

Rethinking continuity in general practice for people with incurable illness:

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Abstract

Background

People with terminal diagnoses often derive substantial benefit from continuity of care, a core function of primary care that is also central to high-quality palliative care. Malignant mesothelioma is an incurable cancer caused by asbestos exposure, yet little research has examined how individuals with this condition experience continuity within general practice or how primary care contributes to their palliative needs.

Aim

Using malignant mesothelioma as a lens, this study explored how people living with, or caring for those with, this condition experience continuity in UK general practice, and examined the work required to navigate the healthcare system during a life-limiting illness.

Methods

Longitudinal qualitative interviews were conducted with patients, close persons, and healthcare professionals, generating case studies analysed using reflexive thematic analysis and the Candidacy Framework. Five individuals contributed in a patient and public involvement capacity.

Findings:

Fifty-four interviews formed nine case studies centred on individual patients. Three themes emerged: (1) people with mesothelioma benefit from the generalist, relationship-based care provided by GPs, which often functions as a form of primary palliative care; (2) patients experience distressing uncertainty when navigating a fragmented healthcare system, highlighting gaps in coordination between primary and specialist palliative services; and (3) continuity should be reframed as essential to supporting people with incurable illness, rather than an optional enhancement.

Conclusion

Participants described the intense burden of living with an incurable disease and emphasised that feeling expected, known, and supported within primary care can reduce suffering. These findings underscore the importance of continuity as a mechanism that bridges primary and palliative care, offering relational, informational, and management support across the illness trajectory. Although focused on mesothelioma in the UK, the implications extend to other populations with serious or rare conditions internationally, reinforcing the need for integrated, patient-centred models of care.

Background

Continuity of care is typically defined as *“the extent to which a person experiences an ongoing relationship with a clinician and the coordinated clinical care that progresses smoothly as the patient moves between different parts of the health service”*. (1)(p5) International variation in the provision of continuity in general practice reflects differences in the structure and constituents of healthcare systems, such as: the balance between full-time and part-

time working patterns; the degree of incentivisation of same-day access; and the size and constitution of practice teams. (2–4)

There is a wealth of knowledge recognising the benefits and risks afforded by continuity, and the facilitators and barriers to its provision. Most studies have demonstrated beneficial outcomes, such as reduced mortality, more appropriate prescribing and greater clinician productivity. Existing research has identified groups of individuals that may particularly benefit from continuity of care, such as those with an incurable diagnosis. (5–12) There is a growing literature in the palliative care context that demonstrates an association between continuity in general practice with reduced use of urgent and emergency hospital care towards the end of life; a key policy priority. (13–18) However, few studies to date have explored how people with life-limiting conditions actually experience continuity in this setting.

Using malignant mesothelioma as a lens, this study explored how people living with, or caring for those with, this condition experience continuity in UK general practice and investigated the work required of them to navigate healthcare services and achieve continuity. Mesothelioma is an incurable, malignant disease caused by asbestos exposure. It affects the lining of certain organs, most commonly the pleura, (19) and there are no existing curative treatment options. (20) Given the uniformity of palliative care need among this patient population from diagnosis, and the fact that multiple providers and fragmented services are often involved in their care; (21) research involving people with mesothelioma provides insight into the sharp end of the spectrum regarding the need for, and potential benefit from, continuity. Though this study was undertaken in the UK, it has clear relevance to an international audience, especially those countries with similar primary care health systems to the UK.

Methods

Aim

To understand the experiences of continuity in UK general practice among people with mesothelioma, their close persons (CPs), and their healthcare professionals (HCPs); how they achieve this (or not); and how it affects their healthcare service use.

Research question

What does ideal yet realistic continuity look like, for people living with or supporting those with mesothelioma in UK general practice, within the wider healthcare system context?

Methods

This paper reports findings from qualitative longitudinal interviews with people with mesothelioma, their CPs and their HCPs, used to form detailed case studies. The study is reported according to the Standards for Reporting Qualitative Research (SRQR) guidelines. (22) (*Appendix 1: Standards for Reporting Qualitative Research (SRQR) guidelines*)

Patient and public involvement (PPI) was integral to the research process from design to dissemination. Five individuals were recruited from the Mesothelioma UK Research Centre PPI panel at the University of Sheffield, and all had personal experience of mesothelioma and were familiar with continuity within the healthcare context.

