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The family physician's role in palliative care: views and experiences of patients with cancer

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Key messages

- Few studies report patients' perspectives of their family practitioner's (FP) palliative care role.
- This interview study explored cancer patients' experiences of FP palliative care.
- Patients want a better balance of family practice accessibility and continuity.
- Challenges facing UK primary care are relevant to other international systems.
- Further research is required to improve continuity in primary palliative care.

Abstract

Background

Family physicians (FPs) are a vital component of palliative care, given their generalist expertise, relationships with patients, and knowledge of community services. Little is known about how patients understand their FP's role in palliative care.

Aims

This study aimed to explore patients' views and experiences of:

1. The FP's role in providing palliative care to patients with cancer
2. The facilitators and barriers to the FP's ability to fulfil this perceived role

Methods

Qualitative data were obtained through semi-structured interviews with adults with a cancer diagnosis known to an inner-city hospice in England. Thematic and discourse analysis were undertaken.

Results

Fifteen participants reported their perceptions of the FP's role in palliative care: prescription management; home visits; care coordination; and emotional support. Observed facilitators and barriers to good FP palliative care were identified: accessibility to FP; continuity of care; FP's attitude and interpersonal skills; time and staffing levels; FP's involvement in diagnosis; and communication between primary and secondary care.

Conclusion

Accessibility and continuity were highlighted as key challenges within FP palliative care. The broadening responsibilities and competitive pressures facing FPs may undermine their capacity to effectively deliver palliative care. Further research needs to clearly define the respective roles of the FP and the specialist in palliative care delivery, so as to determine optimal models of FP palliative care provision in terms of accessibility and continuity.

MeSH keywords

Palliative Care; Cancer; Primary Health Care; Primary Care; Physicians, General Practice; Physicians, Family

Background

Few studies report service users' perspectives of their family physician's (FP's) palliative care role, however significant research has been undertaken from the professional viewpoint.

(1) It is recognised that patients' views are a key component of service evaluation, (2) and an important research priority to improve FP palliative care provision at a time when the organisation of family practice is evolving. (3)

The traditional perception of the FP in many settings is a doctor embedded in the community, always accessible and familiar to their patients. (4) Previous research suggests that patients with palliative care needs particularly value both accessibility and continuity in their FP. (5, 6) However, the changes to the structure of UK family practice over the past decades have hindered the capacity of FPs' to meet patients' needs and expectations. (5, 6)

In the context of this UK-based study, a family practice with 10000 patients experiences about 100 deaths each year, or 20 deaths for each full-time equivalent FP. (7) Palliative care is therefore high on FPs' agendas, particularly given that the majority of such care is provided by generalists. (1, 8, 9) The current literature highlights that FPs are considered well equipped to provide palliative care due to the breadth of their responsibility, their capacity to develop on-going relationships with patients and families, and their ability to coordinate healthcare resources and to visit patients at home. (10, 11)

This qualitative study explores patients' views and experiences of the current role of FPs in palliative care. Perceived barriers and facilitators to the effective delivery of palliative care by FPs were identified. The terms 'family physician' and 'family practice' will be used throughout and are to be considered synonymous with the terms 'general practitioner', 'primary care physician', and 'primary care' and 'general practice'.

Aims

To explore patients' views and experiences of:

1. The role of the FP in providing palliative care to adult patients with cancer
2. The facilitators and barriers to the FP's ability to fulfil this perceived role

Methods

Patients' perceptions of palliative care provided by their FPs were obtained through audio-recorded face-to-face semi-structured interviews between December 2017 and June 2018.

Sociodemographic data were also collected. The interview topic guide and study documents were developed in alignment with the study aims; current literature; (10, 12, 13) discussions with two public and patient involvement (PPI) groups; two palliative care consultants independent of the project; and the team's clinical and research experience. (*Table 1*)

Participants within the two PPI groups (n=11) provided insight regarding personal experience relating to the project aims, study design and ethical considerations.

[Table 1: Interview topic guide]

Setting and Recruitment

Adult patients with cancer known to an inner-city hospice in England were approached by their clinical care team, provided with written study information and asked whether they would agree to be contacted by EC to discuss participation. Inclusion criteria comprised adult patients with a cancer diagnosis that were known to the hospice (attending the day unit, respite ward or being visited at home) and able to understand and communicate in written and spoken English.

