

# Delivering end-of-life care for patients with cancer at home: Interviews exploring the views and experiences of general practitioners

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## Abstract

Many patients with terminal cancer wish to die at home and general practitioners in the United Kingdom have a critical role in providing this care. However, it has been suggested general practitioners lack confidence in end-of-life care. It is important to explore with general practitioners their experience and perspectives including feelings of confidence delivering end-of-life care to people with cancer. The aim of this study was to explore general practitioners experiences of providing end-of-life care for people with cancer in the home setting and their perceptions of confidence in this role as well as understanding implications this has on policy design. A qualitative study design was employed using semi-structured interviews and analysed using thematic analysis. Nineteen general practitioners from London were purposively sampled from eight general practices and a primary care university department in 2018–2019, supplemented with snowballing methods. Five main themes were constructed: (a) the subjective nature of defining palliative and end-of-life care; (b) importance of communication and managing expectations; (c) complexity in prescribing; (d) challenging nature of delivering end-of-life care; (e) the unclear role of primary care in palliative care. General practitioners viewed end-of-life care as challenging; specific difficulties surrounded communication and prescribing. These challenges coupled with a poorly defined role created a spread in perceived confidence. Experience and exposure were seen as enabling confidence. Specialist palliative care service expansion had important implications on deskilling of essential competencies and reducing confidence levels in general practitioners. This feeds into a complex cycle of causation, leading to further delegation of care.

## KEYWORDS

Cancer, end-of-life, end-of-life care, general practice, general practitioners, palliative care, qualitative research

## What is already known about the topic

- Palliative and end-of-life care need is projected to increase exponentially, largely due to deaths from cancer.

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- Primary care is instrumental in enabling patients to die in the community, providing symptomatic relief and care for people nearing the end of life.
- International studies have demonstrated general practitioners lack confidence in delivering end-of-life care.

### What this paper adds

- General practitioners lacked confidence with what they perceived to be complex practical skills in delivering end-of-life care, in particular, prescribing, pain-management, ACP and communicating with families.
- A spread of confidence levels existed with exposure and experience viewed as enablers to confident practice.
- Expansion of specialist palliative services and poorly defined roles between specialist and generalist services contributed to difficulties delivering end-of-life care.

## 1 | INTRODUCTION

End-of-life care is provided to individuals approaching the end of their life, typically those expected to die within 12 months (Marie Curie, 2021). In the United Kingdom, 28% of deaths are cancer related and in 2018, 18.1 million new cancer cases and 9.6 million cancer-related deaths occurred worldwide (Ferlay et al., 2019; Office for National Statistics[ONS], 2018). Palliative care, which encompasses end-of-life care, aims to improve the quality of life (QoL) for patients and families through prevention and relief of suffering (World Health Organisation, 2020). Globally, palliative care need is projected to rise exponentially, with an 87% increase in palliative patients with serious suffering between 2016 and 2060 (Sleeman et al., 2019).

Sixty percent of patients with cancer prefer end-of-life care to occur at home or usual place of care (Gomes et al., 2011). A drive to support this has been a clinical priority evidenced through international policies and guidelines (Department of Health[DoH], 2008, 2012a, 2012b; Institute of medicine, 2015; Parliamentary Assembly, 2018).

Primary care is instrumental in providing care in the community, acting as the main point of contact for people dying at home (DoH, 2008; Mitchell et al., 2016). General practitioner (GP) home visits reduce the odds of dying in hospital (Henson et al., 2016; Winthereik et al., 2018). GPs show an improved ability over specialist services to facilitate home deaths and improve diagnostic accuracy and application of evidence-based treatment (Mitchell, 2002; Nakanishi et al., 2020). Many GPs view their role in delivering end-of-life care as vital, ensuring good standards of patient care (Mitchell et al., 2016).

Recognising the importance GPs play in delivering end-of-life care is highlighted through international policies that support GPs' involvement in end-of-life care (DoH, 2008, 2012a; National Palliative Care Strategy, 2018). GPs are well placed to provide end-of-life care for patients with cancer when their working environment allows and with specialist support (Green et al., 2018; Johnson et al., 2020). However, research has demonstrated poor satisfaction levels of bereaved relatives and patients, rating care from GPs as worse than nurses and palliative care specialists, indicating a need for in-depth exploration into this area (ONS, 2015; Pivodic et al., 2016).

