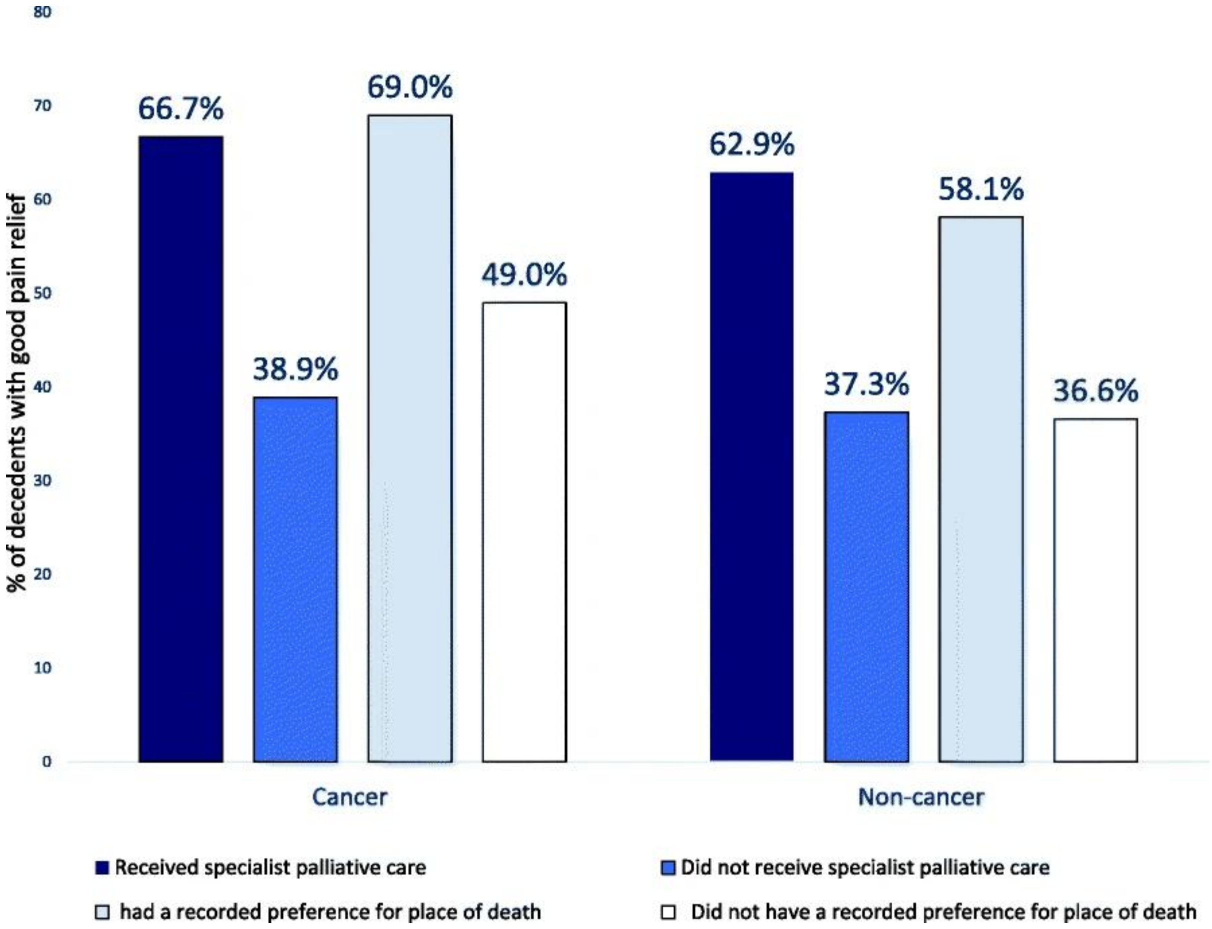

Fig 2 | Proportions of decedents with good pain relief at home by cause of death and palliative care status during the last three months of life.

Table 1 | Decedent and respondent characteristics

	Number of respondents	Unweighted % [95%% CI[1]]	Weighted % [95%% CI]
Decedent's age			
18-74	14888	34.2 (33.8 -34.7)	39.1 (39.0 -39.3)
75-84	13903	32.0 (31.5 -32.4)	30.9 (30.7 -31.0)
85+	14718	33.8 (33.4 -34.3)	30.0 (29.8 -30.1)

Decedent’s gender			
Male	20820	47.9 (47.4 -48.3)	48.4 (48.2 -48.6)
Female	22689	52.1 (51.7- 52.6)	51.6 (51.5-51.8)
Cause of death			
Cancer	21737	50.0 (49.5 -50.4)	48.8 (48.6- 48.9)
Non-cancer	21772	50.0 (49.6-50.5)	51.2 (51.1- 51.4)
Deprivation (IMD)			
1 (Most socio-economically deprived)	7197	16.5 (16.2 -16.9)	18.6 (18.5- 18.8)
2	8191	18.8 (18.5 -19.2)	19.8 (19.7- 20.0)
3	9476	21.8 (21.4 -22.2)	21.5 (21.4- 21.7)
4	9458	21.8 (21.4- 22.2)	20.7 (20.5 -20.8)
5 (Least socio-economically deprived)	9187	21.1 (20.7 -21.5)	19.4 (19.3- 19.5)
Length of illness prior to death.			
< 1 month	4607	10.7 (10.4 -11.0)	10.5 (10.4-10.4)
> 1 month, < 6 month	9745	22.6 (22.2- 23.0)	22.0 (21.9-22.1)
> 6 month, < 1 year	6631	15.4 (15.1 -15.7)	15.4 (15.2- 15.5)
> 1 year	22106	51.3 (50.8-51.8)	52.1 (52.0-52.3)
Respondent’s age			
18-49	7663	17.9 (17.5 -18.2)	19.6 (19.5-19.7)
50-59	12531	29.1 (28.7- 29.6)	29.1 (29.0 -29.3)
60-69	13772	31.2 (30.8- 31.7)	30.5 (30.4-30.7)
70-79	6594	15.3 (15.0 -15.7)	14.8 (14.7-14.9)
80+	2952	06.5 (06.3 -06.8)	06.0 (05.9-06.1)
Respondent’s gender			
Male	16632	40.3 (39.8 -40.7)	40.3 (40.2-40.5)
Female	24690	59.7 (59.3 -60.2)	59.7(59.5-59.8)
Respondent’s relationship to decedents			

Wife/Husband/Partner	14670	34.2 (33.8 -34.7)	35.5 (35.4 -35.7)
Son/Daughter	22745	53.1 (52.6 -53.6)	50.7 (50.5 -50.9)
Other	5420	12.7 (12.3 -13.0)	13.8 (13.6 -13.9)

Table 2 | Care and service characteristics in the last 3 months by cause of death

	Total % [95%% CI]	Cancer % [95%% CI]	Non-cancer % [95%% CI]
Specialist palliative care at home (yes)	35.7 (35.5-35.8)	62.7 (62.5-63.0)	9.9 (9.7-10.0)
Recorded preference for place of death (yes)	24.6 (24.5-24.7)	36.6 (36.4-36.9)	13.1 (12.0-13.3)
Urgent care provided out of hours			
Not at all	21.3 (21.2-21.4)	18.4 (18.2-18.6)	24.1 (23.9-24.3)
Yes	78.7 (78.6-78.8)	81.6 (81.4-81.8)	75.9 (75.7-76.1)
Once or twice	33.1 (33.0-33.3)	35.9 (35.7-36.1)	30.4 (30.2-30.7)
Three or more	45.6 (45.4-45.8)	45.7 (45.5-45.9)	45.5 (45.2-45.7)

All percentages were weighted by sampling weight and non-response weight.

Table 3 | Proportions of decedents with good pain relief in the last 3 months by cause of death and service characteristics

	Total % [95%% CI[1]]	Cancer % [95%% CI]	Non-cancer % [95%% CI]
Overall	47.8 (47.6-47.9)	56.4 (56.1-56.6)	39.6 (39.3-39.8)
Specialist palliative care at home			
Yes	66.2 (65.9-66.5)	66.7 (66.4-67.0)	62.9 (62.2-63.7)
No	37.5 (37.3-37.7)	38.9 (38.5-39.2)	37.3 (36.8-37.3)
Recorded preference for place of death			
Yes	66.0 (65.7-66.4)	69.0 (68.6-69.4)	58.1 (57.5-58.8)
No	41.7 (41.5-41.9)	49.0 (48.7-49.3)	36.6 (36.4-36.9)
Urgent care provided out of hours			
Not at all	45.3 (44.9-45.7)	54.9 (54.4-55.5)	38.2 (37.8-38.7)
Once or twice	48.6 (48.3-48.9)	56.3 (55.9-56.7)	39.9 (39.5-40.3)
Three or more	49.6 (49.3-49.8)	58.2 (57.9-58.6)	41.2 (40.9-41.6)

All percentages were weighted by sampling weight and non-response weight.

Table 4| Logistic regression of factors associated with good pain relief at home.

	Univariate model			Multivariable model		
	OR	95% CI	P value	OR	95% CI	P value
Specialist palliative care at home						
No[b]	1	-		1	-	-
Yes	3.26	3.21 to 3.31	< 0.001	2.67	2.62 to 2.72	<0.001
Recorded preference for place of death						
No [b]	1			1		
Yes	2.72	2.68 to 2.77	< 0.001	1.87	1.84 to 1.90	< 0.001
Urgent care provided out of hours			< 0.001[a]			<0.001[a]
Not at all[b]	1	-		1	-	-
Once or twice	1.14	1.12 to 1.17	< 0.001	0.89	0.87 to 0.91	<0.001
Three times or more	1.19	1.17 to 1.21	< 0.001	1.05	1.03 to 1.07	<0.001
Cause of death						
Non-cancer[b]	1	-		1	-	-
Cancer	1.97	1.95 to 2.00	< 0.001	1.08	1.06 to 1.10	< 0.001
Decedent's age			< 0.001[a]			< 0.001[a]
18-74[b]	1	-		1	-	-
75-84	0.86	0.84 to 0.87	< 0.001	1.22	1.19 to 1.24	< 0.001
85+	0.78	0.77 to 0.80	< 0.001	1.46	1.43 to 1.50	< 0.001
Decedent's gender						

Male[b]	1	-		1	-	-
Female	0.92	0.90 to 0.93	< 0.001	1.03	1.01 to 1.04	0.001
Deprivation (IMD)			< 0.001[a]			< 0.001[a]
1 (Most socio-economically deprived)[b]	1	-		1	-	-
2	1.18	1.15 to 1.20	< 0.001	0.98	0.96 to 1.01	0.16
3	1.07	1.05 to 1.09	< 0.001	1.03	1.01 to 1.05	0.04
4	1.14	1.12 to 1.17	< 0.001	1.04	1.01 to 1.06	0.003
5 (Least socio-economically deprived)	1.17	1.14 to 1.19	< 0.001	1.01	0.98 to 1.03	0.54
Respondent’s relationship to decedents			<0.001[a]			<0.001[a]
Son/Daughter[b]	1	-		1	-	-
Wife/Husband/Partner	1.68	1.66 to 1.71	<0.001	1.50	1.47 to 1.53	<0.001
Other	1.05	1.03 to 1.07	< 0.001	1.13	1.10 to 1.16	<0.001
Length of illness prior to death.			< 0.001[a]			< 0.001[a]
> 1 year[b]	1	-		1	-	-
< 1 month	0.60	0.59 to 0.62	< 0.001	0.92	0.90 to 0.95	< 0.001
> 1 month, < 6 month	0.86	0.84 to 0.87	< 0.001	0.91	0.89 to 0.92	< 0.001
> 6 month, < 1 year	1.10	1.08 to 1.12	< 0.001	1.01	0.98 to 1.03	0.63

[a] P value for overall effect; [b] Used as a reference variable.

OR = odds ratio; CI = confidence interval; IMD = Index of Multiple Deprivation

4.5 Discussion

Our analysis of 43,509 patients who were cared for at home before death showed that receiving specialist palliative care and having a recorded preference for place of death were found to be strongly and independently associated with good pain relief in the last 3 months of life. These findings have contributed to evidence supporting the need for, and the benefits of, specialist palliative care and recording preferences for place of death for patients with advanced disease. Furthermore, we have demonstrated that respondents who were spouses or partners of the decedents were much more likely to report better pain relief than respondents who were sons or daughters. A major strength of this study is that we used data from the first national survey on the quality of end-of-life care in England. The response rate was modest (45%), which could lead to bias. However, the response rate provides a suitable sample size for analysis at the national level and the weighting method we used corrected for non-response and sample biases [30]. We have also combined 5 data sets, 2011–2015, to increase the sample size in order to improve data robustness. The validated questionnaire and the large sample size provided good statistical power from which generalisable findings can be made. Our study has a number of limitations. A key drawback is that it was an analysis of a post-bereavement survey which used the perceptions of the decedent's relatives as a proxy measure of the quality of care experienced by the patient. Retrospective ratings of end-of-life care by the decedent's relatives could be different from the actual experience of the decedent. Research is difficult to conduct on patients with advanced progressive disease, and although the validity and reliability of proxies are questionable, they may need to be accepted and utilised as a valuable part of end-of-life research [33]. Without this proxy measure, there are only a few poorly powered studies that can inform important policy documents and the practice of end-of-life care. Moreover, retrospective studies allow for more representative samples to be studied as they are not limited to diseases such as cancer that have an identifiable terminal phase. It is better to have imperfect recollections from proxies than it is to have no perceptions of end-of-life care at all [33]. In addition, recall bias cannot be excluded due to the timing of data collection being 4–11 months after death and the possibility of inaccurately recalling subjective aspects such as pain. Another important limitation of the findings is that we were only able to demonstrate an association between improved pain relief and specialist palliative care and recorded preference for place of death, but we cannot demonstrate causality. However, it is entirely plausible that contact with specialist palliative care or discussing and recording the preferred place of death results in better pain relief, particularly because of the emphasis by specialist palliative care clinicians on symptom management and expertise in the use of opioid analgesia. The counter-argument that patients with good pain relief ‘cause’ a referral to specialist palliative care is much less plausible as eligibility criteria for referral to specialist palliative care services include symptoms that are uncontrolled or complicated, i.e. patients who have poor pain relief or not good pain relief [34]. This might also imply that patients referred to specialist palliative care had worse baseline pain than those not referred and that the impact of specialist palliative care on pain relief is underestimated in this analysis. The association between good pain relief and recording the preferred place of death is more difficult to explain. It may represent engagement in broader aspects of advance care planning, which includes pain management strategies, and perhaps reflects greater communication and engagement with healthcare professionals, both of which might lead to better pain outcomes. The type of respondent influenced recollection of pain relief; spouses and partners rated pain relief better than sons or daughters. Spouses and partners are likely to have had closer contact than sons or daughters and perhaps represent a more reliable account. Conversely, spouses and partners are more likely to be older and have potentially different (lower) expectations of healthcare services and interventions than younger sons and daughters, resulting in inflated views of outcomes. Finally, we cannot exclude the possibility of uncontrolled confounding by factors that were not measured within the survey, for example, the presence of other symptoms that might trigger palliative care referral, other services that patients received that were not captured within the survey questions or presence of depression or anxiety within decedents or respondents. Interestingly, decedents aged 75 and older were less likely to experience good pain relief compared to younger decedents in the univariable analysis, but following adjustment and multivariable analysis, decedents aged 75 and older had significantly higher odds of good pain relief compared to younger decedents (Table 4). The reason for this swing in the direction of the association might be due to confounding with other variables in the final multivariable model. While we checked and found no evidence of a high degree of multicollinearity, associations between both the outcome and age and another variable(s) are likely to be present. This is the largest study that shows a significant association between receiving specialist palliative care at home and improved pain relief within routine clinical services. Previous research has found an inconclusive relationship between palliative care support and improved pain relief. A US national study by Teno et al., which is one of the very few national surveys of family perspectives on end-of-life care, supports our findings [35]. These authors found that in 512 patients who died at home, pain relief was significantly better in the 256 patients who received care at home with hospice services compared to receiving only home nursing services. In a systematic review and meta-analysis of trials [19], which examined the effectiveness of home palliative care, only 3 of 9 studies in which pain was an outcome measure found statistically significant positive effects on pain relief.