The case study approach provided sufficient depth and detail to answer the research question, and conceptual density was achieved through the triangulation of participant perspectives. (23–25) Service users provided vital perspectives centred on outcomes, and service providers contributed a wider, more detailed overview of how services function and the barriers they encounter in day-to-day practice. (26)

Participants were recruited across the UK with the support of the charity Mesothelioma UK. Study information was advertised on the Mesothelioma UK website, in the magazine, via social media channels and circulated to support groups associated with the charity. Adult patients (> 18 years) with a diagnosis of mesothelioma; the capacity to provide informed consent; and fluent spoken English were eligible to participate. Purposive sampling maximised heterogeneity across characteristics including: age, gender, marital status; geographical location; time since diagnosis; GP practice size; and involvement with a Mesothelioma UK clinical nurse specialist (MCNS). (27) Patient participants were also asked to nominate a CP (family member or friend) and an HCP (for instance, a GP, allied health professional (AHP), an MCNS or secondary care clinician) involved in their care. These individuals were also required to be adults with fluent spoken English and the capacity to provide informed consent. Due to low response rates from GPs, an amendment to the ethical approval process was submitted to enable the research team to recruit GPs (unrelated to the care of patient participants) through professional connections.

Virtual interviews using the Google Meet platform were undertaken to maximise inclusivity given the wide geographical spread of potential participants with a relatively rare diagnosis, and due to the ongoing effects of COVID. Topic guides were semi-structured and based on hypotheses generated from the literature review findings and the research team’s own clinical and academic experience. (*Appendix 3: Topic guide summary*) Patient and public involvement members kindly provided valuable feedback on all participant-facing study documents and topic guides.

Analysis

Interviews were recorded, transcribed verbatim and anonymised. Data were analysed according to the six phases of reflexive thematic analysis as described by Braun and Clarke. (28, 29) When the generated codes had been organised into overarching themes, the data were mapped on to the constructs within the Candidacy Framework, through a deductive, ‘theory-driven’ process. This approach facilitated orientation and organisation of the data within its wider context, and deepened understanding of the decision-making processes employed by those navigating the healthcare system. The computer software NVIVO (1.7.1) supported the practical structuring and management of the data. (30) (*Appendix 2: Summary of data management process*)

Figure 1: The Candidacy Framework

Negotiating the candidacy journey for health services: an extrapolation from Dixon-Woods et al. 2006 (31)

The Candidacy Framework ‘identifies distinct factors that influence the behaviour of individuals, service professionals and systems at all points on the access route to services.’ (32) Dixon-Woods et al. developed this theory about how people access healthcare using ‘critical interpretive synthesis’, a novel approach combining qualitative and systematic review methodology. (31) It enables us to explore if, how, why, and in what circumstances, people recognise themselves as being ‘candidates’ for healthcare services. Individuals may ask themselves questions such as, ‘am I eligible for this service?’ or ‘are my symptoms severe enough to warrant this help?’

Results

Findings reflect the needs and experiences relating to continuity in general practice of people living with a diagnosis of, or caring for someone with, mesothelioma.

Summary of participant demographic information

Data collection ran from 7th January 2023 to 5th April 2023. Nine patient case studies were formed from qualitative data acquired from longitudinal interviews with patients, and their nominated CPs and HCPs. (Fig. 2: Structure of case studies) Thirty participants were included overall. (Table 1: Demographic information of patient, close person and healthcare professional participants) In total, 53 interviews were conducted, and all participants (except one CP) engaged in at least two longitudinal interviews. (Table 2: Number of interviews with each participant)

Figure 2: Structure of case studies

Table 1 Demographic information of patient, close person and healthcare professional participants					
Patients (n = 9)		Close persons (n = 9)		Healthcare professionals (n = 12)	
Age	Range: 63–81 years Average: 69 years	Age	Range: 45–85 years Average: 67.3 years	Age	Range: 29–65 years Average: 46.4 years
Ethnicity	All White Caucasian	Ethnicity	All White Caucasian	Ethnicity	All White British
Gender	33% male	Gender	50% male	Gender	25% male
Diagnosis	78% pleural 22% peritoneal	Relation to patient	Husband (n = 2) Wife (n = 3) Sister (n = 1) Son (n = 1) Friend (n = 1)	Clinical role	Consultant oncologist (n = 1) Lung cancer CNS (n = 1) MCNS (n = 4) GP (n = 6)
Marital status	56% married 44% single				
Duration since diagnosis	Range: 4 months-15 years				