Research involving GPs has demonstrated varying confidence in delivering end-of-life care (Magee & Koffman, 2016; Winthereik et al., 2016). Palliative skills identified as worrisome included symptom control, advanced care planning (ACP) and non-somatic care (Magee & Koffman, 2016; Winthereik et al., 2016). Despite this, qualitative research exploring GPs perceived confidence and experiences in delivering end-of-life and palliative care in the United Kingdom is limited.

Education is key for improving confidence, with exposure to death and dying in clinical practice seen as particularly influential (Mcmahon & Wee, 2019; Selman et al., 2017). Global studies report barriers to confidence in end-of-life care include lacking time and continuity, high workload and conflict with patients and families (Balmer et al., 2020; Mitchell et al., 2016). This has led some to conclude that primary palliative care needs urgent attention, particularly within the context of cancer, given the increasing mortality prediction (Mitchell et al., 2019).

Whilst the number of patients dying at home is increasing, it remains the reality for only 40% of patients (DoH, 2012a; Nilsson et al., 2017). By 2040, three-quarters of deaths are predicted to happen outside hospital; meaning, support from community services must increase (DoH, 2012a; Finucane et al., 2019). It is therefore imperative to understand the difficulties that GPs face, to enable and support them in providing community-based end-of-life care (Bone et al., 2017).

Aims:

- To explore GPs experiences of providing end-of-life care for people with cancer in the home setting alongside their confidence within this role.
- To explore the role of GPs in delivering end-of-life care and the implications on clinical practice, service provision and policy.

## 2 | METHODS

### 2.1 | Design

A qualitative study using semi-structured interviews, guided by an interview schedule, developed from the literature and discussions

among the research team. Interviews were analysed using thematic analysis (Braun & Clarke., 2006), guided by the data adopting an explorative and inductive approach.

## 2.2 | Participants and recruitment

UK-based GPs currently employed by the National Health Service (NHS) were purposively sampled for a range of roles, years since

qualified, and experience (Table 1). We monitored for gender, race, religion and age (Table 1). We included GPs in training as they are involved in delivering end-of-life care and ensured we talked to GPs across the career trajectory. Including a range of participants allowed us to maximise the differing experiences GPs had with delivering palliative care, explore different perceptions and feelings of expertise and consider how this may change over time. Additionally, this allowed us to understand the needs of different individuals and how these can be met.

**TABLE 1** Participant demographics

|   | Number  | Percentage |
|---|---|------------|
| <b>Gender</b>   |   |            |
| Male  | 7   | 36.8%      |
| Female  | 12  | 63.2%      |
| <b>Age</b>  |   |            |
| ≤30   | 4   | 21.1%      |
| 31–39   | 9   | 47.4%      |
| 40–49   | 3   | 15.8%      |
| 50+   | 3   | 15.8%      |
| <b>Role</b>   |   |            |
| Enrolled on the UK GP speciality training programme ('GP trainee')      | 7 GP trainee's:<br>1 ST1<br>1 ST2 (part of academic clinical fellowship (ACF))<br>5 ST3 (1 as part of an ACF) | 36.8%      |
| Locum GP  | 1   | 5.3%       |
| Salaried GP   | 4   | 21.1%      |
| GP partner  | 5 (2 were palliative care leads at their general practice)  | 26.3%      |
| Commissioner  | 1   | 5.3%       |
| <b>Experience</b>   |   |            |
| 0 years = currently enrolled on the UK GP speciality training programme | 7   | 36.8%      |
| 1–3 years as a fully qualified GP                                       | 3   | 26.3%      |
| 4–15 years as a fully qualified GP                                      | 6   | 31.5%      |
| ≥16 years as a fully qualified GP                                       | 3   | 26.3%      |
| <b>Ethnicity</b>  |   |            |
| White-British:  | 8   | 42.1%      |
| South-Asian British:  | 4   | 21.1%      |
| Black-British:  | 1   | 5.3%       |
| Indian:   | 3   | 15.8%      |
| Black African:  | 1   | 5.3%       |
| Mixed ethnic backgrounds:   | Black and White British   | 5.3%       |
|   | Asian and White British   | 5.3%       |

*Note:* It includes the gender, ages and ethnicity of participants. The job role they occupy as well as their years' experience since fully qualifying as a general practitioner.