This inner-city hospice setting permitted access to a diverse patient group. Purposive sampling ensured participants varied in terms of socio-demographic characteristics, cancer diagnosis and FP experience. (14) Recruitment was stopped when no new data emerged. (15)

Due to the indirect recruitment process via a large multidisciplinary team, sociodemographic comparison of those who declined to take part with those who consented was therefore not possible.

Data analysis

EC conducted, transcribed, anonymised and uploaded the interviews to NVivo 10 (computer software programme for qualitative data analysis). (16) The content of patients' experiences was analysed using the thematic principles of Framework Analysis (*what* participants stated). (17) The six stages of analysis were employed. (18) The final analytical three-staged framework consisted of three key themes with 10 sub-themes and 18 separate codes. As data collection progressed, it became clear that also applying discourse analysis (*how* participants talked about their experiences) would add depth to findings and identify particular phenomena that could otherwise be overlooked. (19-25) EC applied discourse analysis to the data after all themes relating to content had been identified.

Data validation

Data from three initial interviews (included in the main study) were read and coded independently by EC, HL and PW. Subsequent discussion resulted in minor amendments to the interview structure and the phrasing of certain questions. For example, the project aims were repeated at the close of the interview to capture further comments from each participant. The plausibility of the data was assessed, and preliminary findings aligned to the study objectives. Balanced reporting of data is a recognised validation strategy in qualitative research. (26) We have therefore presented positive, negative and ambivalent participant experiences.

Results

Fifteen adults with cancer were interviewed at their preferred location: participant's home (n=9); hospice day unit (n=2); or hospice respite ward (n=4). (*Table 2*) Interviews lasted on average 37 minutes. The total duration of all interview data was 8 hours 43 minutes.

[Table 2: Demographic participant information]

Key themes and sub-themes

Emergent individual codes were grouped into sub-themes and finally categorised into three key themes according to the project aims: (1) the FP's perceived role in palliative care provision; and (2) the facilitators and barriers to the fulfilment of this role. (*Table 3*)

[Table 3: Key themes]

FP's role in palliative care provision

Home visits

Home visits were a commonly discussed element of the FP's role from two contrasting perspectives. Firstly, some participants expressed frustration that home visits now seem

unattainable and perceived that FPs formerly offered this service routinely. They considered that home visits should remain a key aspect of the FP's role.

'The FP used to... routinely visit patients at home, didn't they? They [FPs] don't ever have that anymore...' [Participant 6, female, 69]

'Even if you've finished your surgery time, you should be able to make room to go and see one of your patients who can't come and see you. I think that is your responsibility as an FP.'
[Participant 11, male, 58]

Secondly, others described being regularly visited at home due to their sociodemographic and medical needs.

'He [FP] came here, to see my husband, because we, we get visits, because of our age, they come to us... I know it's only over the road, but their argument is, we're in our 80s, and you've got to cross a busy road, so they see us here.' [Participant 7, female, 86]

One participant found her current situation ironic given the difficulty she had experienced accessing her FP prior to her cancer diagnosis. She expressed ambivalence towards home visits.

'I got a phone call saying, "the doctor's coming to see you", I said "what for?"... He [FP] said, "this is what I'm going to do now, once a fortnight, I'll come and see you"... You spend your lifetime trying to get an appointment at the surgery then all of a sudden, they're [FP] on your doorstep wanting to see you! I can't believe it. What for?!' [Participant 3, female, 80]

Care coordination

Participants considered arranging referrals to specialist services a key component of the FP's role, and indirectly appeared to depreciate the FP's clinical ability.

'He's an FP, he's there to refer, really, isn't that the role of the FP, to refer you to people who know a bit more? The hospital of course has all the equipment. And he can only refer as far as I can see...'

[Participant 3, female 80]

Many perceived the hospice or hospital team to coordinate their care and meet their needs to a greater extent than the FP. Participants discussed this with a degree of resentment towards their FP.

'Most things come from the hospital, not my FP, my FP is in the background when they should be right up the front... Your FP is responsible for your general health... You go to hospital, they do what they have to do to you, and they report back to your FP, your FP's supposed to take it from there.' [Participant 11, male, 58]

All but one of the participants had been referred to their local hospice palliative care team by a member of their oncology team.