Table 2
Number of interviews with each participant

Patients	Interviews (n=)	Close Persons	Interviews (n=)	Healthcare Professionals	Interviews (n=)	GPs unaffiliated with patient participants	Interviews (n=)
P1	2	CP1	2			HCP10	1
P2	2	CP2	2	HCP2	2	HCP11	1
P3	3	CP3	1			HCP12	1
P4	2			HCP4	2	HCP13	1
P5	2	CP5	2	HCP5	2	HCP14	1
P6	2	CP6	2			HCP15	1
P7	2	CP7	2	HCP7	2		
P8	2	CP8	2	HCP8	2		
P9	2	CP9	2	HCP9	1		
		CP9a	2				
Sub total	19	Sub total	17	Sub total	11		
Sub total	47					Sub total	6
Total (n=) interviews	53						

Key findings following thematic analysis of qualitative data

Findings are presented according to three key themes: 1) People with mesothelioma benefit from generalist care provided by GPs; 2) Patients experience distressing uncertainty when trying to navigate the fragmented healthcare system; and 3) We must reframe continuity as 'essential', not just an 'added bonus'.

Theme 1: People with mesothelioma benefit from generalist care provided by GPs

People with mesothelioma are considered to have palliative care needs from diagnosis, given the lack of existing curative treatment options. Despite the rarity of mesothelioma; patient and professional participants suggested that people with this diagnosis primarily require generalist, holistic care from GPs, rather than needing them to have detailed knowledge about the disease itself.

HCP11: 'I'm probably showing my ignorance but if somebody came to see me and they had mesothelioma, that doesn't mark them out as complex to me, like, they're just a patient, not "just", you know, but they are a patient with a cancer diagnosis that is going to be terminal, and I can manage that.'

Skills relating to empathic communication, palliative care delivery, and advance care planning were considered vital. However, it was acknowledged that training and experience in palliative care provision among GPs is variable.

HCP11: 'Some people haven't had great training in palliative care, and it's frightening to some people. There are colleagues of ours who can't initiate an advance care planning conversation well, they're still asking people if they'd like to be resuscitated and I think there is still huge variation and we've all got our strengths.'

Some GPs choose to develop expertise in particular clinical areas. For example, one patient reflected on the fact that she had been advised by her GP to seek support from an alternative clinician as his special interest was diabetes. She consequently felt alienated by her GP and practice team. This sense of fear and isolation was expressed by several patient participants who felt the need to adopt an expert persona by learning about the condition themselves. Alternatively, patients and CPs reported leaning towards specialists and away from general practice, thus potentially reducing continuity with their GP practice team.

P5: 'He knew nothing about mesothelioma. He said he was trained in diabetes, so he had never actually met mesothelioma before, so, I sort of lost faith in him actually, so that's why I said, "I'm taking command, you know, I'll deal with it", I researched as much as I could, I spoke to as many people, I went to as many conferences...'

Patient, CP and HCP participants reported that traits that define a 'good' GP include being: human; caring; a good listener; generous with time; clinically competent; proactive; and willing to learn. It was felt that such HCPs recognised the value of continuity, so were more likely to advocate and take responsibility for achieving it, for example by booking their own follow-up appointments.

HCP12: 'Obviously you can't treat your own family members, but you treat people exactly how you want your family members or yourself to be treated... It's like, your patient is somebody else's dad.'

HCP11: 'I think it's [continuity] more challenging now, but I think it is still possible with, if there's a will to do it. I think it's beholden to us as individuals. Like, if I see a patient and I think that they need continuity, then I need to arrange to see them again, like myself, like, "I'm gonna come and visit you again in two weeks' time" rather than wait for another crisis to bubble up for them.'

Theme 2: Patients experience distressing uncertainty when trying to navigate the fragmented healthcare system

Several GP participants reflected on the increasing tendency of GPs to subspecialise, so as to create a manageable workload for themselves. They suggested this to be a necessary response to the increasingly complex health and social care needs of the population that are seemingly impossible to address without breaking them down into wieldy chunks.