ST1: General Practice Speciality Training year 1.

ST2: General Practice Speciality Training year 2.

ST3: General Practice Speciality Training year 3.

ACF: General Practice training forms part of an Academic Clinical Fellowship (ACF). The ACF Programme is a national initiative offering specialist training to those who can demonstrate that they have outstanding potential for development as a clinical academic.

GPs were recruited from two sources: (a) general practices in London and (b) an academic primary care department. We approached known contacts of the research team using snowballing methods to identify additional participants. Recruitment of participants and interviews continued until no new ideas were generated from interviews (i.e., data saturation) (Glaser & Strauss, 2017).

### 2.2.1 | Inclusion criteria

- Qualified GPs OR on the UK GP training programme (GP-trainee).

### 2.2.2 | Exclusion criteria

- Foundation year doctors (The UKs mandatory 2-year training programme for newly qualified doctors).
- Long-term non-practicing/retired GPs.

## 2.3 | Procedure

General practices were identified from a list of teaching sites for a university primary care department. The research was presented at practice meetings. Nominated site leads were asked to distribute study information sheets. Willing participants contacted the research team directly to arrange participation. Additional participants known to the research team or identified via snowballing methods were contacted directly by the research team or referee. Eligibility was confirmed with interested participants, a convenient interview location and time arranged. Written informed consent was obtained before data collection. No participants dropped out; three GPs failed to respond.

The face-to-face interviews were conducted within the research department or at the GP's own practice. One interview was performed over Skype. For time purposes, two participants interviewed together, no other participants requested this. No interviews needed repeating. The topic guide—pilot tested in two interviews—was revised following research team discussions. Interviews ranged from 22 to 97 min, conducted between 01/2018 and 10/2019 by a female medical student (KW) trained in qualitative research methods. Participants were informed that interviews formed a BSc project.

Ethical approval was obtained from (University College London) Research Ethics Committee (12517/001), and Health Research Authority approval was granted (240582)

## 2.4 | Analysis

Interviews were audio recorded, transcribed verbatim, supplemented by detailed field notes and analysed using thematic analysis methods (Braun & Clarke, 2006). Data collection and analysis

conducted in parallel informed an iterative development of the topic guide and data collection (Greenhalgh, 2010). Analysis adopted an inductive approach among a multidisciplinary team (MDT), generating discussions about the data and increasing the rigour (Mays & Pope, 1995). Two researchers (including the interview conductor), a psychologist and public health doctor (ND,KW,HB) read and individually coded three-transcripts. One researcher coded all remaining transcripts (KW). Regular research team meetings were held to discuss new and emerging codes, revise the coding frame and discuss overarching themes. Data were managed using NVivo (version11). To increase the understanding and construct of themes, as well as rigour, disconfirming evidence and negative cases were explored within the data (Mays & Pope, 1995).

## 3 | FINDINGS

Nineteen participants were interviewed: seven GP trainees (on the UK GP training programme), four salaried GPs, six GP partners and a commissioner (Table 1). Participants ranged from 27 to 59 years old; 63.2% were female. Time as a qualified GP ranged from 0 (GP trainees) to 31 years, with a range of ethnicities (Table 1).

Five overarching themes were derived from exploring GPs perceived difficulties, confidence and experience in delivering end-of-life care: (a) the subjective nature of defining palliative and end-of-life care; (b) importance of communication and managing expectations; (c) complexity in prescribing; (d) challenging nature of delivering end-of-life care; (e) the unclear role of primary care in palliative care:

### 3.1 | Subjective nature of defining palliative and end-of-life care

Participants varied in defining palliative and end-of-life care, and what they entailed, causing uncertainty around when to classify a patient as end-of-life and when to involve other members of the community palliative team. GPs mostly used the terms interchangeably, although some distinguished between the concepts, typically describing the type or focus of the care. It was frequently stated that palliative care was not limited to end of life, but end-of-life care was an important subsection of palliative care:

I think they're completely different, palliative care from my perspective is about symptom control of any disease at any stage...(GP14: Academic registrar: ST3)

In line with the end-of-life care definition being those expected to die within 12 months, participants sometimes discussed the term using a timeframe. However, no consensus was met on the duration, ranging upwards from a couple of weeks:

It [end-of- life care] would normally be the last... few weeks of life (GP6: Registrar: ST3).