Conclusion

Our study indicates that patients at home who are approaching the end-of-life experience substantially better pain relief if they receive specialist palliative care or have a recorded preference for place of death, regardless of their disease aetiology. Policymakers should consider how to ensure improvements in pain management for patients at home through advice and support from community specialist palliative care services.

Abbreviations:

CI: Confidence interval; IMD: Index of Multiple Deprivation; NHS: National Health Service; ONS: Office for National Statistics; OR: Odds ratio; RCTs: Randomised control trials; VIF: Variance inflation factor; VOICES: Views of Informal Carers - Evaluation of Services

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Authors' contributions: YE, NW and MIB conceived and designed the study. YE, TF and MIB wrote the statistical analysis plan. YE cleaned and analysed the data, and YE and MIB interpreted the data. YE, NW, TF and MIB revised the manuscript and approved the final manuscript. YE is the guarantor for the study. All authors read and approved the final manuscript.

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Chapter 5: Timely identification of patients with cancer who may benefit from palliative care in primary care: A qualitative study of current barriers and the potential benefits of electronic screening for identification

5.1 Abstract

Background*:* Timely access to palliative care can enhance the quality of life and end-of-life care for patients with advanced cancer. However, many are identified late in their disease trajectory. Automatic screening is suggested to aid early palliative care integration in primary care. This study aimed to explore barriers to the timely identification of patients with cancer who may benefit from palliative care in primary care and evaluate the benefits of using electronic screening for this purpose.

Methods: Semi-structured interviews were conducted with patients with advanced cancer and healthcare professionals (HCPs) in primary care. Patients who had been referred to palliative care from primary care were included. Thematic Analysis was used to analyse the data.

Results: Six patients and 12 HCPs participated. Four themes emerged: a lack of systematic approach, limited time and resources, difficulty talking about palliative care, and a lack of continuity of care and interprofessional collaboration.

Conclusions: Significant barriers to the timely identification of patients with cancer with potential palliative care needs were identified by patients with cancer and HCPs in primary care. These need to be addressed. Findings suggest that enhanced collaboration between primary and secondary HCPs is essential to facilitate early identification. Furthermore, we highlight the need for more research on patient-centred communication strategies for end-of-life care. A standardised, automated tool may help integrate palliative care earlier. Further research is needed to assess such a system's effectiveness and explore its outcomes, cost-effectiveness, and implementation barriers in primary care.

5.2 Background

Palliative care is a comprehensive and patient-centred approach to care that addresses the needs of patients with incurable progressive disease by assessing and managing physical and psychological symptoms, providing family support, and enhancing spiritual well-being (1). To achieve these objectives, it is crucial to identify patients with unmet palliative care needs early in their disease trajectories (2).

There is increasing evidence of the effectiveness of palliative care in improving quality of life and reducing symptom burden for patients with advanced cancer, primarily when delivered early in the illness trajectory (3-12). However, many patients with advanced cancer who could benefit from palliative care are identified late or do not receive palliative care at all (4, 13, 14). In addition, access to palliative care is uneven and geographically inequitable (15, 16).

Identifying patients with potential palliative care needs in primary care is challenging. Despite efforts to develop effective identification systems, such as the Gold Standards Register, their applicability and usability are limited by a lack of accuracy (17). There is increasing international interest in using electronic medical records to identify patients who could benefit from palliative care (18-20). Employing technology may play a role in efficiently identifying these patients and reducing the workload burden for busy clinical staff in primary care (18, 21, 22). However, there is limited qualitative data detailing the views on integrating these electronic screening tools into clinical practice, as well as the perspectives of healthcare providers and patients on palliative care needs and the current barriers to timely identification (23).

The aims of this qualitative study were: (1) to understand the perspectives of patients with cancer and healthcare professionals on barriers to the timely identification of potential palliative care needs in patients with cancer in primary care; and (2) to explore the potential benefits of integrating an electronic screening tool for this purpose.

5.3 Methods

5.3.1 Study Design

A qualitative approach using semi-structured interviews with general practitioners (GP), district nurses (DN) and patients with cancer who were referred to specialist palliative care services from primary care was utilised in this study. This study was informed by a pragmatic research paradigm (24, 25).

Data collection commenced in February 2020 and was suspended in March 2020 due to the COVID-19 pandemic. In July 2020, an amendment to the protocol to conduct the remaining interviews virtually was approved. Data collection was completed in March 2021.

My study was approved by the East of Scotland Research Ethics Committee and Health Research Authority (IRAS project ID 271648, REC reference 20/ES/0009) in January 2022. The present study reports this research using the Standards for Reporting Qualitative Research Framework (26).

5.3.2 Participants

Purposive and maximum variation sampling was used to recruit a representative sample of participants.

Patients were eligible to participate if they met the following inclusion criteria:

- Diagnosed with advanced cancer who has been referred to palliative care through their GP or a district nurse.
- 18 years of age or over.
- Able to speak and understand English.
- Able to give informed consent.

Patients were excluded if they exhibited severe cognitive dysfunction, which would impede their participation in the study or were deemed too ill by the hospice staff. Healthcare professionals were eligible if they provided care for adult patients with cancer in their routine practice as a GP or district nurse (generalist registered nurse providing nursing care in primarily home settings) (27).

5.3.3 Procedure

Patients were recruited from a hospice in the North of England in February and August 2020. Eligible patients were identified and approached by research nurses at St Gemma's Hospice, who passed their contact details to the research team if they were interested in participating.

DNs were recruited from a community healthcare trust in the North of England. GPs were recruited from two sources: (a) general practices in two cities in the North of England and (b) the Academic Unit of Primary Care at a university. Healthcare professionals were recruited between August 2020 and February 2021. Invitations to participate in the study were sent to GPs by a regional Research and Development (R&D) team. Interested GP participants contacted the research team directly. The research team contacted additional potential GP participants from the Academic Unit of Primary Care at the university. DNs from the community healthcare trust were approached by research nurses at a local hospice, and their contact details were passed to the research team if they were willing to participate. Interested participants were screened for eligibility.

Before taking part in the interviews, all participants were given information sheets explaining the purpose of the study, and informed consent was obtained.

Patients recruited in February 2020 were provided with the option of meeting either in a quiet room at the hospice or at their homes. After that, due to COVID-19 pandemic restrictions, all interviews were conducted virtually with patients and healthcare professionals.

We used different semi-structured interview schedules for patients and healthcare professionals to explore their perspectives on how and when patients are identified as needing palliative care, as well as the barriers to timely identification. Participants were also asked about their thoughts on the potential benefits of integrating a screening tool for the identification of patients with cancer who may benefit from palliative care in primary care. A topic guide was used to guide the semi-structured interviews (see Appendix B.1 and B.2).

The first two interviews were conducted by two researchers together: a senior research fellow with experience in qualitative research (SP) and a PhD researcher who was new to qualitative research (YE) to acquaint himself with the interview technique. The remaining 16 interviews were conducted by one researcher (YE).

None of the participants withdrew from the study. Interviews were audio-recorded and transcribed verbatim. Interview data used pseudonyms and was anonymised before being stored securely.

5.3.4 Data analysis

Interview transcripts were analysed using thematic analysis to draw out key themes from the data (28, 29). The analysis process involved six stages: familiarisation with the data, coding, searching for themes, reviewing themes, defining and naming themes, and writing a report.

The primary data analysis was conducted by YE, who met regularly with the research team members (SP and LZ) to discuss emergent themes and the preliminary results. In this study, we combined data from patients and healthcare professionals into one dataset to provide an in-depth understanding of barriers to identifying patients with cancer who have palliative care needs in primary care and the potential benefits of implementing an electronic screening tool for identification. NVivo 12 software was used for data organisation and management throughout the analytic process.

5.4 Results

5.4.1 Participant characteristics

A total of 12 healthcare professionals participated in the interviews, comprising eight GPs and four District Nurses (DNs), including one Associate Community Matron (Table 2 details clinician characteristics). The individual interviews with healthcare professionals lasted between 21 and 36 minutes, with an average duration of 29 minutes. All healthcare professional interviews were conducted virtually.

In addition, six patients with cancer were interviewed: four women and two men, all of whom were white (Table 1 details patient characteristics). The mean age of the patients with cancer was 71.3 years. The interview durations for these patients ranged from 25 to 53 minutes, with an average duration of 35 minutes. The first five patient interviews were conducted in person, while the last interview was conducted virtually due to COVID-19 pandemic restrictions.

Table 1. Healthcare professionals' characteristics

	GPs	**DNs**
Number	8	4
Mean age in years	43.5	46.25
Sex (female)	3	3
Interview duration (range)	28 (21-35)	31 (23-36)
Work experience		
Less than 10 years	2	1
10-20 years	4	1
More than 20 years	2	2

Table 2. Patients with cancer's characteristics

Patient's number	**Age in years (mean age; 71.3)**	**Sex**	**Ethnicity**	**Marital status**	**Diagnosis**	**Interview duration (min)**
1	84	Female	White	Widow	Unknown primary	30
2	68	Female	White	Married	Sarcoma	39

3	61	Female	White	Married	Breast cancer	34
4	64	Female	White	Divorced	Bowel cancer	25
5	77	Male	White	Married	Pancreatic cancer	53
6	74	Male	White	Married	Lymphoma	29

5.4.2 Themes

Four themes were identified during the analysis. These were:

- lack of systematic approach
- limited time and resources
- talking about palliative care is difficult
- lack of continuity of care and interprofessional collaboration

In the following sections, each theme will be described in relation to the barriers identified and the potential benefits of using an electronic screening tool. Appendix B.3 contains examples of quotes to support the themes of the theoretical framework.

5.4.2.1 Theme 1: Lack of systematic approach

Barriers

Many healthcare professionals and patients highlighted the lack of a systematic approach to the timely identification of patients with potential palliative care needs in primary care. Numerous GPs and DNs expressed concerns about the current methods used to identify patients with potential palliative care needs in primary care. They explained that the process is often subjective, heavily reliant on clinical experience and that screening tools and guidelines are not routinely utilised:

"It's very subjective… just hypothetically speaking. Two doctors from the same practice could go and assess the same patient on a Monday morning and come out with a different view because it's subjective and it depends what you pick up, and what you do with that information." DN (D002*)*

Additionally, they explained that during the COVID-19 pandemic, many general practices lacked regular multidisciplinary meetings to discuss patients with potential palliative care needs. Consequently, it was "*more down to the individual to recognise somebody presenting with symptoms that might need palliative care involvement" GP* G008)

Some healthcare professionals highlighted the lack of regular and systematic assessments of patients with cancer's needs and follow-up, which leads to delayed identification of any deterioration in patients' conditions. This is seen as a significant barrier to ensuring a smooth and planned transition to palliative care.

"If we're seeing people and managing them well, we should be knowing that they're getting worse, knowing that they're going into amber, going into red so we can support them on that journey because it's one they're only ever going to do once." GP (G007)

"We still are able to get palliative services to them but I think that's more of a last minute emergency right, we really need your input now, rather than a planned routine referral where we can sort of you know get them a bit of a better care delivery." GP (G005)

Some healthcare professionals highlighted that the current lack of a systematic approach in practice can lead to inequalities in identifying patients with potential palliative care needs. They noted that patients from ethnic minoritised groups and the most socio-economically deprived areas are less likely to be identified using current methods, indicating that more efforts are needed to address these disparities. *"If you add into that the complexities around ethnicity, deprivation, culture, we find you know and again the statistics will show … the percentage of people from different non-Caucasian background is very small who are receiving palliative care." GP* (G007)

Potential benefits of introducing electronic screening tools

Healthcare professionals and patients with cancer suggested that integrating an electronic screening tool into primary care can assist GPs and DNs in early detection of deterioration in patients with cancer, ensuring that those with potential palliative care needs are not missed. Some healthcare professionals believe the electronic screening tool could serve as "*a backup check"* to ensure no individuals who could benefit from palliative care are missed. They argued that using a standardised and electronic approach could reduce subjectivity and aid in identification and decision-making, especially for "more junior, inexperienced staff". This method could provide a consistent framework to support less experienced staff in making informed decisions regarding palliative care.

"So that would make different professionals go through it, in a systematic way, to cover anything, and then … it would identify, particular pathways perhaps, to what needs to happen, would be a benefit. Because that will take out the subjectivity." DN (D002)

Some healthcare professionals suggested that the electronic screening tool could be integrated into current practice by using it to triage patients for MDT reviews in primary care:

*"We have these [MDT] meetings monthly anyway, so if, it might be that you know you get those tasks and then either you look at them yourself, or you look at in the meeting, and then you discuss if there's a need." GP (*G006)

Healthcare professionals and patients believe integrating electronic screening tools into primary care could address the lack of a systematic approach by ensuring a planned and smooth transition to palliative care. These tools would provide patients and healthcare professionals with the necessary information to initiate the palliative care process and make informed decisions about the transition. *"Identifies this group of patients the earlier for us the better really. We know that if we can engage with them [early] that would be a lot better." GP (*G008)

"It would be better for clinicians to identify these patients earlier because you can then proceed with things like advanced care planning so you've got more time to prepare." GP (G005)

5.4.2.2 Theme 2: Limited time and resources

Barriers

GPs and DNs indicated that understaffing, time constraints, limited resources, and extra workload posed by COVID-19 led to focusing on meeting only patients' most urgent needs, rather than proactively identifying patients with cancer who have unmet needs.

Healthcare professionals described time constraints as a significant barrier in the community to identify patients with palliative care needs, which has become more challenging during the COVID-19 pandemic. Many GPs found the standard consultation time insufficient to discuss and identify complex needs and to have effective communication.

“One of the difficulties around palliative care, to do it well it takes a lot of time.” GP (G001)

Many patients with cancer with uncontrolled symptoms were often unable to see their GP which could lead to a significant delay in identifying and meeting their unmet needs.

*“If you’ve got somebody who’s got palliative care needs, they are competing with everybody else to try and get access so they can be missed.” GP (*G006)

“Very difficult, sometimes 2 or 3 weeks in order to get an appointment .... When I see the GP which I have to say he usually looks rather, or she looks rather tired with the pressure of work.” Patient with cancer *(P005)*

Some GPs and DNs were concerned about variations between GP practices in terms of staffing, resources and workload. This might affect the quality of services provided and increase the disparity of services accessed based on economic status.

*“My current practice is in a very affluent area and I think they have more resources and more staff per patient and that makes life easier to do those sorts of things. My previous practice was in a very deprived area and struggled.” GP (*G002)

In addition, some GPs indicated that healthcare professionals’ lack of knowledge of available services could be a barrier to identifying and meeting palliative care needs.