'No, it was a nurse, at the hospital, that referred me to the hospice.' [Participant 4, female, 48]

Some participants felt the burden of responsibility for their own care coordination, given their perceived lack of support from their FP.

'Every time I see the oncologist, they send a report for me... and another one for my FP. But I always make sure I carry my report when I go to my FP. Because, when I reach there [FP practice], I don't know if they [FP] are lazy to read what is in the system [practice computer system], how, how, they [FPs] don't even notice that I have changed chemo already...they don't know.' [Participant 4, female, 48]

Prescription management

All participants discussed their FP's involvement in prescribing medication, which was frequently reported as the FPs' sole role in palliative care.

'No, I don't go to them [FPs] at all really, and if I went... my commerce with them would be merely, renewal of prescriptions.' [Participant 2, female, 83]

Further, participants said that their FP was advised on what to prescribe by a specialist (hospital or hospice). Interviewees seemed to devalue their FP by suggesting that they are not responsible for clinical decision-making, but rather for the administrative task of ensuring the prescription reaches the local pharmacy. Some spoke disparagingly of their FP and seemed to have little confidence in their competence. One participant implied that their FP perhaps did not need to be involved in their care.

'That's where the hospice is making the decisions [about medication] because I think that's the palliative care thing. Erm... so, I haven't really spoke to the FP about it... Perhaps he [FP] shouldn't be involved, but he's the one I have to get the drugs through.' [Participant 12, female, 72]

Emotional support

Participants placed importance on their FP's role in providing emotional support.

'Just the emotional support, that you hope for from an FP when they haven't got anything [treatment] to offer you.' [Participant 8, male, 70]

However, some reflected disparagingly that FPs did not seek to address emotional needs such as ascertaining end of life care preferences.

'Well... they [FPs] don't ask, do they? So, a phone call now and again, would have been nice.' [Participant 14, male, 83]

Perceived facilitators to FPs providing palliative care

Flexibility with time

Some participants stated that their FP was flexible, tailoring the consultation time to their needs.

'No, if I go in and wish 2 minutes... we [FP and patient] talk for 2 minutes, and if it's half an hour or whatever, we talk... All doctors are flexible.' [Participant 5, male, 70]

Accessible/available FP

Participants considered their FP to be readily accessible and available, highlighting flexibility as a key facilitator to an effective doctor-patient relationship.

'I went there [FP practice] one Saturday, I didn't even have an appointment. I went to make one, and she [FP] was in the reception, and... she said, "Mr X!" ... "I glad you're here... I really want to talk to you". I said, "do you want me to make an appointment?" She said, "come, come" and we sit down, and we talk for about 15, 20 minutes.' [Participant 5, male, 70]

Effective communication between primary and secondary care

Participants spoke highly of the communication from secondary to primary care and reported receiving clinic letters. Some assumed, and some knew for a fact, that their FP was also receiving them.

'When the FP, well they [FPs] did know about it because you know, the hospital sent everything through... If I take a scan at the hospital, my FP get a letter about it. They [FPs] know everything that's going on, yeah.' [Participant 5, male, 70]

FP's involvement in timely cancer diagnosis

Some participants spoke highly of their FP's involvement in diagnosis and felt that they had acted quickly and appropriately.

'He [FP] knew something wasn't right... The pain in the back he didn't like that. He [FP] tried to do it as quick and fast as he could.' [Participant 7, female, 86]

FP's attitude and interpersonal skills

Many participants spoke favourably of their FP's attitude, placing emphasis on this above all attributes they considered necessary in a 'good doctor'.

'She was a nice FP, really, erm... but... empathy and insightfulness is what you are looking for in an FP...is, very valuable, and very hard to find... Character... Very much so.'

[Participant 8, male, 70]

Participants seemed to value when their FP exposed their 'human' side and perceived having a close doctor-patient relationship if their FP had opened up about their personal experience.

'He [FP] has got some experience, because his father died of cancer, only a couple of years ago... He might be more sympathetic.' [Participant 9, female, 84]

One participant valued an FP's interpersonal skills over continuity. She advised that she would be happy to see different FPs as long as they were respectful. She held the pragmatic perspective that she would not always be able to access the same doctor.