Participants focused definitions of palliative and end-of-life care on the holistic patient-centred nature rather than specific timeframes, viewing this approach as aligning with the fundamentals of general practice. At the core of this was identifying and meeting the individuals' preferences, considering their not only medical but also psychological and social needs. GPs stated the importance of family well-being as well as that of the individual:

End-of-life care...means making sure that the patients' needs...are met...everything from biological perspective, physical health, mental and psychological, social health and also the health of carers.(GP15: Registrar: ST3)

All participants stated end-of-life and palliative care were for all conditions and experienced GPs witnessed this change. However, many discussed patients with cancer remain the main beneficiaries of palliative care, specialist and generalist. Participants discussed this was because predicting prognoses was easier for cancer, enabling and supporting successful specialist palliative care referrals. Some indicated care could not be adequately delivered without advanced planning, for example, when patients enter a period of fast deterioration leaving little time to involve specialist palliative care teams:

(In cancer) there's always a bit more anticipation... of end-of-life... if you've got somebody who deteriorates quite quickly from dementia, sometimes you don't get all of that stuff in place'[...]but sometimes cancer patients actually deteriorate quite quickly, and we don't manage to get palliative care in. (GP9: Partner)

Related to this were discussions regarding guidelines and policies. Participants appreciated these tools for standardising care, making it equitable and offering GPs a framework in which to work. The Liverpool care pathway, an integrated care pathway for dying patients intended to transfer best practice from hospices to other clinical areas of care and settings (Ellershaw & Wilkinson, 2003), was frequently discussed as an example. It was viewed as useful by participants despite issues surrounding its eradication in 2014 following mounting criticism and a national review (Clark & Seymour, 2018). Where local schemes for improving end-of-life care existed, these were viewed favourably. Some participants felt current guidance was poor and lacked clarity. There was minimal discussion of the Gold Standard Framework (GSF), despite it being a practical and systematic, evidence based approach to improving end-of-life care that has gained popularity as a tool for community end-of-life care providers (The Gold Standards Framework, 2019):

I think it doesn't help there's no national guidelines, I think that's one thing where we had the Liverpool Pathway...and now the guidance is very wishy-washy and patient-centred but there's no...'you should give this'...that makes it harder because then it becomes a decision that the GP has to make to vulnerable

patients family members. (GP14: Academic registrar: ST3)

### 3.2 | Importance of communication and managing expectations

All GPs respected patient's preferences doing everything possible to fulfil these, including keeping patients at home. Some struggled with managing families' expectations and explaining the patient's condition and prognosis:

I think the hardest thing of all is communication, it's talking to patients and understanding and getting them on the same wavelength. (GP14: Academic registrar: ST3)

The process of ACP was seen to be left until GPs felt patients were end of life. Uncertainty in when end of life began appeared to make starting these preparations difficult. This included ACP, cardiopulmonary resuscitation discussions and knowing when to offer the range of patient-services available. This was viewed as easier to conduct for cancer, due to the predictability of deterioration, than for other chronic conditions. However, GPs discussed leaving ACP discussions until late stages left them unprepared when patients deteriorate quickly, despite the cause of death:

(In hospital) we're not doing anything that can't be done at home...you just think 'what a waste, what a shame', you don't want it, the patients don't want it, yet, we can't get things in place or sorted out because it didn't happen in advance'(GP14: Academic registrar: ST3)

There was the opinion that these were challenging aspects of healthcare and communication which, when faced with the barriers of time-restraints and high workload, the importance of the discussion was sometimes overlooked:

when you're busy you're rushed, you don't have time, do you really want to go and have a difficult conversation with this person's family about how they want to die and what medicines they want and DNARs (GP14: Academic registrar: ST3)

Conversations about end of life were seen to be affected by the willingness of the patient and family to engage in discussions and their approach to their health, as well as the willingness of professionals, influenced by a perceived culture within healthcare about death and dying:

he was really pragmatic...I had the conversation about end-of-life, they're really hard conversations, but he [patient] made it easy (GP13: Partner)

one of the most challenging aspects [conversations about death and dying]... just skirting around the issue of prognosis... that they're actually dying.(GP15: Registrar: ST3)