HCP12: 'There's too much to know now. It changes so quick. It's extremely tricky... General practice can't continue as it is. And it probably should be more that like, for example, I am useless at managing menopause; it changes too often. I don't see enough. I'm not up to date with it. There is no point a lady coming to me to talk to me about the menopause, not because I'm dismissing the symptoms, she's just not gonna get the best outcome. She's better off seeing one of my colleagues who have more interest in it. So, we should probably navigate people around our own interests as well...'

However, the resulting additional burden placed on service users was acknowledged. Patient, CP and HCP participants all conveyed doubt as to exactly 'who does what?' in the healthcare system. They reflected that the concept of the 'family team' is replacing the term 'family doctor'. Many patients reported experiencing high levels of stress due to their uncertainty of how to navigate the healthcare system to get what they need. A GP participant suggested that for a large, multidisciplinary system to function well, all individuals involved must be aware of what is available.

HCP10: 'I'm there three days a week, somebody else is there two different days a week... We have a weekly meeting which is just for us and... then we tack on either district nursing, palliative care, mental health, physio team, social work team. So, there's nearly a hundred people associated. I think it's [continuity] perfectly possible, with decent resources and a big, big practice.'

Within this study, patients with either minor complaints or serious symptoms generally understood how to navigate the healthcare system to get help. However, patients presenting with intermediate needs, that did not neatly fit into either of the 'non-urgent' or 'very urgent' categories, struggled to know where to seek help. They described feeling afraid and pressurised to make the correct decision, so as not to 'waste the doctor's time'.

P6: 'I don't want to pressure them because I understand how busy it is, I know what a difficult job they've got. Somebody sitting there moaning and complaining, doesn't help anything, you don't get anywhere like that... It makes me want to deal with everything myself. Well, it affects your mental health as well because you don't know where to turn. Should you bother them? Should you not bother them? Are you doing the right thing by not bothering them? Should you be more proactive? Should you complain? Well, from my experience of complaining that just makes the situation worse.'

Similarly, HCPs felt more comfortable being able to signpost patients with symptoms that overtly fit into either 'urgent' or 'routine' pathways. Several MCNSs reiterated that the middle 'grey area' was more difficult to articulate and understand for service users and providers alike.

HCP8: 'We have an emergency number for the guys on treatment but that aside is, that's considered to be the urgent number. There's no moderately "I might need somebody" number. So, I think that's the middle line, isn't it?'

Uncertainty is a clearly a significant stressor in the mesothelioma care context for both patients and professionals, and a concept well within the remit of GPs, who are trained to manage ambiguity and the psychological impact thereof. (33)

Theme 3: We must reframe continuity as 'essential', not just an 'added bonus'

Patients and CPs expressed varying levels of understanding of continuity within the healthcare system. Patients' perceived need for, and expectations relating to, continuity seemed shaped by their cultural beliefs, symptom severity, and experience of the healthcare system. Ultimately, it was noted that if patients are not aware of the term continuity, or of the value it may bring, they may not know how to access or advocate for it.

P6: 'The only regular contact I have is with the oncologist, who I've seen, about five times. But I don't know who I'm supposed to be going to. Is the oncologist above the GP? Do they work hand in hand? Is one of them going to argue against the other? [Laughs]'

Patient, CP and professional participants reflected that the system feels led by managers far removed from the 'front-line', and referenced the apparent focus of governmental policy on access, which can inadvertently lead to a detrimental impact on continuity. It was acknowledged that clinics are measured in the number of patient contacts, thus productivity is assessed quantitatively, rather than in the quality or content of consultations. Patient participants often perceived access as a fundamental, basic necessity, and continuity as an extra, 'nice to have', bonus element of care. Professional participants suggested that this perspective could prevent patients from proactively seeking out continuity.

HCP11: 'Our routine capacity is so under pressure that we're seeing most things like, I don't even bother challenging it, but lots of people make same day appointments, and I don't blame them because the wait for a routine appointment might be a month... I think demand feels like it's greater than it ever was, and all the numbers say that we're all providing more appointments than we ever were.'

It was frequently articulated that NHS general practice is not appropriately designed for today's society. Patient, CP and HCP participants indicated that delivering continuity in the current system requires creativity, as it is not considered essential. Creativity is hampered by burnout among individuals within an overburdened system. Rather than being able to provide proactive, holistic care; GPs reported that their day-to-day work involves 'firefighting'.

HCP15: 'I do think that if we had enough time to sort out the continuity, we would have to the time to be creative again, because I think one of the things that happens when you get close to burnout is you lose your creativity.'