'If people [FPs] are nice and treat me with respect, I could see a different one, [FP] it doesn't matter, because you can't cling to one, and he [FP] might have work to do, or he's not well his self... We don't know if he's on duty or not, he might be at home, you can't get him if he's at home!' [Participant 7, female, 86]

Perceived barriers to FPs providing palliative care

Lack of time/short-staffing

Some participants viewed FPs as being target-driven and inflexible. They reported feeling rushed to express their concerns, which appeared to tarnish the doctor-patient relationship.

'Yeah, they [FPs] just want to rush. Because they say... "there is not time in the system", because they can't give more than... 10 minutes... you have to rush.' [Participant 4, female, 48]

Many participants considered short-staffing as a result of changes in the NHS to be responsible for FPs being unable to spend sufficient time with patients. They spoke with nostalgia of the health system 'how it was'.

'The system [NHS] is... overwhelmed, they've [government] changed everything, put them [FPs] under more pressure... they [FPs] never have enough time, because we don't have enough of them [FPs]... Being honest, the system [NHS] needs to go back to how it was, not have all these cuts...' [Participant 11, male, 58]

Inaccessible/unavailable FP

The challenge of negotiating the complex appointment system was mentioned by numerous participants. They referred, with great frustration, to the apparent rigidity of the booking system and the stringent adherence of reception staff to practice rules and regulations.

'You go to the FP clinic in the morning, and you queue up... I was the first one in the doctor's surgery... the receptionist said, "no, there's no appointments"... as if she was telling me, "nobody's going to see you."' [Participant 15, female, 66]

Lack of continuity with named FP

Most expressed dissatisfaction and frustration that they did not have continuity with a particular FP. Participants reported feeling anonymous and isolated from their FP. Some perceived continuity of care to be an outdated, unachievable concept within the current NHS.

'Every time I go [to the FP practice] there's a different FP you see, you know... 9 out of 10 times you go it's a different one. No consistency.' [Participant 10, male, 78]

'Back in the days, your FP knew your whole family. Nowadays, like, your FP doesn't really know you, they only know you by computer, they know your name, they don't know who your mum is, they don't know who your sister is.' [Participant 11, male, 58]

Some felt more able to develop a relationship with their oncologist or surgeon than their FP, as they were allocated to a particular consultant who had accompanied them through their treatment.

'My surgeons went through it from the beginning with me, so when I go to the hospital... they know what I've been through, it's easier to talk to them, what you're feeling, alright they're surgeons... they won't know exactly what to say, but they will know, the medical skill behind it. And being part of being the surgical team, you have a closer feeling, a closer bond with them.' [Participant 11, male, 58]

Many reported that most FPs at their practice work part-time, which they felt resulted in fragmented care and compromised relational continuity. They reflected on the apparent

change over the past few decades, and perceived that the staff structure had previously consisted of mostly full-time FPs.

'The FP came that I'd never seen or heard of before, apparently he's only there two days a week... I think there used to be four [FPs] there all the time, but I don't know what's happened to them.' [Participant 1, female, 89]

'I start going there [to FP practice], I think it was 1996... we used to have one doctor [FP] allocated to us. So, it was good, at that time... But they [FPs] change, and now, they say, "no, you just have to see the one [FP] that is available".' [Participant 4, female, 48]

However, one participant held a divergent view about continuity. She had seen one FP frequently for a year before her eventual diagnosis in Accident & Emergency (A&E), and reporting feeling that he was 'fed up' with her. She discussed the potential adverse effects of relational continuity and suggested that the fresh perspective of a new clinician may have expedited her diagnosis.

'My FP said, "I've done all the scans for you... what do you want me to do, woman?" Maybe he was just a little bit tired of me, coming there... wanting him to do something for me... After he said that, I just never wanted to go to see him, for anything. So, I was diagnosed in A&E, in the hospital.' [Participant 15, female, 66]

FP's lack of knowledge

Some participants perceived FPs as having limited cancer-related knowledge due to their broad and copious workload. They considered the hospice staff, or their oncologist, to have

more relevant experience and therefore considered them better placed to meet their needs. A perceived lack of continuity with their FP seemed to strengthen this stance.