“Knowing that something can help a patient, you’re more likely to offer it.” GP (G005)

Potential benefits of introducing electronic screening tools

Many GPs and healthcare professionals believed that using electronic screening tools to identify patients with potential palliative care needs has vast potential in improving time efficiency and reducing workload in primary care. Some GPs and DNs agreed that proactive work for identification *“makes a big difference”* for patients with potential palliative care needs and *“it might save time in the long run.”*

“Well it’s catching people early isn’t it, I think that will overall that’s a good investment and it will be less workload.” DN (D004)

*“Something you can quickly read and say ah, now I understand why you need a palliative care review. I think it makes it much more quicker … they’ll [*healthcare professionals*] probably find it time efficient.” GP* (G005)

Another potential benefit identified by the participants was organising work. The initial screening can be done by a practice administrator who can *“manage the administrative aspects”* and allocate the assessment tasks to the most suitable team or healthcare professionals.

“The searches, they could be run by admin, the data team, that’s fine.” GP (G005)

5.4.2.3 Theme 3: Talking about palliative care is difficult

Barriers

Patients with cancer and healthcare professionals described several barriers to initiating conversations about palliative care and prognosis, which contributed to delays in identifying those who might benefit from such care. One key barrier was the negative perception of palliative care, which many patients associated with imminent death. This often led to fear, distress, and avoidance, which in turn increased professionals’ hesitancy to raise the topic.

“When he first mentioned [palliative care] I thought does he know something I don’t? Am I going to die tomorrow, you know because that was the thought I had in my mind about what a hospice actually does.” Patient with cancer (P004)

Such associations were particularly difficult to manage when patients were still receiving active treatment or had not accepted their diagnosis. Healthcare professionals expressed concern that raising palliative care in these circumstances could cause upset or be misinterpreted.

“That’s just about rescued them but they don’t want to engage in the palliative services because he just doesn’t accept it.” District Nurse (D003)

Professionals commonly described these conversations as both emotionally challenging and time-consuming. Time constraints, uncertainty about patient readiness, and fear of diminishing hope all contributed to delays. One GP reflected on the importance of offering choice but noted that opportunities were often missed:

“At some point, somebody has to say when do you want to stop and actually once we asked that question of her and her family, they wanted to stop but nobody had ever given them the option.” GP (G007)

Some clinicians expressed concern that early referral to palliative care could be perceived as treatment failure, and that this perception might lead to distress or disengagement. There was a shared view that timing was delicate; referrals perceived as premature could, in some cases, result in a negative experience for the patient and their family.

Cultural and language barriers were also highlighted as significant challenges. In some cultures, family members may withhold information from the patient or take over decision-making. This dynamic was particularly difficult when patients did not speak English and relatives served as informal interpreters.

“I have families where actually my patient doesn’t speak English and so it can be hard to know how much my patient knows of their diagnosis. I may have their sons or daughters not wanting them to know that they’re dying, but then I can see that this patient is actively dying and probably knows themselves, so there can be a cultural element there with a language barrier.” GP (G004)

In such situations, healthcare professionals sometimes felt they were *“treating the family instead of treating the patient.”* These issues further hindered clear, timely communication about end-of-life care, particularly in sensitive cases where beliefs about death and illness differed between families and clinicians.

Patients with cancer and healthcare professionals identified multiple barriers to effective communication about palliative care and prognosis, which potentially delaying the identification of those who might benefit from such care. Negative beliefs and attitudes, coupled with limited knowledge and awareness, often hinder the initiation of end-of-life conversations. Many patients view palliative care as synonymous with death, leading to shock, fear, and avoidance, thereby increasing the hesitancy of healthcare professionals to initiate discussions about palliative care transitions.

“When he first mentioned [palliative care] I thought does he know something I don’t? Am I going to die tomorrow, you know because that was the thought I had in my mind about what a hospice actually does.” Patient with cancer (P004)

Moreover, stereotypes that view early involvement in palliative care *“as a failure”* of treatment can destroy patients' hope and cause distress, significantly delaying its initiation, particularly among patients actively undergoing cancer treatment. Additionally, some healthcare professionals felt that premature referrals to palliative care "*can be counterproductive*" and may result in *“a negative experience for the patient.”* This reluctance delays crucial conversations about care options, as highlighted by a GP:

“At some point, somebody has to say when do you want to stop and actually once we asked that question of her and her family, they wanted to stop but nobody had ever given them the option.” GP (G007)

Additionally, a lack of cultural understanding and language barriers could inhibit effective communication with patients about palliative care and act as a barrier to the identification process. Discussion with patients with cancer and their families about palliative care *“can be limited by cultural beliefs and different expectations from family”*. In some cultures, families prefer to be involved in every conversation and decision-making process, sometimes to the extent that healthcare professionals find they are treating *“the family instead of treating the patient.*”

Relying on a family member as a translator may lead to miscommunication. For instance, if the family member comes from a culture that avoids discussing death, they might hesitate to translate words from the doctor that mention death.

“I have families where actually my patient doesn’t speak English and so it can be hard to know how much my patient knows of their diagnosis I may have their sons or daughters not wanting them to know that they’re dying but then I can see that this patient is, is actively dying and probably knows themselves so there can be a cultural element there with a language barrier.” GP (G004)

Many healthcare professionals also observed that the conversation about palliative care, prognosis and preferences is *“time-consuming”* and “*can be quite challenging”,* particularly for young patients and *“patients who have been actively treated”. These factors contribute to the delayed introduction of* palliative care.

Many healthcare professionals also observed that discussions about palliative care, prognosis, and patient preferences *“can be quite challenging”* and *“time-consuming",* particularly for younger patients or those still undergoing active treatment, as well as for individuals who do not accept their diagnosis. These factors collectively contribute to the delayed introduction of palliative care.

"That's just about rescued them but they don't want to engage in the palliative services because he just doesn't accept it." DN (D003)

Potential benefits of introducing electronic screening tools

Healthcare professionals discussed the potential benefits of integrating electronic screening tools into primary care to facilitate conversations about palliative care and improve identification. One of the main advantages is that it allows time for preparation. Contacting patients beforehand, either by letter or telephone, can help "*to alert them to what we're discussing*" and ensure they are "*mentally and psychologically prepared to have that discussion.*"

Additionally, GPs and DNs agreed that using a screening tool *"that predicts what time somebody had left"* and provides a summary of background information can help initiate and facilitate palliative care conversations.

"If there's a clinical summary that … explains those things [reasons for palliative care referral], that's perfect. If not then it's a lengthy conversation for the clinician." GP (G005)

5.4.2.4 Theme 4: lack of continuity of care and inter-professional collaboration

Barriers

Patients and healthcare professionals highlighted the lack of continuity of care and coordination of care as significant barriers to identifying patients in need of palliative care in primary care.

Both healthcare professionals and patients perceive a significant challenge in not being able to see the same GP consistently. This lack of continuity requires GPs to *"go through the whole history every time,"* which *"takes away the focus from what the actual problem"* is, causing frustration for both patients and their families rather than addressing the patients' immediate and pressing needs.

“There’s a big move in practice to make it demand orientated rather than continuity of care oriented. In primary care generally, we are losing the continuity of care because access, fast access is being prioritised over that and I think that works really well for some conditions particularly acute conditions but things like palliative care I think they are losing out because it’s becoming much harder to have continuity.” GP (G002)

Some patients with terminal cancer have expressed difficulties in accessing healthcare services after ceasing cancer treatment. Many of these patients find it challenging to receive assistance from healthcare professionals after ending their cancer therapy.

“*I just mentioned it to my oncology professor said you know I’ve not seen my breast nurse for 3 years really and I don’t seem to be getting any help to say I’ve got terminal cancer. There’s nobody there for any help or anything.”* Patient with cancer (P003)

Most healthcare professionals indicated that there is a lack of inter-professional collaboration between primary and secondary healthcare, which may lead to discontinuity of care, duplicated efforts, miscommunication between healthcare professionals and patients, and situations where *"patients can become overwhelmed with people wanting to see them."*

"There’s a bit of separation between secondary care, district nursing and the CNS services. So sometimes I think we can duplicate things.” DN (D003)

One barrier identified was the reluctance of healthcare professionals to initiate palliative care or refer a patient to palliative care services when they are not familiar with the patients or during out-of-hours. This hesitancy can lead to *"a big delay"* in identifying and managing unmet palliative care needs. *"Because they don’t know these patients ... they are very reluctant to fast track these patients for the care….Very reluctant to write the anticipatory drugs."* DN (D002)

Many primary care professionals reported a lack of clear communication with secondary care regarding patients' terminal diagnoses, treatments, prognoses, and end-of-life discussions. Consequently, this can delay the identification of patients with potential palliative care needs:

"We're very much guided by communication from secondary care…it's very difficult to come in as a GP who's not a specialist and say you know, yes you're having treatment for your mesothelioma, I know this isn't curative and let's talk about your advanced care planning because you're going to die soon." GP (G004)

Potential benefits of introducing electronic screening tools

Healthcare professionals highlighted the potential benefits of using electronic screening tools to enhance communication and inter-professional collaboration between primary and secondary care, thereby facilitating identification. One GP suggested that sharing key information about palliative care from the electronic screening tool across organisations could allow *"everyone to access that information,"* which would improve care coordination and the timeliness of the identification process.

Several GPs mentioned a major advantage of the electronic system in improving collaborative decision-making. Electronic screening tools enable smoother interactions between primary and secondary care, enabling healthcare professionals from both sectors to work together more efficiently to identify patients, assess their needs, and "decide who was the best person to go and start that initial conversation."

"A 2 part document where the tool is started by secondary care and completed by the GP so the consultant in secondary care, maybe the lung consultant, the oncologist would fill in the form at the beginning and say this is the treatment but even with treatment this is the prognosis the patient is aware of." GP (G001)

Some healthcare professionals have also stated that when relational continuity of care is difficult to achieve, an electronic screening tool could assist with the informational and management aspects of continuity of care: *“As continuity and as you know because obviously in community there’s, “sometimes you’ll get staff from outside the team, from another team coming to help out. [They] will just walk in and pick up some of those domains or problems so I think yeah that would work.”* DN (D002)

5.5 Reflexivity

I am a medical doctor with a Master’s degree in Public Health. My research experience has primarily focused on quantitative methods, including statistical analysis, secondary data analysis, and systematic reviews. While doing my PhD, I was also working as a research assistant and part-time as a doctor in emergency departments. In that role, I often saw patients with advanced progressive diseases who came to A&E with uncontrolled symptoms and palliative care needs. Some were referred by their GPs or district nurses, others came on their own or were brought in by family. Many of them had palliative care needs, but there was no formal system or tool in place to identify and support them early. Palliative care teams only worked Monday to Friday during the day, which made things even harder. These experiences made me interested in how we could identify such patients earlier and more fairly.

Although I had experience with numbers and data, this was my first time working with qualitative research. At the start of the study, I had some assumptions about screening tools. I thought they might be seen as an added burden for GPs who are already stretched and managing multiple responsibilities, including other screening tools and numerous care demands. Given the pressure on primary care, I was concerned that introducing another tool could be met with resistance or might not be practical. I also thought that patients might feel worried or confused if they were flagged by a computer, particularly without clear communication. In addition, I believed that time pressure would be one of the biggest challenges in identifying patients with palliative care needs. However, at the same time, I believed that many GPs were keen to have a more structured or formal way to identify this subset of patients. But during the study, and especially through the interviews, my views started to change as I listened to the different challenges and ideas shared by participants.

The first two interviews I did were with my supervisor, who has good experience in qualitative research and had done a similar study on symptom management in cancer patients. Observing him and working together helped me understand how to ask open and thoughtful questions. It also helped me become more aware of the importance of being flexible, listening carefully, and letting participants lead the conversation. After these interviews, I reflected on my own approach and learned how to make my style more relaxed and focused on what mattered to participants.

I think that some healthcare professionals may have seen me as a colleague because I am a doctor too. This might have made them more comfortable speaking openly with me, but it’s also possible that they assumed I already understood certain things and didn’t explain them fully. With patients, I was careful to explain that I was not involved in their care. I tried to use clear and kind language and create a space where they felt safe to speak about such a sensitive and emotional topic. I was mindful that discussing end-of-life care could be difficult, and I aimed to offer a supportive and respectful environment throughout.

My medical and research background also influenced how I understood the data. I was especially interested in the practical side of using electronic screening tools and how they could fit into everyday clinical work. But I was also careful not to focus only on that. Talking with my supervisors regularly helped me check my own views and consider different interpretations.

This reflexive process was important for my learning. It helped me understand how my background, experiences, and beliefs shaped the research. It also reminded me to stay open to different views and to represent participants’ voices as fairly and honestly as I could.

5.6 Discussion

5.5.1 Main findings and comparisons with other studies

This study provides valuable insights into the perceptions of patients with cancer and healthcare professionals regarding the barriers to timely identification of patients with potential palliative care (PC) needs in primary care, as well as the potential benefits of electronic screening tools.

Current barriers:

Our findings highlight several key barriers to the timely identification of patients with cancer with potential palliative care needs in primary care. These barriers include a lack of systematic approaches, time constraints, limited resources, communication challenges, poor continuity of care, and inadequate inter-professional collaboration.

A key finding is the absence of systematic and agreed criteria for identifying patients with potential palliative care needs in primary care. Screening tools are not routinely used, and the identification process largely relies on clinical judgement, which can be subjective and vary significantly between practitioners. Previous studies have also highlighted the limitations of current identification instruments, noting that they are time-consuming and prone to subjective assessments influenced by clinical experience and judgement (30-32).

Continuity of care is crucial for timely identification of patients with cancer with potential palliative care needs. Our study aligns with previous research showing that poor informational continuity and lack of coordination can hinder access to palliative support, particularly during out-of-hours services (33-35). The study also revealed significant challenges in identifying patients from ethnic minoritised groups who have lower access to palliative services (36-41). These challenges include language difficulties, cultural misunderstandings, and a lack of culturally sensitive communication, which can result in inequalities within primary care settings (40, 42, 43).

Although measuring the effect of the COVID-19 pandemic was not one of our study aims when data was initially collected at the beginning of 2020, conducting most interviews during the pandemic provides additional context to understand challenges to the identification process. Our study identified several factors affecting the identification process during the pandemic, including difficulties accessing healthcare services, the shift to remote consultations, increased pressure on service provision, and prioritisation of emergency responses (44-47). These challenges exacerbated pre-existing inequalities, particularly affecting disadvantaged groups (45, 48). An observational study found that policies introduced during the pandemic in the UK may have adversely impacted ethnic minoritised groups at the end-of-life (38).

Potential benefits of using electronic screening tools:

Our qualitative study revealed significant potential for electronic screening tools to overcome barriers in primary care, particularly concerning palliative care identification. The findings indicated that these tools could enhance time efficiency and reduce workload, as many GPs and DNs noted. This proactive identification of patients with potential palliative care needs benefits patient outcomes and resource allocation. Practice administrators can handle initial screenings and administrative tasks, thus streamlining workflows and improving efficiency in care delivery (49).

Electronic screening tools facilitate better communication and continuity of care (50, 51). They help prepare patients for palliative care discussions by providing prior notifications and summarised background information, which aids in initiating and facilitating conversations. Sharing essential information across primary and secondary care enhances collaborative decision-making, ensuring all relevant healthcare professionals are informed and can contribute to the patient’s care plan. This aligns with the observations of Haranis (2023), who noted improvements in communication and coordination due to electronic tools (22).