Discussion

Summary

This study sought to understand how those affected by mesothelioma experience continuity of care in general practice at individual, practice, and healthcare system levels; with a specific focus on people's ability to achieve their desired level of continuity. General practice teams need to be aware of what mesothelioma means for patients from a generalist, holistic perspective; rather than have detailed knowledge about the disease itself. Ultimately, the needs of people living with mesothelioma may not be addressed if integration and continuity do not facilitate patients being supported by both specialist mesothelioma-focused services, and generalist services that can provide holistic care.

Strengths and limitations

Case studies enable deep understanding of experience and context, which is essential when exploring a complex and multifaceted concept like continuity. (24, 25) Each patient case study was strengthened by the contributions of CPs and/or HCPs; conceptual density was achieved through this triangulation of perspectives. (23) The recruitment process and resulting wide geographical spread of participants enhances the representative and generalisable nature of the findings. Participants were required to have 'fluent spoken English', which may have hindered participation of some patients. One third of patient participants were male, which is not reflective of the fact that mesothelioma is more common in men, but may reflect the increased tendency for females to engage with research, (34) or participate in support groups. (35) Participant views may not be representative given the selection bias that is inevitable when involving people in research that involves their active participation in interviews. (36)

Comparison with existing literature

The key challenges articulated by study participants echo the experiences of people with other life-limiting diagnoses. (37) The terminal nature of mesothelioma was repeatedly highlighted as its most important feature by patients, CPs, and HCPs alike. The rarity of the mesothelioma diagnosis was apparently superseded by the patient's palliative care needs, and it was felt that people with mesothelioma could be appropriately cared for by generalist HCPs. That said, patients and CPs described feeling safe if HCPs in general practice were familiar with mesothelioma; were willing to learn about it; or had close connections with specialists.

The fact that the MDT is increasingly complex, and thus has the potential to hinder continuity, was commonly expressed throughout this study. Exploration of this theme revealed underlying uncertainty of the roles of HCPs within the MDT, complicating interprofessional relations and patient experience. Burch et al. described the experiences of continuity among patients consulting routinely with GPs at two extended-access providers in northern England between 2021 and 2022. They suggested that *"without knowledge and experience of local health systems, even a medically knowledgeable clinician can fail to provide patients with seamless care."* (38)(p303) It is intuitive that if a GP is to act in a coordinating, signposting role, they must be aware of services or colleagues to which they can refer. Multidisciplinary team working within general practice is considered essential if there is any chance of meeting future demand, but role clarification is urgently needed. (39)

Participants reflected on the fact that there are not enough GPs, and reported that the nature of the workload has changed as a result. Rather than being able to provide proactive, holistic care, GPs reported that their day-to-day work feels like 'firefighting'. Kajaria-Montag et al. explored data from primary care consultations from 10% of the English population over a 10-year period. They found that an imbalance between workforce and workload is the main barrier to continuity of care. (40) This echoes data from NHS Digital which shows that the total number of monthly appointments between 2017 and 2023 increased by 31%, despite a reduction in the number of fully qualified full time equivalent (FTE) GPs. (41) The impact of the scarce resources on the care that HCPs can provide is acutely palpable in the palliative care remit. This is particularly concerning given that *'how we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services.'* (42)

The perception of health as an ability rather than a state of being aligns with the Candidacy Framework, which reflects the considerable bargaining required of patients to seek help. (43) Accessing healthcare requires several steps in a complex pathway to be completed successfully. Doing all of this, in addition to having a particular preference about who to see, takes effort. Further, people have differing levels of support and advocacy from their social network. Given the existing variation in ability among patients, inequity in how they experience the healthcare system is inevitable. Patients must be met 'where they're at', not where we think they are: efforts to ensure continuity should be tailored appropriately to individual need. (44)

One patient participant with significant unmet needs described feeling reluctant to 'bother' her GP practice. She did not consider herself 'bad enough' to take up clinicians' time. This reflects patients' 'struggles to negotiate eligibility for medical time'. (45)(p113) Service users are expected to make 'appropriate' choices as they use healthcare services, despite an increasingly complex and resource-constrained system. (21, 46) Within this study, patients with needs at either end of the spectrum, namely either minor complaints or very serious acute need, generally understood where to seek help. Similarly, HCPs felt more comfortable being able to signpost patients to such pathways. However, patients presenting with needs in the middle, grey area of urgency and complexity, often found it more difficult to know where to seek help and described feeling fearful that they may waste the doctor's time if they did not make the correct decision.