'Well he's [FP] got more to do. He's got other things to do. And X [palliative care specialist nurse] is more or less confined to the hospice, where everybody in there is at death's doorstep... she's got that, critical end of life situation, that she's familiar with.' [Participant 3, female, 80]

'The oncologist, because, he knows, your problem, your cancer... so they [oncology team] are used to dealing with this. Yeah. And now, the FP... sometimes when I go to the FP, he doesn't even know [about current treatment]. I have to explain myself [about current treatment] every time I go to the FP.' [Participant 4, female, 48]

FP's involvement in delayed cancer diagnosis

Some perceived their FP to have delayed their cancer diagnosis by not referring them to a specialist in a timely manner.

'She [FP] said I'd got an infection in the water, she gave me antibiotics... She did that, five times. She should... have done more... you can imagine, the length of time that all took. Eventually, she said to me, "I think I'd better refer you". So... she sent me to a doctor, [urologist] that only um, dealt with prostate cancer, so I had to go back to her again, for another letter for a different doctor...' [Participant 1, female, 89]

FP's lack of proactivity

Some interviewees reported that their FPs had never checked how they were managing following their cancer diagnosis.

'They don't ask, do they? I don't even know if they know I'm here. They haven't contacted, no. They should be following me up all the time. Once I went from the hospital to the hospice, they should be making enquiries, "how's he getting on?" all that business, but I don't think that's happening.' [Participant 14, male, 83]

Others expressed disappointment that their FP did not make contact after having received their clinic letters. As a result, some felt isolated and unsure of their FP's role.

'The hospital sent letters... Well, whatever we [oncologist and patient] discuss, it goes to me FP, and it states... "We [oncology team] are referring Mr X back into your [FP's] care, we would be grateful if you could give him some strong laxatives and some strong painkillers". Of course, nobody [FP] got in touch with me until 7 months later!' [Participant 13, male, 66]

Uncertainty of the FP's role in palliative care

Some participants expressed uncertainty about their FP's role, particularly given the substantial support they received from the hospice and other teams.

'You don't know who to turn to, because you're not really under your FP, because you don't know at what point you're under your FP at... I don't know what the role of my FP is... I really don't know what one expects out of one's doctors... there's nothing continuous

anywhere, it each has to go through its own department... It's difficult when you've got the hospice and the doctors' [FP] surgery. ' [Participant 12, female, 72]

Limited/varied patient understanding of palliative care

Understanding of palliative care varied, however the common impression among participants was that palliative care is predominantly concerned with medicating physical symptoms.

'Painkillers would come under palliative I'd imagine...' [Participant 2, female, 83]

Some expressed complete uncertainty as to what palliative care constitutes.

'Honest to God I don't know! I hear them talk about this thing [palliative care], but sure, I really do not know.' [Participant 5, male, 70]

Some thought that palliative care should only be provided by specialists.

'I think the hospice should do this [provide palliative care], because, in the eyes of joe public, this is what the hospice is all about... looking after people who are on the point of dying, and making sure that their last few hours, or days, is as smooth as possible.' [Participant 14, male, 83]

One participant reflected on the finality of the term 'palliative care'. She considered it a potential barrier, which may deter patients from seeking help for their palliative needs.

'It doesn't give you hope if you think that's what you're going in to.' [Participant 12, female, 72]

Such misconceptions appeared to be a significant obstacle to patients requesting or expecting support for holistic needs from their FP.

Discussion

Main findings of the study

This study explored service users' views of FP palliative care. Key aspects of the FP's role were identified: prescription management; home visits; care coordination; and emotional support. The perceived facilitators and barriers to such roles appeared to influence participants' health-seeking behaviours and observed outcomes. Barriers were highlighted by participants to a much greater extent than facilitators. However, many factors had the potential to be perceived as both a barrier and a facilitator, and the patient's interpretation seemed heavily based on the particular FP's attributes and attitude. For example, some participants viewed FPs as being too busy and felt rushed, whereas others stated that FPs were able to be flexible, tailoring consultation time to patient need. Participants often spoke negatively about their experiences, particularly in relation to issues of power. For instance, some expressed frustration and a sense of lack of control as a result of government-led FP contractual changes. Discourse analysis therefore provided valuable insight as to how decisions made at governmental level are experienced by service users.

Findings from this study are consistent only in part with prior research. The current literature suggests that service users consider FPs well-placed to provide palliative care due to their ability to undertake home visits; the scope of their clinical responsibility; capacity to develop

continuing relationships with patients and families; and central role in coordinating healthcare resources. (10, 11) However, many participants in this study considered maintaining a relationship with a particular FP impossible within the current model of family practice and often perceived home visits as unattainable. Moreover, many felt uncertain of their FP's role, and viewed it as primarily administrative.