However, hospital deaths due to cancer were often viewed as unchangeable events, precipitated by patient's families during times of crisis, due to complex end-of-life malignant symptoms. This appeared to suggest a lack of control over care. Despite good end-of-life communication and ACP, these were viewed as inevitable:

I think it's family... we do what we think's in the patient's best interest but actually have no control over how the family feel... how anxious they are... if they feel that at the end of the day it's best for the patient to die in a hospital setting then they will, they will make that call at the end.(GP9: Partner)

Some discussed the need for 'realistic', honest conversations with families about all aspects of end of life and managing their expectations, not limited to cancer. GPs views on nutrition and hydration often differed to the lay public, with difficulties in conveying to families the appropriateness of simple oral care at end-of-life. However, uncertainty over what symptoms they may experience and when to have these discussions created difficulties:

Giving food and giving fluids, we're treating... the carers worry rather than the patients... that's about communication (GP14: Academic registrar: ST3)

GP: You wouldn't sit down with someone and say actually you know 'it gets really mucky, you'll have to wipe diarrhoea of the side of the chair... you don't have those really frank conversations

Interviewer: do you think that's something that needs to change?...

GP: Would anyone want to do it?...I think there needs to be... better education[for family]about what's expected... But I don't know how or when you'd do that. (GP13 :Partner)

### 3.3 | Complexity in prescribing

Many expressed lacking confidence and caution surrounding end-of-life prescribing. Whilst other symptoms such as terminal agitation were occasionally highlighted, participants mostly discussed cancer pain management. This was much more pronounced among less experienced GPs. However, experienced GPs expressed double checking and gaining advice from other MDT members:

(the most challenging aspect of end-of-life care) drugs, like analgesia and knowing what to give them and how much.(GP3: Registrar: ST3)

I'm not very experienced in end-of-life... medicines... the doses need careful titration; you have to be very meticulous... because they are potentially very harmful drugs.(GP6: Registrar: ST3)

Less experienced GPs attributed minimal experience as the causative factor for lacking confidence in prescribing. However, more experienced GPs attributed fear in pain management to a historical remnant from the Harold Shipman era, something not discussed by less experienced GPs (Baker, 2004). Those who felt knowledgeable and were more experienced described the need to maintain safety, but that GPs tend to be overly cautious, particularly with pain management:

After Harold Shipman...GPs became more anxious about using opioids, we used to be very confident with the...(doctrine of double effect)...after Harold Shipman people got more worried about...the rules and regulations...in the earlier days if somebody was really struggling in pain we wouldn't hesitate to relieve that pain.(GP5: Partner)

When prescribing, GPs were either an integrated active member of the clinical team—working closely with palliative care specialists—or appeared to be a step removed, simply signing off prescriptions for others who were better informed but unable to prescribe themselves (e.g., palliative care nurses):

in the community, the palliative care nurses...just ask us to sign things off. (GP7: Salaried GP)

### 3.4 | Challenging nature of delivering end-of-life care

The impression throughout interviews was that delivering end-of-life care is challenging, impacting on GPs feelings of confidence. Some felt other aspects of general practice were equally complex; however, the majority expressed that it was one of the most challenging subsections. It was noted that GPs generally felt end-of-life care for those with cancer was easier than for other conditions:

I don't know if it's something that I would say that I'm confident with, but you know, I'm... more comfortable with it now than I have been previously (GP15: Registrar: ST3)

I would still refer to the better judgment of the palliative care team[...] So, I probably don't feel 100% confident' (GP9: Partner)

Although not universal, older GPs, those with more years of experience and those occupying roles with more responsibility displayed more confidence in end-of-life and palliative care.

At this... practice there's a number of partners who are very... experienced and knowledgeable about this so actually they seem very confident, and so it's more sort of the trainee end where you see people that are... not so confident.(GP6: Registrar: ST3)

Education through experience and exposure was seen as the gold standard for confidence building. Whilst senior GPs reported access to education had increased across their careers, this was not in the form of 'practical' experience, which was reported as decreasing.