A patient's passage through the healthcare system was deemed smoother (and continuity was considered better) if HCPs advocated for them, for example if a specialist nurse contacted the GP practice to request that a patient be booked in for a blood test. Therefore, a large, but often hidden, part of clinicians' roles on both sides of the primary-secondary care interface includes supporting patients with administrative, access and orientation needs. (47) The system needs further capacity and flexibility if HCPs are to consistently fulfil this role for patients. Currently, it is reliant on such professionals going 'above and beyond', which is unsustainable. Non-clinical staff, such as receptionists, certainly have a role to play in supporting patients to achieve continuity. Patient, CP and HCP participants in this study discussed the objective, tick-box aspect of triage being beneficial at times, in terms of patients with a diagnosis like mesothelioma being able to access an appointment. For example, if a receptionist hears the word 'cancer' they are likely to filter the patient to 'speak to a clinician' regardless of context. If also trained in the value of continuity, such staff may be instrumental in facilitating its integration into clinical practice.

Implications for research, practice and policy

Despite the substantial evidence base, continuity is considered as 'nice to have' rather than 'essential'. The progressive decline of continuity over recent decades seems to have prevented patients from expecting or seeking a longitudinal relationship with their GP. (48) Reinforcement is required of the notion that achieving continuity for the 'little things' enables a firm foundation on which more serious issues could potentially be detected earlier, thus resulting in better outcomes and cost effectiveness. (49) Such insight needs to be reiterated to service users and providers alike, so that both sides of the clinician-patient relationship can contribute to achieving a common goal of continuity.

Given the ever-increasing multidisciplinary nature of the healthcare workforce, patients need to understand the unique skill sets of HCPs involved in their care to navigate the system effectively. A significant amount of education is clearly required to manage the expectations of service users, who may be unfamiliar with the day-to-day workings of a GP practice and the wider healthcare system. If the public are increasingly involved in and educated about the inner workings of the healthcare system, they may better understand the importance of continuity, and advocate for it more effectively.

The existing literature recognises that certain people benefit markedly from continuity. (5–12) In the context of this study, the following patient attributes highlighted a particular need for continuity: palliative care needs; culturally or geographically isolated; limited language or technological competence; and a limited social support network. Hopefully the 2025-26 NHS GP Contract, which advocates incentivisation of the identification of people who may particularly benefit from continuity, will contribute to the efforts required to facilitate its provision in practice. (50)

Conclusion

Participants described the intense burden of living with and dying from an incurable disease with a poor prognosis. However, feeling held, understood, and expected, alleviated some of their suffering. Patients defined these as fundamental elements of 'good' care, but felt they had somehow been overlooked in governmental policy. Continuity clearly has a significant impact on how people feel, which is surely the precise point of healthcare. Using malignant mesothelioma as a lens, this study explored how people experience continuity in UK general practice and investigated the work required of them to navigate the increasingly multidisciplinary healthcare system. Findings are relevant to other international contexts, such as those with primary care systems similar to the UK; and other patient populations, for instance those with rare conditions or incurable diagnoses.

Abbreviations

• AHP	Allied Health Professional
• CP	Close Person
• FTE	Full Time Equivalent
• GP	General Practitioner
• HCP	Healthcare Professional
• MCNS	Mesothelioma UK Clinical Nurse Specialist
• MDT	Multidisciplinary Team
• MUKRC-S	Mesothelioma UK Research Centre – Sheffield
• NHS	National Health Service
• P	Patient
• PPI	Patient and Public Involvement
• SRQR	Standards for Reporting Qualitative Research
• UK	United Kingdom

Declarations

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Ethical approval and consent to participate

This study was conducted in line with the Helsinki Declaration, and received University of Sheffield ethical approval on the 24th June 2021 (REF 039695). Two ethical amendments were submitted, both on 14th February 2023 (approved on 21st February 2023) and 28th March 2023 (approved on 3rd March 2023). All participants provided informed consent prior to taking part in the study.

Consent for publication

The enclosed manuscript has been read and approved by all authors. It is not under active consideration for publication elsewhere, has not been accepted for publication, nor has it been published in full or in part.