Strengths and limitations of the study

This study adopted a qualitative approach; consistent with the majority of existing evidence. (10) Interviews provided first-hand, in-depth descriptions of a diverse inner-city population's views and experiences of the FP's role in palliative care. Findings from a single qualitative interview study are not generalisable. Further studies are required to strengthen the knowledge base and inform future practice and policy.

Participants were all known to a hospice palliative care team. This sampling approach was chosen given the difficulty in defining and identifying patients with palliative care needs. (27) Participants may have considered their FP's role in palliative care delivery as minimal, given their involvement with the hospice. Recruitment from family practices may have yielded unbiased, but less varied, data. All participants had a cancer diagnosis, so care variation between those with malignant and non-malignant conditions was not discussed. (28)

At the time of data collection, EC was an academic FP trainee (not working clinically in the recruitment area). Participants were made aware of her role in clinical practice and her non-clinical role in this research context. (29) EC's varied experience of family practice, proactive interest in palliative care research, and personal perspective that FPs need to be involved in palliative care delivery, were considered when collecting and analysing data.

What this study adds

FPs are traditionally considered familiar and accessible to patients. (4) Idealistic FP palliative care would possess the exact balance of accessibility and continuity; the two main challenges highlighted in the current literature (5, 30) and the findings from this study. Some participants acknowledged the limited continuity of the FP-patient relationship and reported receiving isolated episodes of care. Some reflected that they often had to choose between waiting to see their preferred FP or quickly accessing an alternative, less sought-after FP.

Existing international literature suggests that continuity of care reduces mortality, increases patient satisfaction and medication compliance and decreases hospital use. (31-35) However, the current family practice model in England hinders relational and informational continuity. For instance, there are both an insufficient number of FPs, and a higher proportion with increasingly diverse working patterns. (36) Out-of-hours care is no longer the responsibility of individual Family Practices; having round the clock access to one's own FP ended with the 2004 UK GP (General Practice) contract. (4, 5) The appropriate sharing of patients' preferences between electronic patient record systems remains a significant difficulty, particularly given that an increasing number of healthcare professionals are involved in a patient's care. (5)

The broadening roles and responsibilities of FPs, and the competitive pressures they face, may undermine their accessibility to patients with palliative care needs. Factors such as the uncertainty surrounding the FP's role and frustration with negotiating complex systems, as expressed by patients in this study, are likely to be a direct result of recent contractual changes and clearly hinder effective FP palliative care. To contextualise such study findings; the fragmented UK NHS has undergone significant change since its conception. (4) Prior to the introduction of the Family Doctor Charter in 1966, patients viewed family practice as

solely constituting their individual FP. The Charter resulted in the development of multidisciplinary teams within larger, more complex practices. For example, reception staff now facilitate structured appointment systems; the roles of nurses and other practice staff continue to expand; and FPs increasingly focus on non-clinical work such as training, administration and commissioning. (4, 37) Alternative access points such as FP Hubs allocate services to members of the family practice team other than the FP. (4, 37) Also, patient choice is diversifying via ‘any willing provider’ contracts, facilitating competition with independent sectors. (4, 37)

Though this study was conducted in the UK, it is likely to have application in many different settings where palliative care is dominated by specialists and family practice risks being sidelined. (38, 39) What were once seen as key FP responsibilities may increasingly be considered the territory of palliative care, a speciality that has grown progressively over the last fifty years. (38, 39) Some study participants deemed their FP redundant in palliative care provision. For example, they considered their FP’s duty to lay solely in prescription administration and regarded their specialists as responsible for clinical decision-making. This has been reported in previous research among patients with both palliative and chronic conditions. (10, 38) Participants in this study were all known to a hospice, though the help they reported valuing from their hospice team did not fall under the remit of specialist palliative care. Furthermore, the hospice involvement may have affected the FP’s reactivity, as they may have assumed the hospice were managing their patient’s needs. Supporting FPs to resume their central role in palliative care could relieve pressure on specialist resources. A joint venture by the RCGP and Marie Curie entitled the ‘Daffodil Standards’ is currently being piloted at selected UK family practices. It aims to embed FPs firmly in the centre of a community approach to improve the quality of palliative care. (39)

The quality of palliative and end of life care is considered ‘a measure of society as a whole’ and ‘a litmus test for health and social care services’. (9) It is therefore important to all stakeholders that we get this right. Rather than being a negative reflection on current family practice, could this be a spotlight on the priorities of people with palliative care needs? Given the notably altered structure and expectations of family practice, what is a contemporary realistic model of continuous and accessible care? Continued research is crucial to influence future practice and policy development, and support a more tailored, patient-centred approach to service design and delivery of FP palliative care.