I suppose the hands on stuff probably, I think it's useful... to have training, but... me definitely the best way of learning is certainly hands-on, so from experience... seeing the patients, discussing options(GP6: Registrar: ST3)

The time and resources needed to ensure good end-of-life care created a high workload of patients and was seen as challenging to GPs. Cancer end of life was seen as more demanding than deaths from other chronic conditions due to the likelihood of malignant end-of-life symptoms. The nature of primary care means time restraints cause a barrier to end-of-life experience and exposure, seen as vital for confidence building and impacting this over time. This creates concern amongst GPs regarding overreferral and overreliance on palliative care teams, viewed as detrimental to end-of-life care in general practice in the future:

possibly we discuss with the palliative team too quickly... we feel a little bit uncomfortable so let's go straight to palliative care... it might be that you need a little bit of advice so next time you can deal with these situations by yourself. (GP4: Registrar: ST1)

Despite this, other members of the MDT were generally viewed positively, and negative comments focused on refusal of referrals or limited services in the minority of cases.

### 3.5 | The unclear role of general practice in end-of-life care

Throughout the interviews, a universal consensus over GPs' role in end-of-life care was absent. A clear pattern of struggling to define the remit and responsibilities was present, with the sense that delineation of tasks was unique to each MDT. Participants tended to describe their role in three ways: (a) coordinator of care—involving setting up relevant services and the care plan, acting as mediator between different healthcare teams and organising referrals; (b) supportive MDT member—less pro-active than the coordinator, offering

support to palliative care specialists when required; (c) key worker—provider of end-of-life care, leading the delivery of care, being advised and supported by the larger MDT:

1. In latter years it's more... coordinator... as the palliative care services have expanded, I'm a person who coordinates... I need to make sure that out-of-hours...and ambulance services know what's happening, correspondence with oncology is shared with everybody.(GP5: Partner)
2. A lot of the work is done by the palliative care team... they would lead the care of that patient... we would be supporting them... when it comes to that stage.(GP8: Salaried GP)
3. I think we have to do the hands-on bit... because we're kind of in charge of the care in the community.(GP1: Locum)

Despite a mixture of opinions on the role of GPs in end of life, it was generally viewed as important. Many felt end-of-life care was becoming specialised and compartmentalised, following the overall pattern of medicine. Although most were against further specialisation, a minority viewed it as the way forward. For many this focused on the benefits this entailed for the patient, viewing specialist teams as better equipped to perform care:

I think... it's such an important thing to do well and not make mistakes... I think it's better that there's a small group of people who are specialists doing it day-in-day-out than having a GP who maybe does it every few years(GP7: Salaried GP)

At a less extreme view of specialisation, some participants acknowledged that certain tasks should not and no longer are within a GPs remit. This surrounded syringe drivers, ACP and initiating or stopping treatments. Prescribing a syringe driver was seen as challenging and setting one up is now viewed as better performed by community nursing. Older GPs noted previously this was within their remit. Most GPs had never set up a syringe driver, with mixed views regarding whether participants could set one up in an emergency:

My time is better spent looking after complex patients... I guess it's an argument about resources... we don't go round changing dressings and other things so...why would you want us to set up syringe drivers? (GP14: Academic registrar: ST3)

Participants had mixed opinions on their role in ACP, discontinuing medication and end-of-life discussions. Some felt it imperative whereas others felt they had a role in this, but mostly should be organised by other teams. Patients living with cancer were viewed as having large MDTs with multiple specialists better equipped to perform these jobs. Stopping medication was particularly viewed as the oncologist's remit. Identifying when ACP should occur proved difficult relating to the problems GPs had in defining end of life. This was more challenging for non-malignant end of life:

if someone's... discharged to the community, although the GP definitely has a role there hopefully all those things (ACP) should be in place and sorted out.(GP6: Registrar: ST3)

## 4 | DISCUSSION

Participants described their experiences as challenging, along five main themes: (1) the subjective nature of defining palliative and end-of-life care; (2) importance of communication and managing expectations; (3) complexity in prescribing; (4) challenging nature of delivering end-of-life care; (5) the unclear role of primary care in palliative care. Confidence ranged among GPs delivering end-of-life care to people with cancer at home. Enablers of confidence were experience, exposure and education.