Moreover, these tools can standardise the recognition of deterioration in patients with cancer by providing a consistent framework for early identification and decision-making. This approach is particularly beneficial for junior staff, ensuring that no patient requiring palliative care is overlooked and facilitating a smoother transition to palliative care. Using a computerised standardised screening tool can reduce practice variations and inequities in access to palliative care (52) (49). Similar to previous studies, our data indicated that electronic screening tools could prompt earlier conversations with patients with cancer about prognosis and palliative care (53, 54). They may improve prognostic confidence, particularly among less experienced healthcare professionals, and increase the extent to which they use prognostic information to guide treatment decisions at the end-of-life (55-57).

5.5.2 Limitations

This study has some limitations. During the COVID-19 pandemic, all interviews were conducted virtually to comply with social distancing measures. This format presented several challenges, including the absence of non-verbal cues, reduced ability to engage with participants fully, and technical issues such as poor internet connections, which may have impacted the depth and quality of data collection (58-60). However, it is important to note that all interviews with patients were conducted face-to-face before the COVID-19 pandemic, except for one. This in-person approach allowed for more in-depth discussions on sensitive topics, often more effectively explored face-to-face (60, 61).

Second, despite efforts by research nurses to recruit participants for our study, significant challenges were encountered, which are consistent with documented barriers in palliative care and cancer research (62, 63). Identifying eligible patients was complicated by rapid patient discharge or death, disease trajectory, and the heavy symptom burden they experience (62). Another contributing factor, as noted by Stone et al. (2016), was the reluctance of clinicians to allow access to patients for research purposes, known as "gatekeeping" (64, 65). This reluctance, although often well-intentioned to protect patients, can limit their autonomy and opportunity to decide whether to participate in research (63).

Third, the generalisability of the findings is potentially limited, as the study was conducted in one region of England, and the participant sample may not reflect the broader patients with cancer population. Despite efforts to recruit a diverse sample, all patient participants were white British or of other white origin aged over 60 years. This homogeneity underscores a persistent challenge in palliative care research: the underrepresentation of ethnic minoritised groups (66, 67). Future research should prioritise addressing these disparities to ensure more inclusive and representative findings, focusing on the unique needs and barriers faced by ethnic minoritised groups (68).

5.5.3 Implications for Research and Practice

Addressing the barriers identified in our study requires enhanced collaboration and communication between primary and secondary care healthcare professionals. Integrating electronic screening tools could support these efforts by providing a standardised method for identifying patients needing palliative care, reducing subjectivity, and ensuring no patient is overlooked. Additionally, research is required to develop and implement patient-centred, culturally appropriate communication strategies to improve patient and family engagement in end-of-life care discussions.

Electronic screening tools hold significant potential for improving the timely identification of primary care patients with palliative care needs (21, 49). Despite their promise, challenges remain in their implementation. Many AI models are developed in hospital settings, limiting their applicability in primary care (50, 69). These models often focus on mortality prediction rather than identifying specific patient needs, resulting in late referrals (21). Additionally, many models are built on biased datasets, leading to algorithmic bias and limited generalisability (70, 71). The lack of rigorous external validation further complicates their broad application (50, 72).

Future research needs to prioritise understanding the acceptability of electronic screening tools among healthcare professionals and patients, addressing concerns and ensuring transparency in AI-driven decision-making. Developing models integrating self-reported symptoms with clinical data for a comprehensive assessment of patient needs will be essential (73). Including patients in all stages of the development of electronic screening tools and understanding their needs is crucial. Rigorous external validation of models across diverse populations and healthcare settings is necessary to ensure their generalisability and effectiveness (20).

In summary, our qualitative study highlights the significant potential of electronic screening tools to transform palliative care in primary care settings by overcoming key barriers. However, achieving this potential requires continuous research, better data quality, ethical oversight, and thorough validation. These steps will ensure that electronic screening tools can improve palliative care delivery, leading to better patient outcomes and more efficient healthcare systems.

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Chapter 6: Discussion and conclusions

6.1 Overview of research aims and principal findings:

The thesis explored the process of identifying patients who may benefit from palliative care in primary care, examined barriers to timely identification, and evaluated the advantages of electronic screening, as described in section 2.1.

To achieve the research aim, a systematic review (Study One) was conducted to identify existing screening tools for the identification of patients with advanced progressive diseases who are likely to have palliative care needs in primary care and evaluate their accuracy. In Study One, I conducted a comprehensive search of the published literature across four databases, yielding 25 studies that met the inclusion criteria. These comprised twelve observational studies (including prospective observational and cross-sectional designs), nine mixed-methods studies, three randomised controlled trials, and one service evaluation study. Most of these studies included patients with a range of conditions, including both cancer and non-cancer illnesses.

Among the ten screening tools identified, seven were paper-based, while three utilised electronic case-finding instruments. The Surprise Question was a key component in most paper-based tools, which primarily relied on predicting death or deterioration as proxies for identifying individuals with potential palliative care needs. Across the 25 studies analysed, the percentage of patients identified as having potential palliative care needs varied greatly, from 0.49% to 79%. Only eight of these studies provided information on the accuracy of five screening tools. However, these studies exhibited a moderate to high risk of bias. The accuracy of the screening tools was evaluated against several reference standards, including 3-month mortality, 12-month mortality, 24-month mortality, and clinical assessment. Sensitivity rates ranged from 3% to 94%, while specificity rates varied between 26% and 99%.

As part of my PhD thesis, two observational studies were conducted to enhance the understanding of palliative and end-of-life care experiences within the community. These studies, Study Two and Study Three, utilised 5-year data from the National Survey of Bereaved People (VOICES), an annual population-based mortality follow-back survey, combined with the Office for National Statistics (ONS) mortality data. I used multiple logistic regression analysis in both studies to estimate adjusted odds ratios (AORs) with 95% confidence intervals (CIs). These studies (Study Two and Study Three) aimed to provide insights into factors associated with improved pain relief, better end-of-life care experiences, and the essential role of palliative care in enhancing them.

In Study Two, which involved 63,644 individuals who received home-based care before their death, it was found that 28% of the deceased received home-based specialist palliative care at the end-of-life. Those more likely to receive specialist palliative care included individuals who died from cancer (adjusted odds ratio [AOR] 11.66; 95% confidence interval [CI] = 11.45 to 11.86) and those with good continuity of primary care. Conversely, decedents were less likely to access specialist palliative care at home if they were older or lived in areas of higher socio-economic deprivation.

Additionally, logistic regression analyses of Study Two aimed at identifying factors associated with the overall quality of end-of-life care and other quality of end-of-life indicators. Better overall quality of end-of-life care was significantly associated with receiving palliative care support at home (AOR 1.86; 95% CI = 1.84 to 1.89) and good continuity of care in primary care (AOR 2.03; 95% CI = 2.01 to 2.06). Improved overall quality of end-of-life care was also linked to living in areas of lower socio-economic deprivation, White ethnicity, dying from cancer, and dying outside the hospital.

Study Three, which involved 43,509 individuals who were cared for at home before their death and experienced pain, aimed to examine the factors correlated with good pain relief at home during the last three months of life. Decedents were more likely to receive good pain relief at home if they had received specialist palliative care (AOR = 2.67; 95% CI, 2.62 to 2.72) and had a recorded preferred place of death (AOR = 1.87; 95% CI, 1.84 to 1.90). Additionally, decedents who died of cancer and older decedents were more likely to experience good pain relief.

In Study Four, semi-structured interviews were conducted with patients with advanced cancer referred to palliative care from primary care, as well as primary care healthcare professionals (GPs and district nurses). The aim was to explore barriers to the timely identification of patients with cancer who may benefit from palliative care in primary care and examine the potential benefits of electronic screening for this purpose. Study Four identified several barriers to the timely identification of patients with cancer needing palliative care in primary care settings, including the absence of a systematic approach, resource and time limitations, poor communication, and lack of coordination and continuity of care. The study also highlighted the impact of socioeconomic and ethnic disparities on access to palliative care, pointing to a pressing need for more equitable healthcare practices. Furthermore, the challenges posed by the COVID-19 pandemic have exacerbated existing barriers, emphasising the need for adaptable and resilient healthcare systems.

Lastly, the study discussed the potential benefits of integrating electronic screening tools into primary care. Such tools could standardise the identification process, improve efficiency, and reduce the workload on clinical staff. They could also facilitate more timely and appropriate conversations about palliative care, helping smooth patient transition and ensuring that their needs are met more effectively.

6.2. Summary of findings and contribution to the literature

6.2.1 Effectiveness and usability of current screening tools for identifying patients with potential palliative care needs in primary care

The identification of patients in primary care who may benefit from palliative care is crucial but challenging. Significant gaps exist in the effectiveness and usability of current screening tools for identifying these patients. This section examines these gaps and the implications for primary care practice.

A significant issue with current tools, as evidenced in my systematic review and other studies, is the considerable variation in identification criteria across tools and the characteristics of the targeted population, leading to inconsistent results and differences in the percentage of patients identified across studies (1, 2). For example, the NECPAL screening tool includes functional and cognitive decline assessments, psychological needs, and symptom burden. In contrast, the Surprise Question (SQ) primarily aims to predict mortality by asking healthcare professionals if they would be surprised if the patient died within a specified time frame (Study One). The application of the same screening tool, such as the Surprise Question, can yield very different results depending on the population. In studies focusing on patients with advanced progressive diseases, identification ranged from 41% to 79%, whereas more general populations showed identification rates between 1.6% and 11.7% (Study One).

The SQ is one of the common screening tools, and it is used alone or as part of other screening tools due to its simplicity and ease of use, requiring no extensive training (3). This makes it particularly valuable in environments with limited time and resources. A recent systematic review and meta-analysis by Gupta et al. (2024) found that the SQ showed modest accuracy, with significant variability in its effectiveness depending on the population and the context in which it was used (4). However, the SQ has limitations, particularly its reliance on subjective judgment, leading to variability in accuracy (3). Different practitioners may have different thresholds for what they consider surprising, resulting in inconsistent identification of patients who may benefit from palliative care. Gupta et al. (2024) also indicated that the sensitivity of the SQ was lowest in primary care settings compared to other settings (4). This means it may miss patients with unpredictable disease trajectories and less obvious palliative care needs, such as those with advanced heart failure or COPD (5).

This lack of uniform indicators and clinical triggers essential for effectively initiating palliative care in general practice is a significant issue (1, 2). The absence of standardised criteria for involving palliative care services often results in an inconsistent and subjective identification process, leading to potential disparities in patient care, as evidenced by my qualitative study and other research (6). This issue is compounded by the absence of evidence-based cutoff values for these screening tools, which hinders the ability to systematically identify patients who would benefit from palliative care, thereby preventing automatic and objective patient assignment (7-9).

Current evidence, including my systematic review, shows significant variation in the accuracy of existing screening tools (10, 11). These tools demonstrated limited effectiveness, particularly in sensitivity and specificity (Study One). Sensitivity rates varied widely, ranging from 3% to 94%, while specificity rates ranged from 26% to 99%. Furthermore, the positive predictive value across all screening tools consistently fell below 50%, except for one study. Studies that focused on individuals with advanced progressive diseases consistently reported higher sensitivity compared to those examining a broader primary care population. Additionally, variations in outcome measures, including assessments of short-term versus long-term mortality, may also contribute to the differences in sensitivity observed across various studies.

Insufficient sensitivity in screening tools can lead to missed opportunities for timely access to palliative care, potentially worsening the quality of life and end-of-life outcomes for patients, and increasing the utilisation of healthcare resources at the end-of-life (12-14). Conversely, inadequate specificity may prematurely identify patients as needing palliative care, leading to inappropriate triage to palliative care pathways, further straining limited primary care and palliative care resources, as well as inducing anxiety among patients A low positive predictive value exacerbates these issues, leading to the misallocation of palliative care services and causing distress among patients and their families. (15, 16). Therefore, achieving a balanced combination of sensitivity, specificity, and positive predictive value is crucial for designing effective screening tools (16).

Identifying patients with complex and unpredictable disease trajectories, such as those with COPD, dementia, and heart failure, presents considerable challenges (17, 18). Prognostic models for non-cancer chronic diseases often fail to deliver accurate predictions, complicating the timely recognition and addressing of palliative care needs. (11, 19-21). The progression of dementia, for example, is notably unpredictable, varying greatly between individuals and even within the same individual over time (21, 22). Similarly, conditions like COPD and heart failure are marked by varying degrees of severity and periods of exacerbation and remission (19, 20).

Furthermore, this reliance on prognostic tools, which frequently fail to deliver accurate predictions, severely limits the entire palliative care identification process (23, 24). Prognostic uncertainty frequently complicates the initiation of end-of-life discussions, presenting considerable challenges for healthcare professionals in determining the appropriate timing for these conversations (25). Reliance on uncertain prognostic information can inadvertently delay crucial palliative care interventions, potentially leading to unnecessary distress and reduced patient trust (6). Due to these limitations, patient identification for palliative care in primary care often relies on clinical experience, personal intuition, and subjective judgement, as evidenced in my qualitative study and supported by other research (26, 27).

A primary challenge in initiating timely palliative care is identifying individuals who could benefit from such care. (10, 26). It is impractical for healthcare professionals to conduct comprehensive assessments for every patient (28). Additionally, not every patient approaching the end-of-life requires specialist palliative care, and conversely some patients with a relative long prognosis have complex symptoms that could be helped by specialist palliative care support. Implementing a two-tier process, where the initial step incorporates screening to identify patients with potential palliative care needs, followed by a comprehensive assessment of those needs, can help address this challenge (28-30).

Drawing on insights from the systematic review (Study One), I have developed a conceptual diagram (Figure 1) that illustrates the patient identification and assessment process for palliative care needs. Initially, a screening instrument is used to identify patients with advanced progressive diseases who are experiencing a declining health trajectory and could benefit from a palliative care assessment. This tool should not only predict mortality and decline but also aid in identifying unmet needs. Once these needs are identified, holistic assessments can determine how to best meet them, discerning whether patients require generalist palliative care or should be referred to specialist palliative care services. Regular reassessment is essential, especially at key transition points in the disease trajectory.

Establishing a well-defined pathway for palliative care screening and needs assessment in primary care offers numerous benefits, including more efficient resource allocation and timely palliative care for patients with complex needs (31). This structured approach improves patient identification and ensures prompt initiation of appropriate interventions, leading to proactive care delivery and improved quality of care (23, 30).

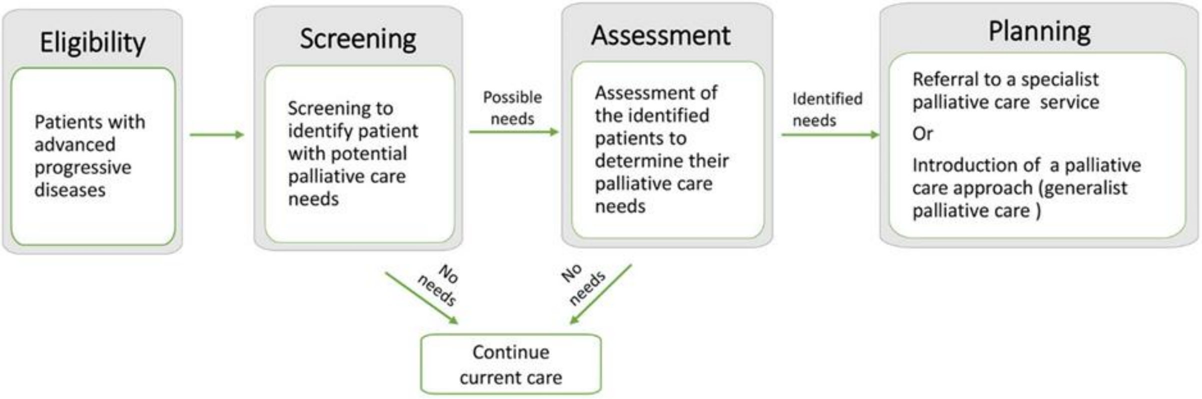

Figure 1.