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Competing interests

Nothing to declare.

Contributions

EC: study design, patient and public involvement, data collection, transcription, data analysis, manuscript writing, submission to journal

HL: support with study design and ethical approval process, supervision of data analysis, manuscript editing

PW: overall study supervision, manuscript editing

JN: recruitment coordination, manuscript comments

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Approval

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Table 1: Interview topic guide

Participant's illness experience

- ✓ Cancer journey (from diagnosis to current)
- ✓ Understanding of palliative care
- ✓ Current palliative care needs

Participant's GP experience

- ✓ Practice attributes
- ✓ Relationship with named GP/other GPs
- ✓ GP involvement in cancer/palliative care
- ✓ Involvement of other services/healthcare professionals and the perceived interdisciplinary communication

Participant's thoughts on an ideal GP-patient relationship in the palliative care context

- ✓ GP's role in providing palliative care
- ✓ Facilitators to good GP palliative care
- ✓ Barriers to good GP palliative care

Table 2: Demographic participant information

<i>Participant</i>	<i>Age</i>	<i>Gender</i>	<i>Diagnosis</i>	<i>Ethnicity</i>	<i>Living arrangements</i>	<i>Partnership status</i>	<i>Interview location</i>
1	89	Female	Metastatic bladder cancer	White British	Lives alone	Widowed	Hospice respite ward
2	83	Female	Colorectal, breast and ovarian cancer	White Irish	Lives with friends	Single	Home
3	80	Female	Metastatic breast cancer	White British	Lives alone	Divorced	Home
4	48	Female	Metastatic breast cancer	Black African	Lives with sibling	Single	Hospice respite ward
5	70	Male	Metastatic gastric cancer	Black Afro-Caribbean	Lives with spouse	Married	Hospice day unit
6	69	Female	Metastatic atrial sarcoma	White British	Lives with spouse	Married	Hospice day unit
7	86	Female	Metastatic lung cancer	White British	Lives with spouse	Married	Home
8	70	Male	Metastatic lung cancer	White British	Lives alone	Widowed	Home
9	84	Female	Colorectal cancer	White European	Lives alone	Widowed	Home
10	78	Male	Metastatic prostate cancer	Black Caribbean	Lives with son	Widowed	Home
11	58	Male	Bladder cancer	Black Afro-Caribbean	Lives with spouse	Married	Home
12	72	Female	Metastatic pancreatic cancer	White British	Lives with spouse	Married	Home
13	66	Male	Metastatic colorectal cancer	White British	Lives alone	Single	Hospice respite ward
14	83	Male	Metastatic pancreatic cancer	White British	Lives alone	Widowed	Hospice respite ward
15	66	Female	Metastatic pancreatic cancer	Black Afro-Caribbean	Lives alone	Divorced	Home

Table 3: Key themes

<i>Key themes</i>	<i>Sub-themes</i>	<i>Individual codes</i>
FP's perceived role in palliative care provision	Organisational factors	Home visits
	Clinical factors	Care coordination
	Human factors	Prescription management
Perceived facilitators to FP provision of palliative care	Organisational factors	Emotional support
		Flexibility with time
		Accessible/available FP
		Effective communication between primary and secondary care
Perceived barriers to FP provision of palliative care	Clinical factors	FP's involvement in timely cancer diagnosis
	Human factors	FP's attitude and interpersonal skills
	Organisational factors	Lack of time/short-staffing
		Inaccessible/unavailable FP
		Lack of continuity with named FP
	Clinical factors	FP's lack of knowledge
		FP's involvement in delayed cancer diagnosis
	Human factors	FP's lack of proactivity
	Patient understanding	Uncertainty of the FP's role in palliative care
		Limited/varied patient understanding of palliative care