### 4.1 | Subjective nature of defining palliative and end-of-life care

The terms end-of-life care and palliative care are often confused (Hui et al., 2014; Shipman et al., 2008; Van Mechelen et al., 2013). In the current study, participants often used the terms synonymously. However, many were able to distinguish between the two. The stage of disease to which end-of-life care referred was not uniformly understood, but some participants discussed a specific timeframe, whilst palliative care had no such timeframe. All acknowledged the holistic, patient-centred approach to both palliative and end-of-life care, understanding its scope beyond cancer.

Despite this, participants often left palliative care measures (ACP and specialist palliative care referrals) until patients were end of life, preventing early involvement of specialist and primary palliative care which has been shown to improve outcomes and keep patients at home (Abernethy et al., 2013).

The delay of palliative care measures and the uncertainty of when end-of-life care begins can miss the opportunity to plan for end of life, allowing patients to 'slip through the net' and die without adequate support or medical provision. This explains why identifying patients at end-of-life was raised as an educational need for GPs (Selman et al., 2017).

### 4.2 | Importance of communication and managing expectations

Communicating with families about end-of-life care and maintaining the patients' best interests, whilst managing expectations, was a key challenge for practitioners. Due to continuity and rapport, GPs are well suited to candid discussions; however, end-of-life conversations are still perceived as difficult, despite good teaching (Miller & Dorman, 2014; Selman et al., 2017). Participants raised the need for frank discussions surrounding end-of-life symptoms but struggled

with when and who should do this, especially for malignant end of life which was often viewed as the oncologists' or specialist palliative care teams' remit. GPs should be supported in talking about end of life and the use of communication tools could enable this (Davies et al., 2019; Licqurish et al., 2019). These tools should encourage involvement of and clear communication with families and patients who should always remain part of discussions about care.

### 4.3 | Complexity in prescribing

The 2008 End-of-Life Care strategy outlined pain management as a UK priority following findings of opioid under-use at the end of life (DoH, 2008; Greco et al., 2014; The KingsFund, 2010). Yet, complexity in providing symptom control centred around pain management despite the management of other end-of-life symptoms, such as anxiety, being potentially equally complex and dangerous. This was seen even amongst more experienced GPs, conflicting with previous studies that pain-management was an area GPs had higher confidence in (Giezendanner et al., (2017) and Mitchell et al. (2018)). Opioid underprescribing was historically attributed to anxiety surrounding the Harold Shipman case (Gardiner et al., 2012). Only more experienced GPs who practiced during the Shipman era discussed these associations in this study. However, this anxiety may still exist, since pain prescribing was characterised as most challenging among less experienced participants.

Lack of experience also appeared to create fear of pain management, explaining the varied involvement seen in prescribing. Some GPs took a distant approach by prescribing for others thus deferring responsibility to those viewed as specialists. Participants discussed difficulties prescribing and setting-up syringe drivers for cancer pain, reflecting past research (Magee & Koffman, 2016; Winthereik et al., 2016). This was delegated to other MDT members, viewed as no longer the GP's responsibility. However, referral of care is not guaranteed outside of London due to UK service provision, meaning GPs must remain skilled (Mitchell et al., 2012).

### 4.4 | Challenging nature of delivering end of life care and palliative care

Factors influencing confidence and acceptance of participants role in delivering end-of-life care included training and education, as was previously identified in research (Selman et al., 2017; Winthereik et al., 2016). Participants wanted more education across all training levels for end-of-life care, also seen in other studies (Magee & Koffman, 2016; Mitchell et al., 2018). Exposure and experience in delivering end-of-life care (which participants identified as the gold-standard for learning) increased participants' confidence, yet they felt a decrease in these opportunities. This study suggests that the transfer of end-of-life care from GPs to specialist palliative, community and nursing services contributes to this lack of experience. Historically this was thought to be due to the small portion of a GP's caseload that involves end-of-life care (Mitchell, 2002).



Time restraints and the high workload associated with end-of-life patients—especially malignancy related end-of-life patients—were found to increase referrals to specialists, corroborating past research (Brazil et al., 2010; Giezendanner et al., 2017; Mitchell et al., 2012). Additionally, GPs viewed specialists as superior at facilitating seamless advanced care with better continuity, conflicting with evidence showing that GPs involvement improves outcomes and facilitates home deaths (Nakanishi et al., 2020; The KingsFund, 2018). This suggests a subconscious lack of confidence.