The process of patient identification and assessment of palliative care needs

6.2.2 Challenges and barriers to timely identification of patients with potential palliative care needs in primary care

Identifying patients in primary care who may benefit from palliative care services is a complex and multifaceted process (32-36). As discussed in the previous section, both my systematic review (Study One) and my qualitative study (Study Four highlighted the absence of a standardised approach to identifying such patients as a significant challenge (1, 2, 6, 37).

Effective and open communication about palliative care is crucial yet challenging, particularly in primary care (2, 23, 38). Healthcare professionals often find it difficult and sometimes hesitate to initiate conversations about palliative care and prognostication (1, 38). My qualitative study found that many patients view palliative care as synonymous with death, leading to shock, fear, and avoidance. This perception increases the hesitancy of healthcare professionals to initiate discussions about palliative care transitions (Study Four). A recent survey study reveals that patients frequently find communication with healthcare professionals ineffective due to several factors: healthcare professionals may use medical jargon that is unfamiliar to patients, may not listen effectively, or may appear to dismiss patient concerns (23).

Additionally, there is a significant issue with healthcare professionals delaying or withholding crucial information about a patient’s health status or prognosis (36, 38). This hesitation often arises due to the unpredictable trajectory of diseases, particularly non-cancer illnesses, and prognostic uncertainty (1, 25). Such delays in discussing prognosis can delay the initiation of palliative care, ultimately impacting the quality of care and the patient’s quality of life (1, 2). Honest and transparent communication is essential not only for building trust but also for ensuring that patients and their families are fully informed and can participate actively in making informed decisions about their care(2, 36). Enhancing communication skills among healthcare professionals, particularly in how they convey sensitive information about prognoses and palliative care options, is critical (38).

Another major barrier to timely identification in primary care of patients who may benefit from palliative care, as identified in my qualitative study, is the persistent negative beliefs and limited awareness among patients and healthcare professionals. This finding is aligned with previous studies, which have shown that negative stereotypes and stigma about palliative care were a significant barrier to its delivery (6, 25, 32, 39, 40). A recent systematic review indicates that healthcare professionals sometimes view palliative care negatively, seeing the term itself as a barrier (6). Many believe that introducing palliative care might reduce a patient's hope or suggest giving up on treatment, a belief also identified in my qualitative study (6). This misconception severely hinders timely discussions about palliative care, delaying appropriate care interventions at the end-of-life (40-42).

Cultural competence is crucial in palliative care due to the significant influence of cultural factors on patient experiences and the increasing diversity within communities (25, 43-45). My qualitative study found that cultural and language barriers can inhibit effective communication with patients about palliative care and hinder the identification process (Study Four). In some cultures, openly discussing death can be seen as inappropriate, and withholding terminal diagnoses might be viewed as a compassionate act (43). Additionally, inadequate language proficiency and language mismatches between patients and healthcare professionals can severely impact the palliative care experience (44-47). These barriers hinder the accurate expression of symptoms and needs as well as the essential interactions between healthcare providers and patients, leading to poor decision-making due to miscommunication (24, 47). Furthermore, building trust, which is crucial in palliative care, becomes much more difficult (47, 48).

Reliance on professional interpreters could lead to dissatisfaction because many lack the necessary skills to accurately translate complex medical terms and disease-specific information (47-49). On the other hand, using family members as interpreters, though convenient, carries its own risks. These informal interpreters may omit crucial information, particularly regarding sensitive topics such as death, due to personal discomfort or cultural taboos. (44). Such omissions can severely disrupt communication in palliative care settings, where complete transparency and a comprehensive understanding of the patient’s condition are vital for effective care planning and providing emotional support (44, 46). These communication barriers can delay identifying patients who might benefit from palliative care and hinder understanding their needs, ultimately affecting the timing and appropriateness of care interventions (6, 24, 47).

In primary care, time and resource constraints significantly hinder the timely identification of patients with potential palliative care needs (2, 50-52). The short duration of general practitioner consultations is often inadequate for assessing or identifying patients with potential palliative care needs, especially those with dementia, heart failure, or multiple comorbidities (2, 35). My qualitative study found that general practitioners and district nurses cited understaffing, time constraints, limited resources, and extra workload as reasons for focusing only on patients' most urgent needs rather than proactively identifying those with unmet palliative care needs (Study Four). Many general practitioners found the standard consultation time insufficient to discuss and identify complex needs effectively (Study Four).

This limitation restricts comprehensive assessment of patient needs and preferences and delays necessary palliative interventions (2, 32, 35, 50, 52). Many healthcare professionals feel that persistent time pressures prevent them from engaging in meaningful end-of-life discussions or addressing the concerns of patients' families and caregivers (32, 35, 40). My qualitative study also found that patients feel the strain of limited interactions with GPs, perceiving them as overburdened and unable to provide sufficient time and support (32, 40).

Additionally, primary care resources are often insufficient to meet the extensive demands of palliative care, exacerbated by staffing shortages and a lack of specialised training (51, 53-56). A Canadian study revealed that nearly all health staff participants identified staffing shortages and the need for increased patient interaction time as major barriers to effective palliative care delivery (57). Geographical inequalities in accessing specialist services also exacerbate the challenges in palliative care, influencing decisions regarding including patients on palliative care registers (35). These resource constraints within GP practices significantly hinder their ability to offer comprehensive and effective palliative care, underlining the need for systemic changes to address these barriers in primary care (53, 56).

One of the identified barriers to the timely identification and management of patients with palliative care needs in primary care is the lack of continuity of care and insufficient interprofessional collaboration among healthcare professionals, as highlighted in my qualitative study (42, 58). Coordination of care is often hindered by poor information exchange and ineffective team communication, challenges that are exacerbated when dealing with patients with complex palliative care needs (23, 42). These challenges are evident not only between primary and secondary care professionals but also within primary care teams where structured collaboration is not established (23).

In the community setting, the interactions between general practitioners and district nurses are compromised by a lack of structured consultations, an absence of collaborative care plans, and insufficient comprehensive reporting of care, leading to inconsistent care delivery (23). Furthermore, the transition from secondary to primary care often faces poor handover practices and inadequate information transfer, particularly concerning patient prognostication (35, 59). These challenges are compounded by difficulties in accessing information from secondary care and obtaining specialist advice, impacting the continuity and coordination of care (35, 60). As a result, general practitioners become hesitant to initiate prognostic discussions and consider referrals to palliative care (35).

In out-of-hours services, the inability to access electronic patient records has been identified as a significant barrier, preventing staff from responding effectively to patients' wishes (58). Additionally, my qualitative study revealed that healthcare professionals are often reluctant to refer patients during these hours, which can result in substantial delays in identifying and addressing unmet palliative care needs.

The barriers identified in primary care for the timely identification and management of palliative care needs are multifaceted and interrelated. These include challenges in communication and collaboration across healthcare teams, insufficient continuity of care, and the absence of a systematic approach to identifying patients with potential palliative care needs in primary care. Persistent constraints related to time, resources, and access to specialist advice further complicate the effective delivery of palliative care.

To address these issues, it is essential to implement systemic changes that enhance interprofessional collaboration and improve the structure and frequency of consultations (23). Enhancing training for healthcare professionals in sensitive communication can facilitate better discussions with patients and families about end-of-life care and prognostication (25, 38). Additionally, implementing standardised screening tools and protocols can help systematically identify patients eligible for palliative care early in their care trajectory (2, 9). By addressing these challenges holistically, primary care can provide timely, equitable and consistent palliative care, improving patient outcomes and quality of life at the end-of-life (30).

6.2.3 Associations between specialist palliative care and end-of-life outcomes

Palliative care is designed to improve symptoms and quality of life for patients with advanced progressive disease and their caregivers (61). Growing evidence suggests that palliative care offers benefits, particularly in quality of life and symptom management (62-64). However, it is essential to acknowledge significant limitations in the existing research (62, 64-67).

One of the primary goals of palliative care is to reduce the symptom burden experienced by patients (61). Symptoms such as pain and breathlessness are common among patients with advanced illnesses and significantly impact their quality of life (68-72). Evidence shows that palliative care effectively improves these symptoms (62, 65, 66, 73-76). Holmenlund (2017) found that specialised palliative care interventions in patients with advanced cancer generally led to improved quality of life and reduced physical symptom intensity (65). Similarly, my analysis of five-year data from the National Survey of Bereaved People indicated that home-based specialist palliative care was associated with improved pain relief during the last three months of life for patients with advanced progressive disease. In my study, 66.2% of decedents who received specialist palliative care services at home experienced good pain relief compared to 37.5% of those who did not. This finding suggests a potential role for specialist palliative care in pain management at home (Study Three).

While these findings are important, it is crucial to note that the analyses were based on observational data and therefore cannot establish causality. The associations observed may be influenced by unmeasured confounding factors, such as disease severity, family support, or care preferences, which could affect both the likelihood of receiving palliative care and the quality of outcomes reported. Although the models were adjusted for known variables, residual confounding may persist. These limitations highlight the need for caution when interpreting these results and reinforce the importance of future research using robust study designs to more definitively evaluate the impact of palliative care services.

Most studies show significant improvements in symptoms with palliative care, although a few report minimal or no improvements (74, 77). This variability highlights the complexity of symptom management and the need for tailored interventions. In a meta-analysis by Huo (2022), early palliative care was associated with fewer symptoms and better mood among patients with incurable cancer (73). Despite the moderate effect size and low grade of evidence, this study supports the idea that early palliative care can improve symptom control (73). These findings suggest that while palliative care is generally effective, its impact may vary depending on the patient population and the specific symptoms being addressed. This underscores the importance of personalised approaches to symptom management in palliative care.

Improving quality of life is a central aim of palliative care (61). Several studies have demonstrated that palliative care interventions can enhance the quality of life for patients with advanced illnesses (62, 65, 73, 78). Gautama (2023) found that early palliative care significantly improved the quality of life in patients with advanced cancer (78). This finding underscores the importance of considering multiple dimensions of quality of life beyond physical symptoms. Similarly, Haun (2017) reported that early palliative care significantly improved health-related quality of life, although the effect size was small (62). This Cochrane review highlighted that while quality of life scores increased, the improvements were modest and varied across studies (62). Though potentially clinically relevant, small effect sizes reflect the challenges in achieving substantial quality-of-life improvements in patients with advanced progressive diseases.

Palliative care has been associated with reduced healthcare utilisation, including fewer hospitalisations and emergency department visits (66, 67, 74, 76, 79). This is particularly relevant for patients nearing the end-of-life, as it can reduce the burden on healthcare systems and reduce costs while improving patient experiences (67, 76, 80). Sahlollbey (2020) demonstrated that palliative care interventions substantially reduced hospitalisations for patients with advanced heart failure, with modest improvements in quality of life and symptom burden (66). Similarly, Gonzalez-Jaramillo (2021) found that home-based palliative care consistently reduced hospital visits and overall healthcare costs for patients with cancer and non-cancer diagnoses (76).

Satisfaction with care is an important measure of the success of palliative care interventions (75). High levels of patient and caregiver satisfaction indicate that the care provided meets the needs and expectations of those receiving it (75). Research consistently highlights the positive impact of palliative care on satisfaction levels (64, 75, 78, 79, 81). Chan (2023) found that palliative care was significantly associated with higher patient and caregiver satisfaction among those with progressive neurologic diseases (75). My research also found that patients who received good continuity of primary care and specialist palliative care support at home were more likely to report better overall quality of end-of-life care (Study Two). This improvement in satisfaction was attributed to components such as interdisciplinary teams, home visits, and spiritual care (75). Similarly, Keane (2023) noted that supportive care interventions, including palliative care, often increased satisfaction due to their comprehensive and holistic approach (82).

Family support is crucial in end-of-life care, as it impacts both the patient's well-being and the family's ability to cope with the situation (83, 84). Palliative care aims to support both patients and their families, ensuring that families receive adequate support during this challenging time(83). My analysis of VOICES data found that families of patients who received palliative care were more likely to report feeling well supported (Study Two). Evidence from systematic reviews indicates that palliative care interventions can significantly enhance family support (64, 75, 79, 81). Elliott (2021) reported that speciality palliative care led to improved caregiver-reported outcomes, including reduced stress and better emotional support (64). This is essential, as family caregivers often face significant challenges and effective palliative care can help relieve some of this burden(83).

Despite the positive findings, several limitations exist within the current body of research. One major issue is the heterogeneity of study designs, patient populations, and interventions, which complicates direct comparisons and generalisations (62, 65, 73, 74, 79). Holmenlund (2017) noted the varying aims and outcomes across the randomised controlled trials they analysed, leading to inconsistent evidence (65). Additionally, most trials did not adequately define or implement Best Supportive Care (BSC), resulting in a lack of standardisation and comparability across studies (85). Rubiales (2020) found that most clinical trials did not adhere to established guidelines for Best Supportive Care, leading to significant variability in care standards and outcomes (85, 86). This lack of standardisation could contribute to the mixed results seen in some studies.

The quality of evidence is another concern. Many studies suffer from methodological limitations, such as small sample sizes, potential biases, and lack of blinding (65, 73, 74, 81). This is evident in the systematic review by Haun (2017), where the risk of bias was mostly low, but selection bias and attrition bias were present in some studies (62). Similarly, Huo (2022) highlighted the low reliability and high heterogeneity in their meta-analysis, limiting their conclusions' strength (73).

Furthermore, excluding certain patient groups from studies raises ethical and generalisability concerns (77). Nowels (2023) pointed out that many studies excluded participants with common mental health conditions, which could exacerbate inequalities and limit the applicability of findings to broader patient populations (77). In addition, some studies have reported substantial benefits from palliative care, potentially due to the intensity and comprehensiveness of the interventions provided. Haun (2017), for example, identified a study that reported the largest effect size for early palliative care, which was attributed to a particularly high "dose" of palliative care and the high disease severity of the study population

(62). This suggests that more intensive palliative care interventions may be necessary to achieve significant improvements in patient outcomes.

The benefits of palliative care in improving quality of life and managing symptoms are evident, but the impact on other outcomes, such as survival and psychological symptoms, is less clear (62, 77, 81). The variability in results and the methodological limitations of existing studies highlight the need for more rigorous research with standardised methodologies and diverse patient populations (62, 73, 74). To fully realise the potential of palliative care, future research should focus on adopting these standardised approaches, including a wider range of patient demographics, and thoroughly assessing all relevant domains. This will help ensure that palliative care is both effective and equitable, delivering the best outcomes for all patients at the end-of-life.

6.2.4 Inequalities in access to palliative care services

Despite its well-known benefits, palliative care is not consistently accessible to all patients. These inequities are evident in several areas: the severity of symptoms, identification of needs, access to services, and overall care impact (87).