Competing interests

Nothing to declare.

Author Contribution

EC conceived the research. All authors were involved in study design. EC collected the data. All authors were involved in developing the analysis plan. EC undertook the data analysis, with input from SEM, SM and CG on three transcripts to achieve consensus on the coding framework. EC produced the first draft. All authors were involved in subsequent revisions and approved the final version of the manuscript for submission.

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Data Availability

Data were collected and generated according to the above study design and methods and adhered to ethical and governance requirements and data sharing agreements as applicable. All non-identifiable electronic data were uploaded to the University Research Data Storage (X: drive), and will be stored for ten years. The data will be made available on request through the Mesothelioma UK Research Centre. At the end of the agreed data storage period, all electronic data will be securely deleted by University IT support. All participants provided informed consent prior to taking part in the study.

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Figures

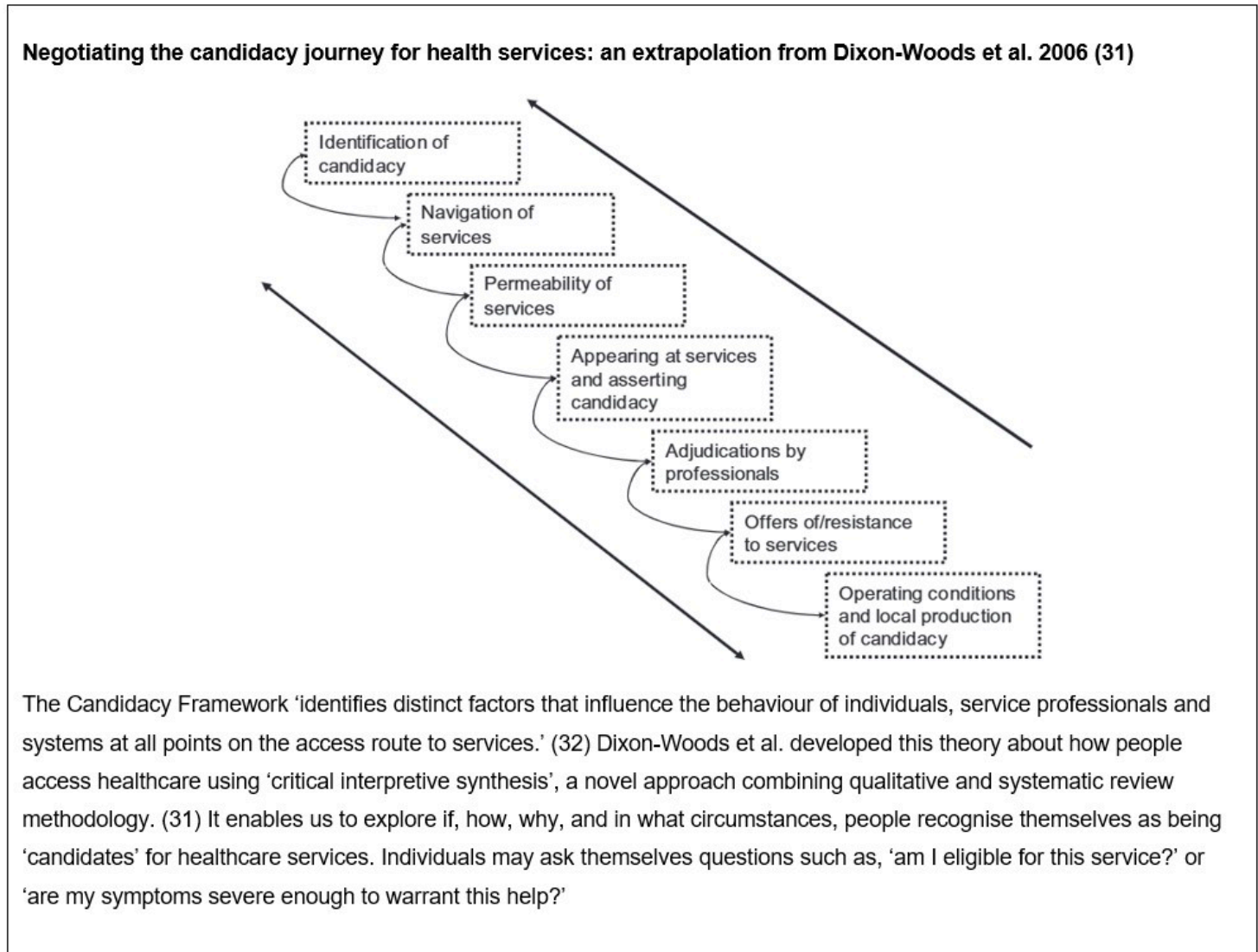


Figure 1

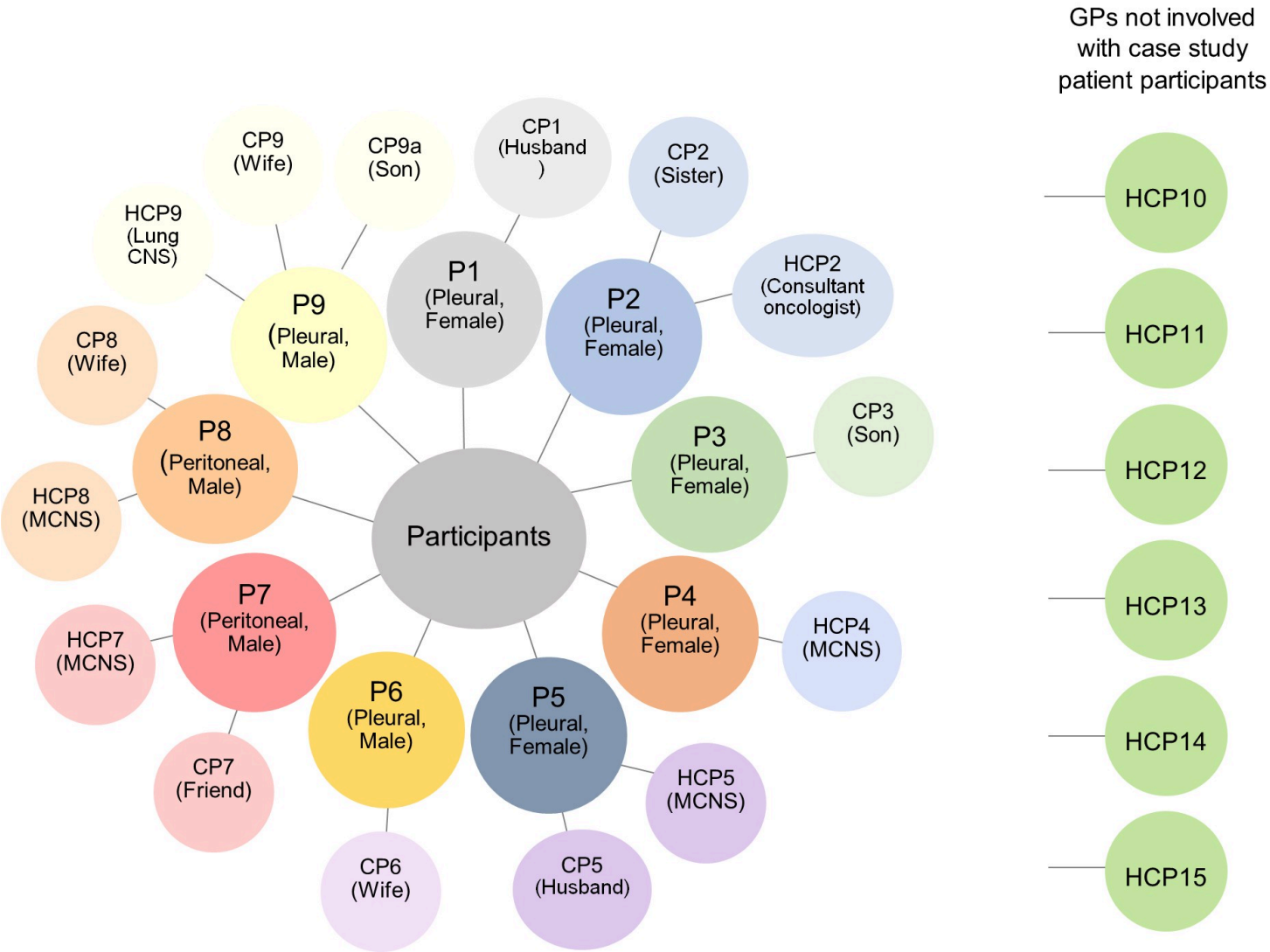


Figure 2

Structure of case studies