#### 4.5 | The unclear role of general practice in end-of-life care

Historically the coordinator role, essential to the MDT, has fallen to GPs (Mitchell, 2014; Winthereik et al., 2016); however, this study, alongside international studies, found GPs unaccepting of this role (Brazil et al., 2010; Mitchell, 2014). The main concern is over care becoming fragmented and uncoordinated as role definitions and responsibilities blur. Whilst participants viewed other members of the community palliative team positively, GPs struggled to determine which service undertook certain tasks, especially for patients with cancer.

The shift of a GP's role to that of 'supportive MDT member' is potentially positive. MDT collaboration encourages education, supportive practice and early engagement of palliative care—essential and effective at improving QoL, reducing service utilisation and enabling all patients (including those with cancer) to die at home (Mitchell, 2014; Mitchell et al., 2012). However, refusal of referrals by other services and the conflict this arises necessitates that GPs lead the community care for these patients (Johnson et al., 2020; Keane et al., 2017).

GPs must remain skilled in end-of-life care in order to meet the rising oncological demand whilst enabling patients to die in their preferred place (Gomes et al., 2012; Sleeman et al., 2019). However, if GPs are underconfident or unwilling to adopt these roles and the skills entailed, it raises concern for the provision of quality end-of-life care in primary care (Bone et al., 2017; Mitchell et al., 2019).

#### 4.6 | Implications for the research, policy and practice

The results indicate that it is not enough for policy, commissioning and services to align and better work together, but rather services need to integrate and clearly identify roles. Palliative care MDT meetings were viewed positively—these should be utilised to establish role definitions and ways of working together. This has been highlighted in the GSF (Clifford et al., 2016), largely covering the care gaps identified in this study, improving and supporting non-specialist community end-of-life care (Hansford & Meehan, 2007).

An important consideration is how to upskill and increase experience of GPs and the wider primary care team, increasing confidence.

End-of-life care will always have a place in the community, but a whole system and multidisciplinary approach with GPs is crucial. Modern medicine has increasingly specialised death, as evidenced by the reliance on specialist palliative services in the current findings. However, there is a growing trend considering how to demedicalise end-of-life care, making it more personalised, social and spiritual (Riley & Drone, 2020; Smith et al., 2018).

GPs lacked confidence within specific practical skills indicating clearer practical advice is needed. Therefore, an applied practical toolkit or guide supporting GPs decisions, such as when are end-of-life and practical elements of care may be more beneficial than producing further guidelines. The GSF has done this to some extent; however, surprisingly participants rarely discussed this. The GSF offers practical guidance including evidence-based prognostic indicators (The Gold Standards Framework, 2019). Smaller scale examples include the use of novel rules of thumb in dementia, which could be applied in cancer care (Davies et al., 2018).

We note the strong focus on pain-management in the interviews; other complex end-of-life symptoms were only briefly mentioned by participants. Future research should probe further other symptoms with GPs; in particular, many with cancer will be older people with multiple comorbidities and it is important to understand how GPs manage these patients.

#### 4.7 | Strengths and limitations

There has been minimal recent research into the GP's perspective on end-of-life care; this is one of the first UK studies to our knowledge to explore GPs experiences in-depth.

Our analysis adopted an inductive approach among an MDT, generating discussion about the data, increasing the rigour. Additionally, the study recruited participants with varying demographics and experience, including GP trainees, academics, locums, salaried GPs, GP partners and a commissioner. However, this paper focuses on GPs as key providers of community end-of-life care, yet the wider community palliative care team combines many allied health professionals. To gain a deeper understanding of generalist end-of-life care the experiences and opinions of all professionals providing, this care is required and should form the basis of future research.

### 5 | CONCLUSION

GPs viewed end-of-life care as challenging, specific difficulties included communication and pain-management. These challenges together with lacking role clarity led to ranging confidence levels, with experience and exposure seen as enablers of confidence. Consideration needs to be taken with the expansion of specialist palliative services and the implication this has on deskilling essential competencies, reducing confidence levels in GPs and in a cycle of causation, leading to further delegation of care.

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## CONFLICT OF INTEREST

The authors whose names are listed above certify that they have no affiliations with or involvement in any organisation or entity with any financial interest or non-financial interest (such as personal or professional relationships, affiliations, knowledge or beliefs) in the subject matter or materials discussed in this manuscript.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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