My analysis of 5-year data from The National Survey of Bereaved People (VOICES) showed that patients receiving home-based specialist palliative care experience significantly better pain relief and overall quality of care compared to those who do not (Study Two, Study Three). However, the survey also highlighted that pain relief is generally the poorest for individuals at home compared to other settings, despite home being the most preferred place for end-of-life care and death (88-90). This indicates a critical gap in home-based palliative care, where the preference for dying at home is not supported by adequate resources for effective pain management (91). This disparity highlights the broader issue of inequality in palliative care access, particularly regarding the care location. While home-based care can offer comfort and familiarity, it often lacks the necessary medical and logistical support that other settings can provide (91). These findings highlight the compounded impact of socioeconomic factors on palliative care access and quality (88).

Socioeconomic status significantly impacts access to palliative care. Patients from lower socioeconomic backgrounds face numerous barriers, including financial constraints and limited health literacy (87, 92). These factors hinder their ability to seek and receive appropriate care, resulting in higher symptom burdens and poorer quality of life (87). Studies have shown that individuals living in the most socio-economically deprived areas are less likely to receive specialist palliative care and more likely to experience severe symptoms and psychological distress (93-95). My analysis of the VOICES data indicated that patients in the most socio-economically deprived areas are less likely to receive palliative care. Consequently, they experience significantly worse pain relief and a lower overall quality of care (Study Two and Study Three). These findings highlight the compounded impact of socioeconomic factors on palliative care access and quality of end-of-life care (87).

In addition, geographical location significantly impacts access to palliative care (88, 96). Patients in rural areas often face severe barriers due to limited healthcare resources and infrastructure (92, 97). These regions typically have fewer palliative care programmes and specialists, leading to delayed referrals and inadequate symptom management (96). This geographical disparity further exacerbates patients' challenges in accessing timely and effective palliative care.

Individuals from ethnic minoritised groups often encounter significant barriers to accessing palliative care. These groups are less likely to be referred to palliative care and are usually underrepresented in hospice settings (97-99). Structural racism within healthcare systems further exacerbates these disparities, leading to unequal care outcomes (99). For instance, minority patients often report poorer pain management and lower satisfaction with their care compared to white patients (93).

My qualitative study found that people from ethnic minoritised backgrounds face several barriers, including language difficulties, lack of translation resources, misunderstandings, insufficient religious and cultural sensitivity, and poor communication (Study Four). These barriers delay timely access to palliative care, often resulting in inadequate symptom management and support at the end-of-life (100, 101).

Cultural competence in palliative care is essential for ensuring equitable and fair access to services. Healthcare providers must be trained to understand and respect cultural differences in health beliefs, practices, and preferences (96, 98). By incorporating culturally appropriate care models and engaging with community leaders, we can bridge these gaps and improve care for diverse populations (93, 98).

My analysis of the VOICES data revealed significant disparities in access to palliative care access and quality of end-of-life care between patients with cancer and non-cancer diagnoses (Study Two and Study Three). Patients with cancer are more likely to receive palliative care support compared to those with non-cancer conditions. Study Four showed that only 39.6% of decedents with non-cancer diseases reported good pain relief, compared to 56.4% of cancer decedents. These findings are consistent with broader literature that highlights significant disparities between patients with cancer and those with non-cancer diagnoses in accessing palliative care (88, 97, 102, 103). Despite having similar palliative care needs, patients with non-malignant disease tend to access palliative care later in the disease trajectory (94, 104-108). This disparity underscores the need for a more inclusive approach to palliative care that addresses the needs of all patients with advanced progressive diseases, regardless of their diagnosis (94, 109).

Furthermore, within the patients with cancer population, notable disparities exist based on the type of cancer. My analysis of the VOICES data indicated that patients with head and neck cancer received more home-based palliative care compared to those with haematological cancers. Other studies have shown similar patterns (110, 111). Despite this, research indicates no significant differences in the prevalence of unmet needs between patients with solid tumours and those with haematological malignancies (112). This suggests that disparities in palliative care delivery and access are influenced more by the type of cancer rather than the actual needs of the patients. These findings highlight the necessity for a better understanding and a more tailored approach to palliative care delivery for different types of cancer (111).

Older adults, particularly those with multimorbidity, have significant unmet needs and a substantial symptom burden (18). Age-related disparities in palliative care access are exacerbated by socioeconomic factors, with individuals living in the most socio-economically deprived areas experiencing more severe symptoms and facing greater challenges in navigating the healthcare system (93, 97). My analysis of the VOICES data showed that older patients are less likely to receive palliative care (Study Two). Other studies show similar results and highlight additional barriers for older adults, such as mobility issues, lack of transportation, and limited social support. (101).

Primary care providers often serve as the first point of contact and can play a pivotal role in early identification of patients with potential palliative care and referral to palliative care services (32, 113, 114). However, significant workforce inequalities exist, disproportionately affecting socio-economically deprived areas and exacerbating these disparities (115). My qualitative study found that practices in wealthy areas tend to have more resources and staff, making it easier to provide comprehensive care. In contrast, practices in socio-economically deprived areas struggle with limited resources (Study Four). Additionally, current screening tools in primary care are ineffective and lack standardisation, resulting in many disadvantaged patients not being identified for timely palliative care (96, 114). My qualitative study found that the lack of systematic practice worsens inequalities, especially for patients from ethnic minoritised groups and socio-economically deprived areas. This highlights the need for targeted efforts to address these disparities (92).

The COVID-19 pandemic worsened these issues, increasing pressure on already stretched primary care services and highlighting gaps in care provision (116, 117). The shift to remote consultations and the reduction of face-to-face interactions disproportionately affected patients from disadvantaged groups (116, 118). This underscores the urgent need for systemic changes to address the longstanding inequity in accessing palliative care in primary care (116, 119). Addressing these disparities requires a multifaceted approach, including implementing standardised screening tools, better resource allocation, and enhanced support for primary care teams.

6.2.5 The role of technology: advancing palliative care identification through electronic screening tools

The role of technology, particularly electronic screening tools, has the potential to significantly improve the timely identification of patients with potential palliative care needs in primary care (120-122). My qualitative study highlighted several key advantages of electronic screening tools. Firstly, they address time and resource constraints. Many general practitioners and district nurses reported that these tools improve time efficiency and reduce the workload by proactively identifying patients who may need palliative care (Study Four). This proactive identification is seen as beneficial for patient outcomes and can save time in the long term (62, 73). One of the findings from my qualitative study is that practice administrative staff can manage initial screenings and handle administrative tasks, optimising resource allocation and improving care delivery (Study Four). This finding is supported by recent research indicating that electronic tools simplify workflows and increase efficiency (120).

Electronic screening tools also help overcome communication issues and improve the continuity and coordination of care (123, 124). My qualitative study found that these tools facilitate timely discussions about palliative care by preparing patients for discussions through prior notifications (Study Four). This preparation includes providing summarised background information that aids in initiating and facilitating PC conversations (Study Four). Moreover, sharing key information across primary and secondary care enhances collaborative decision-making, ensuring that all relevant healthcare professionals are informed and can contribute to the patient’s care plan (124). This was similarly noted by Haranis (2023), who found that electronic tools improve communication and coordination, leading to more effective care planning and delivery (125).

Another significant barrier that electronic tools can address is the lack of standardisation in identifying deterioration in patients with advanced progressive diseases. These tools provide a consistent framework for early identification and decision-making, particularly supporting junior and less experienced staff to ensure that patients are not missed (Study Four). This systematic approach facilitates a smoother transition to palliative care and supports early engagement, which is crucial for better patient outcomes. Similar conclusions were drawn by Kawashima (2024), who found that standardised screening processes help in early detection and improve patient outcomes (121).

Current tools and models for identifying patients with palliative care needs have advanced significantly over time. Early electronic screening tools, like PREDICT and AnticiPal, used fixed rules to identify these patients, but they lacked flexibility and needed frequent updates (126-128).

Recent technological advancements now allow the use of artificial intelligence (AI) in these tools. AI includes machine learning (ML) and natural language processing (NLP) (122, 129, 130). These AI models use information from electronic health records (EHRs), such as patient details and medical history (122, 128, 130).

Machine learning tools use various methods, like logistic regression, decision trees, and neural networks. More advanced models include convolutional neural networks (CNNs) and recurrent neural networks (RNNs) (122, 128). These tools predict outcomes such as mortality or palliative care needs with high accuracy (122). Natural language processing techniques NLP techniques assist by analysing medical notes and patient records to find essential details about symptoms and treatments (129).

Logistic regression models are simple and interpretable, making them suitable for predicting binary outcomes like mortality (128, 130, 131). Decision trees and advanced methods, such as random forests, can handle complex data (48, 75). Neural networks, including multilayer perceptrons and more advanced models, are excellent at identifying detailed patterns in data and are particularly effective in processing unstructured clinical text and time-series data (122, 130).

These artificial intelligence models are usually trained on historical data to identify patterns and relationships, enabling them to make accurate predictions and analyse clinical text effectively (121, 131-133). To ensure their reliability and accuracy, the models undergo rigorous validation using separate datasets (122). Various metrics are utilised for comprehensive performance evaluation, including accuracy, Area Under the Receiver Operating Characteristic Curve (AUROC), sensitivity, specificity, and Balanced Error Rate (BER) (121, 122, 128, 131, 133).

This shift from traditional prognostic tools to advanced artificial intelligence-driven models marks a significant improvement in the dynamic and personalised prediction of palliative care needs, ultimately enhancing patient care and optimising resource allocation (122, 130). The integration of artificial intelligence has allowed for more comprehensive and real-time data access from electronic health records (EHRs), enhancing the accuracy and efficiency of screening tools (128, 131, 134). Additionally, using artificial intelligence in standardised screening processes can lead to earlier identification and better patient outcomes (121, 123, 128, 134) .

Despite the promising benefits of electronic screening tools and artificial intelligence in palliative care, several significant challenges remain. These challenges include their predominant use in hospitals rather than primary care, a focus on mortality rather than needs, data quality issues, lack of validation, technical problems, ethical concerns, generalisability, and existing inequalities (131, 134-136).

Many artificial intelligence models and electronic screening tools have been developed and tested predominantly in hospital settings, which poses a challenge for their application in primary care (123, 131). Hospital settings provide a controlled environment with readily available and extensive patient data, facilitating the development and testing of these tools (130). However, primary care settings are less structured, with more variable data quality and availability, making it challenging to directly transfer hospital-developed tools to primary care (128, 131).

Current artificial intelligence models often prioritise mortality prediction over identifying unmet palliative care (121). This approach can lead to late referrals, as the focus on predicting death may not capture the early signs of decline or the unmet needs of patients with advanced progressive disease (123). Salvador Comino (2023) highlighted that integrating self-reported symptoms with mortality prediction could provide a more comprehensive approach, ensuring timely and appropriate referrals based on patient needs rather than solely on mortality risk (137).

Artificial intelligence models are often built on datasets reflecting healthcare inequalities (132, 135). These datasets often underrepresent disadvantaged groups, leading to biased outcomes when the models are applied more broadly. Teeple (2023) emphasised that algorithmic bias is a significant concern, as models trained on biased data can perpetuate and even exacerbate health disparities (135). Moreover, many models lack rigorous external validation, which is a critical barrier to their reliability, generalisability, and effectiveness (121-123, 130). A recent systematic review underscored that, despite the potential of current machine learning-based tools in palliative care, comprehensive testing and validation are critical to ensuring their reliability and effectiveness (122).

Technical issues, including system compatibility and data integration, present significant challenges (138). Integrating electronic screening tools with existing electronic health record (EHR) systems is complex, particularly due to the use of different data standards and formats across healthcare systems (134, 137). Additionally, low-quality or incomplete data can negatively impact the accuracy and reliability of artificial intelligence models (125, 131).

The use of artificial intelligence and electronic tools in palliative care raises several ethical issues, particularly regarding patient autonomy, informed consent, and the reliance on AI for critical healthcare decisions (120, 131, 136). Petersson (2023) highlights conflicting views among healthcare professionals on sharing artificial intelligence-based information with patients, which can undermine patient autonomy by failing to fully inform patients about their treatment options and the implications of AI recommendations (136) (131). Additionally, the transparency and understandability of artificial intelligence technologies are significant concerns. The "black box" nature of many AI models, where the decision-making process is not transparent, exacerbates these ethical issues, making it difficult for healthcare professionals and patients to trust and understand AI-driven decisions (136).

Communication gaps between healthcare providers and patients further complicate the ethical landscape (120, 131). Hubbard (2021) found that many patients and their carers were unaware of their inclusion in the Palliative Care Register, highlighting a significant lack of communication about the role of computer screening tools in their care plans (120). This gap emphasises the need for effective communication strategies to ensure that patients fully understand their care and the use of AI in decision-making (120, 131, 136).

In conclusion, while electronic screening tools and artificial intelligence hold significant promise for advancing the timely identification of patients with potential palliative care needs in primary care, addressing the current challenges and implications is crucial for their successful integration and optimisation in primary care.

6.3 Limitations of the methods

In this thesis, a wide range of methods were employed to explore and investigate current practices and barriers to the timely identification of patients with potential palliative care needs in primary care in England. These methods included a systematic review of the literature to identify existing screening tools, two observational studies to enhance understanding of palliative and end-of-life care experiences within the community, and qualitative interviews to gain new perspectives on barriers to timely identification of patients with cancer who may benefit from palliative care in primary care, as well as examine the potential benefits of electronic screening tools. Each method has its limitations, which are discussed in detail below.

6.3.1 Lack of accepted reference standards and definitions of patients with potential palliative care needs

A significant challenge identified in this research is the absence of a universally accepted reference standard for evaluating the accuracy of screening tools to identify patients with potential palliative care needs in primary care (10). Most studies, including those in my systematic review, used mortality as a reference standard. However, this approach is fundamentally flawed, as palliative care needs are not always directly related to the time of death, especially for illnesses with unpredictable trajectories, such as organ failures (17). For instance, patients with chronic conditions like chronic obstructive pulmonary disease (COPD) and heart failure often experience periods of exacerbation and remission, complicating the prediction of their end-of-life needs (20).

The reliance on mortality as a reference standard misses the broader and more complex aspects of palliative care needs (6, 25). Only one study in the systematic review used clinical judgement to assess whether the identified patient could benefit from palliative care, which suggests a more holistic approach but still lacks standardisation. Moreover, data on how many patients identified (or missed) by the screening tools had palliative care needs were universally missing. This gap raises critical questions about the actual clinical value of these tools and whether they effectively identify patients with potential palliative care needs.

The lack of a standard reference means that different studies may employ varying criteria and methods, leading to inconsistent and non-comparable results (6, 139). Additionally, the absence of evidence-based cut-off values for these screening tools further complicates the ability to timely identify patients who would benefit from palliative care (7, 9). Addressing these issues is crucial for developing more effective and reliable tools to ensure timely and appropriate palliative care interventions, ultimately improving patient outcomes and the efficiency of healthcare delivery.

6.3.2 Lack of recent and high-quality data to understand experiences at the end-of-life

Understanding patient experiences at the end-of-life presents numerous challenges, particularly regarding the quality and recency of available data. In Studies Two and Three, I utilised data from the National Survey of Bereaved People (VOICES), a population-based mortality follow-back survey. The reliance on proxy respondents introduces variability, as caregivers' experiences and perceptions might not accurately reflect the patient's actual experiences (140). Proxies might project their own experiences or biases, which can alter the reported quality of care.

A review found that while family members’ perspectives often align more closely with patients' needs and desires than healthcare professionals, differences still exist. For example, quality of life was rated as an important component of a good death by 70% of family members, compared to only 35% of patients (141). This suggests that family members and patients may define the quality of life differently. Similarly, "dignity" was reported as crucial by 70% of family members versus 55% of patients, indicating potential differences in how dignity is perceived and valued (141).

The retrospective nature of the VOICES survey inherently limits its capacity to provide real-time data, which is crucial for immediate quality improvement initiatives. This limitation is compounded by its inability to capture the direct voice of the patient, a vital element of patient-centred care (142). Additionally, the data analysed in my observational studies, collected from

2011 until 2015, were gathered before the COVID-19 pandemic. The pandemic has significantly impacted the landscape of end-of-life and primary care, meaning the experiences recorded in these pre-pandemic data may not reflect current realities (119, 143).

The chronological gap between the data collection period and the present day raises significant concerns about the relevance of the findings in the existing healthcare context. The retrospective ratings provided by decedents' relatives could significantly differ from the actual experiences of the decedents due to recall bias, mainly when data collection occurs several months after death (142). The time gap between the death and the survey can exacerbate this issue, leading to potential inaccuracies in the data (144, 145).

Overall, while the VOICES survey provides valuable insights into end-of-life care, it is essential to consider these limitations. The retrospective design and the pre-pandemic data collection period necessitate caution in interpreting the findings. Addressing these limitations is crucial for improving the accuracy and applicability of data, ultimately enhancing the quality of end-of-life and palliative care research and practice.

6.3.3 Underrepresentation and lack of diversity in palliative care research

The underrepresentation of diverse populations in palliative care research significantly limits the generalisability of findings. For instance, the VOICES survey predominantly includes responses from white British individuals, failing to capture the experiences of ethnic minoritised groups. Similarly, in my qualitative study, all patient participants were white (Study Four). This lack of diversity not only affects the broader applicability of the research but also means we miss understanding the unique perspectives, experiences, and potential barriers faced by ethnic minoritised groups. Understanding their views could reveal crucial factors that influence their experiences and access to palliative care, thus offering insights into how these barriers might be addressed.

Language barriers play a significant role, as some individuals from ethnic minoritised groups may not have sufficient proficiency in English, making it difficult for them to understand and respond to survey questions or participate in interviews (146). Additionally, cultural misunderstandings and differences in health beliefs and practices can impede participation. Individuals from ethnic minoritised groups might have different understandings of palliative care, illness, and end-of-life practices that are not adequately addressed or respected in research approaches (147). This cultural gap can lead to mistrust and reluctance to engage with researchers who are perceived as not understanding or valuing their cultural context (148, 149).

Another factor is the lack of representation and inclusivity in research teams. Studies often fail to include researchers who share the same cultural or ethnic background as the participants they are trying to recruit (147). Additionally, the involvement of individuals from minoritised communities in the Patient and Public Involvement (PPI) process is currently insufficient (150, 151). This lack of representation can lead to a disconnect between researchers and potential participants, making it harder to build the trust and rapport needed to encourage participation.

Addressing these barriers requires a multifaceted approach, including improving language accessibility, culturally tailoring research methods, building trust through community engagement, ensuring diverse research teams, and employing effective outreach strategies. By tackling these issues, we can enhance the representation of ethnic minorities in palliative care research and develop more inclusive and effective palliative care practices.

6.3.4 Focus on patients with cancer and its limitations

The qualitative study aimed to explore barriers to the timely identification of patients with cancer who may benefit from palliative care in primary care and to examine the potential benefits of using electronic screening tools for this purpose. While the overall thesis, including the systematic review and secondary data analysis, addressed patients with cancer and non-cancer diagnoses, the qualitative study specifically targeted patients with cancer due to funding constraints. This narrow focus limits the transferability of the findings to other patient populations, such as those with heart failure or COPD, who have different palliative care needs and trajectories (21). Consequently, the applicability of the qualitative findings to a broader patient population is restricted.

In conclusion, while this thesis provides valuable insights into identifying and managing palliative care needs in primary care, addressing the identified limitations is crucial for advancing research and improving patient outcomes. Future studies should focus on standardising identification methods, including diverse populations, utilising high-quality and recent data, and overcoming the inherent challenges in palliative care research. By addressing these issues, we can ensure that palliative care services are more inclusive, effective, and responsive to the needs of all patients.

6.4 Implications for practice and policies

The findings from this thesis have significant implications for both policy and practice in primary care settings, particularly regarding the early identification of patients with potential palliative care needs. The necessity for a systematic approach is underscored by the current lack of standardised guidelines and screening tools to identify patients with potential palliative care needs (2, 10, 23). Given the diverse and unpredictable disease trajectories of illnesses such as heart failure and COPD, it is crucial to develop and implement validated electronic screening tools in primary care(21). These tools can be highly beneficial as they enable regular screening to identify early signs of palliative care needs (120, 122). When such needs are identified, GPs can initiate early discussions with patients and their families about palliative care options and advance care planning and coordinate referrals to palliative care specialists to ensure continuity of care.

Effective communication and continuity of care are crucial (2, 38, 42). Study Four found that poor communication and lack of coordination were significant barriers to timely palliative care. Improving information exchange between primary and secondary care and ensuring that patients and their families are fully informed about palliative care options, are essential steps in enhancing care delivery (23, 42, 58). Structured communication protocols and shared electronic health records can facilitate better coordination, avoid duplication of work, and ensure that no patients are overlooked.

Most patients prefer to spend their last year at home, where they are predominantly under the care of primary care providers (88). This underscores the vital role of primary care in the delivery of palliative care. As GPs and primary care teams are often the first point of contact, there is a pressing need for increased resources, funding, and a greater emphasis on continuity of care in primary care (152, 153). Study Two and Study Three have shown that palliative care is associated with better end-of-life outcomes, such as improved pain relief and overall quality of end-of-life care, particularly when provided in home settings (69, 70, 75, 78).

Enhancing the capacity of primary care to deliver palliative care can help align services with patient preferences, ensuring that more individuals can receive high-quality care at home during their final stages of life (154, 155). This involves expanding the availability of home-based palliative care services to meet the growing demand (156, 157). Comprehensive support for symptom management, psychological support, and assistance with daily activities should be readily accessible to all patients, regardless of their geographical location, socioeconomic status or diagnosis (154). The COVID-19 pandemic has further highlighted the importance of strengthening primary care services (117, 119). The increased pressure on healthcare systems during the pandemic has underscored the need for robust primary care infrastructure capable of supporting patients at home (158).

Additionally, primary care teams must be adequately trained and supported to manage the complex needs of palliative care patients (155, 159). This includes ongoing education and training in palliative care principles, symptom management, and effective communication strategies (154). Ensuring that primary care teams have access to such training and resources is essential for enhancing their capacity to deliver palliative care (154).

Primary healthcare professionals must also be culturally competent and sensitive to the diverse needs of patients from different ethnic backgrounds (148, 160). This involves providing information in multiple languages and training staff in cultural competence to build trust and improve engagement with patients from ethnic minoritised groups (161-163). Cultural competence is not just about language, but also about understanding cultural beliefs, values, and practices that may influence health behaviours and decisions (164, 165). For example, some cultures may have specific preferences regarding end-of-life care, pain management, and family involvement in medical decisions(164, 166). Comprehensive cultural competence training programmes should be implemented in primary care to effectively address these needs (167). These programmes should cover topics such as cultural awareness, communication skills, and the social determinants of health that disproportionately affect minority communities(168, 169).

By developing and implementing these guidelines and training programmes, healthcare systems can better meet the needs of all patients, improve patient satisfaction, and enhance the overall quality of care. This holistic approach ensures that cultural competence is not seen as an add-on, but as an integral part of patient-centred care (170).

6.5 Directions for Future Research

The thesis has identified several important areas for future research. One significant gap is the lack of high-quality, recent data on patient experiences at the end-of-life, particularly in light of the COVID-19 pandemic (171). The pandemic has fundamentally changed healthcare delivery, and understanding its impact on palliative care is crucial for developing responsive care models (172). Future studies should focus on collecting and analysing real-time data to capture current patient experiences and care needs more accurately (173, 174).

Another crucial area for future research is developing and validating screening tools that can accurately and proactively identify patients with potential palliative care needs in primary care, regardless of their specific illness trajectory. This includes creating automated tools that go beyond mortality prediction to identify patients with potential unmet needs and assess their appropriateness of palliative care (122, 175). Moreover, future research should explore the potential benefits and challenges of integrating electronic screening tools into primary care practice. This includes evaluating the effectiveness of these tools, understanding their impact on healthcare provider workload and patient outcomes, and identifying any technical or ethical issues that may arise (134-136).

Research should also investigate the barriers to accessing palliative care among patients with non-cancer illnesses, such as heart failure and COPD. These patients often have lower rates of palliative care utilisation due to factors like a lack of awareness and the unpredictable nature of their diseases (94, 102, 103). Addressing these barriers is crucial to ensure comprehensive, compassionate care for all patients.

Furthermore, there is a pressing need to address the underrepresentation of ethnic minorities in palliative care research. Future studies should focus on developing culturally sensitive research methods, improving language accessibility, and engaging with ethnic minority communities to build trust and encourage participation (148, 149). This approach will help ensure that research findings are more generalisable and that palliative care practices are inclusive and equitable (147).

By addressing these gaps, future research can significantly enhance the quality and accessibility of palliative care, ensuring it meets the diverse needs of all patient populations.

6.6 Conclusions

This thesis highlights the need for a more systematic and inclusive approach to identifying and managing patients with potential palliative care needs in primary care. By implementing electronic screening tools, improving communication and coordination, and addressing cultural competence, healthcare providers can ensure timely and appropriate palliative care, ultimately enhancing the quality of life and end-of-life outcomes for patients with advanced progressive diseases. Future research should continue to develop and validate comprehensive screening tools and explore the barriers and facilitators to effective palliative care delivery in primary care, ensuring that all patients, regardless of their background or illness, have access to high-quality palliative care and end-of-life care.

6.7 References

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Appendix A: Study One supplementary materials

Appendix A.1: the search strategy used on MEDLINE

1. (Family adj3 Physician* or doctor* or Practi* or medicine).ti,ab.
2. (general adj3 pract*).ti,ab.
3. (GP or GPs).ab,ti.
4. (primary adj3 care).ab,ti.
5. Primary Health Care/
6. Family Practice/
7. Physicians, Family/
8. 1 or 2 or 3 or 4 or 5 or 6 or 7
9. "Referral and Consultation"/
10. Mass Screening/
11. tool*.ab,ti.
12. Risk Assessment/
13. instrument*.ab,ti.
14. diag*.ab,ti.
15. consultation.ab,ti.
16. identif*.ab,ti.
17. (case adj3 finding).ab,ti.
18. screen*.ab,ti.
19. assessment.ab,ti.
20. detection.ab,ti.
21. 9 or 10or 11 or 1214 or 15 or 16 or 17 or 18 or 19 or 20
22. Palliative Care/
23. PALLIATIVE MEDICINE/
24. Advance Care Planning/
25. TERMINAL CARE/
26. Terminally Ill/
27. Palliat*.ab,ti.
28. (terminal adj3 Care).ab,ti.
29. (advance adj3 care adj3 plan*).ab,ti.
30. (end adj3 life adj3 care).ab,ti.

31. (end-of-life adj3 care).ab,ti.
32. (terminal* adj3 ill* or patient* disease*).ab,ti.
33. ((near or approach* or close) adj4 (death ordying)).ab,ti.
34. 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33
35. 8 and 21 and 34

Appendix A.2:Bias assessment for randomized control trials (Cochrane risk of bias tool)

Supplementary file 2. Bias assessment for randomized control trials (Cochrane risk of bias tool)

Reference	**Random sequence generation (selection bias)**	**Allocation concealment (selection bias)**	**Blinding of participants and researchers**	**Blinding of outcome assessment (detection bias)**	**Incomplete outcome data (attrition bias)**	**Selective reporting (reporting bias)**	**Other bias**
Mitchell, 2018	Low	Unclear[a]	*Low*	*Low*	*High*[b]	*Low*	Low

[a] Unclear allocation concealment.

[b] Differential drop-out rates between the two groups.

Appendix A.3:: Bias assessment for cohort studies and case control studies

Supplementary file 3.a.Bias assessment for cohort studies (Newcastle–Ottawa Scale)

Domain	Selection				Comparability	Outcome			
Reference	**Representativeness of cohort**	**Selection of non-exposed cohort**	**Ascertainment of exposure**	**Outcome of interest**	**Comparability of cohorts**	**Assessment of outcome**	**Adequate duration of follow-up**	**Adequate follow-up of cohort**	**Total score**
Gómez-Batiste 2017,	1	1	0	1	2	1	1	1	8

Rainone, 2007,	1	1	1	1	0	1	1	0	6
Barnes, 2008,	1	1	1	1	0	1	1	1	7
Moroni, 2014,	1	1	1	1	1	1	1	1	9
Lakin, 2016	1	1	1	1	1	1	1	1	7

Supplementary file 3b. Bias assessment for case control studies (Newcastle–Ottawa Scale)

Domain	**Selection**				**Comparability**	**Comparability**			**Total score**
Author, year	**Is the case definition adequate?**	**Representativeness of the cases**	**Selection of Controls**	**Definition of Controls**	**Comparability of cohorts**	**Ascertainment of exposure**	**Same method of ascertainment for cases and controls**	**Non-Response rate**	
Stow, 2018$_b$	1	1	1	1	1	1	1	1	**8**
Stow, 2018$_q$	1	1	1	1	1	1	1	1	**8**

Appendix A.4: PRISMA checklist.

PRISMA checklist			
Section/topic	**#**	**Checklist item**	**Reported on page #**
TITLE			
Title	1	Identify the report as a literature review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings;	2

PRISMA checklist			
Section/topic	**#**	**Checklist item**	**Reported on page #**
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known about your topic.	4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4
METHODS			
Eligibility criteria	5	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5
Information sources	6	Describe all information sources (e.g., databases with dates of coverage) in the search and date last searched.	5
Search	7	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	S1
Study selection	8	State the process for selecting studies (i.e., screening, eligibility).	5-6
Risk of bias in individual studies	9	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level).	6
Risk of bias across studies	10	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	Not mentioned
RESULTS			
Study selection	11	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	6 & 7
Study characteristics	12	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	7-10
Synthesis of results of	13	For all outcomes considered (benefits or harms), present, for each study: (a) summary of results and (b) relationship to other	11-18

PRISMA checklist			
Section/topic	**#**	**Checklist item**	**Reported on page #**
individual studies		studies under review (e.g. agreements or disagreements in methods, sampling, data collection or findings).	
DISCUSSION			
Summary of evidence	14	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	21-23
Limitations	15	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	22-23
CONCLUSION			
Conclusions	16	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	24

Appendix B: Study Four supplementary materials

Appendix B.1: Topic Guide for patients with in St Gemma's hospice

Topic Guide for patients with cancer in St Gemma's hospice		
	Questions	Prompts
Background to Referral	• Can you tell me a little about yourself and your story?	• When did you first hear about palliative care, and how did that make you feel?
	• Please tell me how palliative care services, such as the hospice, became involved in your care.	• What types of palliative care services have you received, such as hospice care or community nursing?
	• What are your views on the information you received about palliative care?	• How did your GP or nurse introduce the idea of palliative care to you?
		• How was the local hospice or other palliative care services introduced to you by your GP?
Palliative and Supportive Needs	• How does your cancer affect you day-to-day?	• What prompted the involvement of palliative care services? Was there a specific event or problem?
	• What problems were most bothersome when you started palliative care?	• Can you describe any physical symptoms and what helps to relieve them?
	• What are your ongoing needs as a person living with cancer?	• How does your cancer affect you psychologically and socially?
		• What were the most pressing issues you faced at the time of your referral to palliative care?
Barriers to Accessing Palliative Care	• What do you think are the main challenges in accessing palliative care early in your illness?	• What challenges did you face when trying to access palliative care services?
	• Have you experienced any difficulties in discussing palliative care with your healthcare providers?	• Were there any delays in getting referred to palliative care, and if so, what were the reasons given?
		• Have you had issues with the availability or accessibility of palliative care services?
Introduction of an electronic screening tool	• We are developing a tool to help identify patients who might benefit from palliative care earlier. How do you feel about this idea?	• How do you feel about being identified for palliative care through this tool?

		• Do you think using electronic medical records to identify patients is a good idea? Why or why not?
		• What potential benefits do you see in using such a tool for identifying patients who need palliative care?
Communication methods	• What are your thoughts on how patients with cancer should be invited for a palliative care assessment?	• How would you feel about receiving an invitation through a letter, email, phone call, or text message?
		• Why do you think this approach might be appropriate or inappropriate?
		• Is there a better method for inviting patients with cancer?

Appendix B.2: Topic Guide for Healthcare Professional Interviews

	General questions	**Prompt items**
Background	• Please describe your role	• Their role • Typical day/week

		• Number of patients seen (How many patients with cancer do you see every day)
Current practice	• Can you describe how you currently identify patients with PC needs	• How do you identify patients with cancer with unmet PC needs - Any guidelines, methods or criteria (e.g. SPICT, GSF)? • What Actions are taken after identifying people "next step" -assessment of current care, offer PC needs assessment, ACP, end-of-life discussion? • Are prognosis transition to palliative care routinely discussed with patients with cancer in primary care? Do you feel that it ought to be? • Who do you feel should discuss prognosis and transition to palliative care with the patients with cancer? Do these discussions take place? • Do you have in your practice regular GSF meetings or regular multidisciplinary case review meetings where all patients on the palliative care register are discussed (as recommended by QOF)? How often do you have these meetings? • Are there any problems with the current approach/practice?
Content of the screening tool	• We are proposing to develop an electronic screening tool to identify patients with advanced cancer who could benefit from PC. One of the aims of our interviews is to try and find what a screening tool should contain. • What should the screening tool include	• Introduce our domains and ask them to indicate their importance. • You didn't/do think that… was an important domain of a PC screening tool, why is that? • Should a PC screening tool include any additional domains?
Use of electronic screening tool in practice	• The proposed system will alert GPs to patients with cancer who may benefit from PC needs assessment and referral for support • How might the electronic screening tool fit with your current practice?	• What would you do with alert system?/ how would you respond to the alert system? • What actions might you take as a result? • Practical issue with the instrument (e.g. workload) • What would be the advantages and disadvantages of using our electronic tool?
Wider practice	• How might this type of screening fit with the wider practice in the healthcare system?	• Who would be responsible for receiving alerts and responding to them? • Given busy schedules, how should the eligible patients be contacted e.g. email alerts, appointment, telephone? • Whose responsibility is it to assess the identified patients?

		- Who needs to know about actions taken? (GP, oncologist)

Appendix B.3: Examples of quotes to support the themes of the theoretical framework

Theme	Barriers to timely identification	Potential benefits of introducing electronic screening tools
Lack of systematic approach	“It’s very subjective… this is just hypothetically speaking. Two doctors from the same practice could go and assess the same patient, on a Monday morning and come out with a different view, because it’s subjective and it depends what you pick up, and what you do with that information.” DN (D002)	“I think the advantage, I guess you never know what you don’t know so we don’t know how many of these we’re missing off our palliative care list so this I guess it would be like a backup check that there’s not other people out there who might benefit

	“We don’t have any specific guidelines, we don’t use any tool as such, we just erm, I mean I guess a lot of the patients that we see, we see on an ongoing basis and even if we just see them for a short period of time, the chances are we’ll discharge them, they’ll come back at a later so we get to know them pretty well.” DN (D001) “It’s mostly clinical judgement … but there isn’t a tool that we would say look, press a button and that’s telling me to do that, this patient might have the increased palliative care needs.” GP (G005) “[Before COVID-19 pandemic] we were all working more closely and having those informal discussions and meetings and things, that was a lot easier ‘cos we could flag them up and discuss patients sort of on an informal basis. Obviously, that’s a bit harder now … it’s more down to the individual to recognise somebody presenting with symptoms that might need palliative care involvement.” GP (G008) “I don’t seem to be getting any help to say I’ve got terminal cancer do you know what I mean and stuff. There’s nobody there for any help or anything” “[My consultant] was surprised, ‘cos, he said you should be on there he said with you having palliative care he said I can’t understand how nobody’s been in touch he said ‘cos you should be there on the list or something or whatever in the system.” Patient with cancer (P003) “If you add into that the complexities around ethnicity, deprivation, culture, we find you know and again the statistics will show … the percentage of people from different non-Caucasian background is very small who are receiving palliative care. So … how many of those are accessing palliative services and especially from non-Caucasian backgrounds and I think there needs to be a lot more work around that aspect.” GP (G007) “It’s about considering their needs as they go along and you know rather than suddenly people dying because I think the more you walk that journey with	so you know we don’t have a, the list is just however many people are on it.” GP (G002) “Nothing should get lost so it should be easy to say like Mrs Smith or Mr Wilson or something like that, do you know what I mean and it … should be doing a bit more for Mr Wilson or something, let’s invite him here or send him a letter or something.” Patient with cancer (P003) “I think having a tool that helps you identify potential palliative care patient that might need potential palliative care, I think that is a good thing. So I think it would be helpful and often times it’s I mean like I say we have these meetings monthly anyway so if, it might be that you know you get those tasks and then either you look at them yourself or you look at in the meeting and then you discuss if there’s a need.” GP (G006) “it would make life easier in a lot of cases and I think especially for maybe even in cases where more junior inexperienced staff” DN (D001) “So that would make different professionals go through it, in a systematic way, to cover anything, and then it would identify, you know, it would identify, particular pathways perhaps, to what needs to happen, would be a benefit. Because that will take out the subjectivity somewhat.” DN (D002)

	somebody, the more that actually the death is not a surprise" … actually, if we're seeing people and managing them well, we should be knowing that they're getting worse, knowing that they're going into amber, going into red so we can support them on that journey because it's one they're only ever going to do once". GP (G007) "And we still are able to get palliative services to them but I think that's more of a last minute emergency right, we really need your input now, rather than a planned routine referral where we can sort of you know get them a bit of a better care delivery." GP (G005)	
Limited time and resources	"So that reduction in patient contact, face to face contact I think is a barrier to identifying patients with palliative care needs and also patients try to ring in to practices to discuss their problems, … so if you've got somebody who's got palliative care needs, they are competing with everybody else to try and get access to yeah so they can be missed." GP (G006) "Plus, we've just had the covid vaccine rollout you know so we've got receptionists and admin staff ringing people to book them into this covid vaccine clinics …we've got people being released to do all this other work." GP (G006) "One of the difficulties around palliative care, to do it well it takes a lot of time." GP (G001) "Very difficult, sometimes 2 or 3 weeks in order to get an appointment .... When I see the GP which I have to say he usually looks rather, or she looks rather tired with the pressure of work." Patient with cancer (P005) "If we need to be in touch with them [GPs]. It's just that it's very difficult with the Covid." Patient with cancer (P006) "So that can be the tricky things for clinicians … where they might get stuck so I think knowing that something can help a patient, you're more likely to offer it… So	"I guess there is some work there but like I said it's an important group of patients and it does make a big difference and any work that you do at the outset would influence things anyway. It would probably save you work further down the line." GP (G008) "But I suppose if you're proactively doing something it might save time in the long run." GP (G003) "I think that would cut down work in the long run basically is what I'm saying." DN (D001) "Well it's catching people early isn't it, I think that will overall that's a good investment and it will be less workload." DN (D004)

	if I've never been aware that actually you can support a patient …, I'll probably never offer it because I don't know about it." GP (G005) "My current practice is in a very affluent area and I think they have more resources and more staff per patient and that makes life easier to do those sorts of things. My previous practice was in a very deprived area and struggled." GP (G002) "They vary, so some GP surgeries are good at holding the gold standard framework meetings and some surgeries are bad." DN (D003)	"So if the search comes out and then you click a button and it says this is the patient, something you can quickly read and say ah, now I understand why you need a palliative care review. I think it makes it much more quicker and you'll probably have more buy in from clinicians and GPs who want to do the right thing, they'll probably find it time efficient but also you'll find the uptake of doing these reviews much better, the engagement you'll find will be much, much better as well." GP (G005) "I think you, yeah I think it would be fine for an administrator to manage the administrative aspects of it so just coordinating who was going to speak to the patient." GP (G003) "I think there could be non-clinicians like we talked about the data quality role but, that could help identify some but ultimately it's going to be the GP with a clinical mind." GP (G008) "Yeah so the searches, they could be run by admin, the data team, that's fine." GP (G005) "I think when we did it before, new patients were raised by non-clinicians and then it was decided at the meeting by the GP so yeah, so no I think ultimately it's a GP decision but anybody could raise that for it to be discussed at the meeting." GP (G008) "Identifies this group of patients earlier for us the better really. We know that if we can engage with

		them and we can sort of get working that would be a lot better so yes that would be certainly something that I think would be a good idea.” GP (G008) “It would be better for clinicians to identify these patients earlier because you can then proceed with things like advanced care planning so you’ve got more time to prepare.” GP (G005)
Talking about palliative care is difficult	“When he first mentioned [palliative care] I thought does he know something I don’t? Am I going to die tomorrow, you know because that was the thought I had in my mind about what a hospice actually does.” Patient with cancer (P004) It can be quite difficult talking about advanced care planning because discussions about death are difficult anyway and once you start to talk about advanced care planning automatically the patient starts to think about death.” GP (G006) “I work in Bradford, we’re quite, it’s quite a diverse population and so palliative care can be limited by cultural beliefs and different expectations from family ...I will have families where actually my patient doesn’t speak English and so it can be hard to know how much my patient knows of their diagnosis may have their sons or daughters not wanting them to know that they’re dying but then I can see that this patient is, is actively dying and probably knows themselves so there can be a cultural element there with a language barrier.” GP (G004) “Because there is a language barrier with Southeast Asian patients sometimes, we are in danger, and this has come up a few times, of treating the family instead of treating the patient and it’s understanding that family culture I suppose as well.” DN (D004) “So sometimes we have patients who have been actively treated and then when you, when it’s been decided by oncology that there’s no further treatment so we have to go down more of a palliative route, that	“If there’s a clinical summary that that goes in the patient records but that also goes to the patient and then it says so actually at the top our goals are that we are trying to improve access to services to palliative care and please find attached below your summary… So if it explains those things, that’s perfect. If not then it’s a lengthy conversation for the clinician.” GP (G005) “[It would] be great if we had something that predicted what time somebody had left.” GP (G007) “Initially, particularly for such a potentially sensitive matter I think you’d probably want to speak to them. It’s that question regarding how do you alert them to what it is that you’re discussing.” GP (G003) “A letter that explains everything fully with the knowledge, with a caveat, with a caveat that there’s a door open if they want more direct access and more information face to face with the qualified person.” Patient with cancer (P005)

	can be quite challenging depending on the circumstances." DN (D003) "I had a lady last year who was in her mid-40s and she had ovarian cancer … She just would not talk about it to us, to her family anything. She didn't want to know about it and then if you brought, if you brought the you know the topic up she just turned her head away and that was it, it was like a cut off point … and it got to the point where we couldn't, we didn't have that advanced care plan in place because she wouldn't tell is where she wanted to be for her end-of-life care she wouldn't talk about it. There was don't DNR CPR or respect in there so it did hit a crisis and it was awful because she had a massive bleed on the day that she died." DN (D001) "The conversations take time so what we can't do is have a 10 minute quick conversation and think like you might be ready for palliative care and therefore we're going to do this, and it needs a time sensitive, time consuming conversations with patients where you have to understand the background." GP (G007) "At some point we're going to have to stop, this is end-of-life and I think we probably ought to be better at probably speaking to colleagues about actually introducing especially, probably secondary care colleagues some of them and actually introducing palliative care sooner because I think if you, I think people see it as failure." GP (G007) "If the patient gets referred too early it can be counter productive, it can be a negative experience for the patient." DN (D003) "At some point somebody has to say when do you want to stop and actually once we asked that question of her and her family, they wanted to stop but nobody had ever given them the option." GP (G007)	
Lack of continuity of care and interprofessional collaboration	"They keep changing doctors at the surgery so whether they're going to let them know what's, you know I've got a new doctor to talk it over with." Patient with cancer (P003)	"It would be great if we had joined up electronic health record systems that would allow us to do that and everyone could access that information." GP (G002)

	"There's a big move in practice to make it demand orientated rather than continuity of care oriented. In primary care generally, we are losing the continuity of care because access, fast access is being prioritised over that and I think that works really well for some conditions particularly acute conditions but things like palliative care I think they are losing out because it's becoming much harder to have continuity". GP (G002) "The last thing you want and I say this as someone who looked after my parents who both died from cancer, the last thing you want is to have to go through the whole history every time you meet someone new and if you've seen different GPs every time you know that's frustrating from a, you know I perceive it as being very frustrating from a patient point of view and a relative point of view because it's taking away the focus from what the actual problem is whereas someone that you know well and have got a bit more of a relationship with, they under, they already know what the problem is." GP (G002) "And then so they knew I never seen, heard anything, so I just mentioned it to my oncology professor said you know I've not seen my breast nurse for 3 years really and I don't seem to be getting any help to say I've got terminal cancer. There's nobody there for any help or anything." Patient with cancer (P003) "Cos although our staff at … are quite diverse, we haven't actually got any Southeast Asian backgrounded staff or anybody that speaks you know Urdu or Gujarati so that yeah I think that can be a barrier for ongoing relationships with patients sometimes." DN (D004) "So if my secondary care colleagues have sent me a letter that has said very clearly that this patient is now for palliative care and there is no further active treatment available to them then that is a really easy point for me to come in." GP (G004)	"I think one of the biggest solutions for that is just having transparency on electronic records of when somebody's done something." GP (G003)

	“We’re very much guided by communication from secondary care… if secondary care hasn’t broached that discussion at all or we don’t know that they have, it’s very difficult to then come in as a GP who’s not a specialist and say you know, yes you’re having treatment for your mesothelioma, I know this isn’t curative and let’s talk about your advanced care planning because you’re going to die soon.” GP (G004) “Once you hit the out of hours’ servicers … because they don’t know these patients, particularly… They are very reluctant to fast track these patients for the care. Very reluctant to write the anticipatory drugs, so you’ll see a lot of patients that get seen on Sunday, and it’ll all get bounced to their own GPs on Monday. So there’s actually a big delay there, on a, particularly a weekend.” DN (D002)	