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The views of older people on community-based multi-disciplinary team caseloads and informal carers about health and care services in two Integrated Care Pioneer sites in England

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Abstract

Objectives: Community-based multi-disciplinary teams (MDTs) were among the most widely reported health and care integration initiatives in the Integrated Care Pioneers in England. Such MDTs bring together staff from different sectors to co-ordinate and plan care for patients, who are often older, have multiple long-term conditions and risk hospital admission. As part of our evaluation of MDTs in two contrasting Pioneers, we explored MDT patients' and informal carers' perspectives on health and care services. As the COVID-19 pandemic started during data collection, we also wanted to understand its impact on patients' access to services.

Methods: We conducted qualitative interviews with 44 patients aged 60 or over, with long-term conditions, and on the caseload of one of 11 participating MDTs. We also undertook qualitative interviews with 15 carers. Interviews took place between November 2019 and March 2021. Interview transcripts were coded in NVivo-12 and analysed thematically.

Results: In addition to formal services, patients often relied on informal care. Valued aspects of care included equipment and home modifications that supported independence, timely access to and continuity in care, effective information-sharing, professionals who made them feel that their needs mattered, and having a named contact. Where challenges were experienced (e.g. with accessing professionals, communication, and care quality), patients and carers sometimes felt abandoned. While some patients mentioned being on an MDT caseload, few reported having a care plan. The impacts of caring on informal carers were sometimes considerable. COVID-19 affected patient and carer wellbeing, but the new ways of accessing care generated by the pandemic were valued by some participants.

Conclusions: As long as challenges remain, patients and carers are unlikely to perceive care as joined-up and patient-centred. If truly integrated and holistic care is to be provided, barriers (such as the lack of shared patient records) must be addressed. Even where MDTs function primarily to co-ordinate rather than deliver care, they could better communicate their co-ordinating role, and MDT discussion outcomes, including care decisions, to patients. Informal carers' needs also require greater attention by MDTs.

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Introduction

Having multiple long-term conditions is associated with increased rates of hospitalisation and general practice consultations.[1] The percentage of adults who need help with at least one daily living activity increases with age,[2] while many of those who provide informal care report feeling isolated, and experience financial difficulties and health problems associated with caring responsibilities.[3] In England, health care is financed through general taxation and primarily provided free at the point of access through the National Health Service (NHS). Adult social care (e.g. domiciliary care) is means-tested and financed by combined central and local government and private payer funding. The multiplicity of providers and funders creates challenges to co-ordinating care for people with multiple needs and their families.

Better coordinated care is hypothesised to lead to individual and system-level benefits.[4,5] Three national pilots designed to better integrate health and social care have been implemented since 2008 and integrated care remains high on the Government's agenda in England,[6] with the 2022 Health and Care Act[7] placing 42 Integrated Care Systems on a statutory basis. Each has an Integrated Care Board responsible for planning and aligning the health and care services in geographical areas with populations of 500,000 to three million.

The 25 Integrated Care and Support Pioneers (which operated between 2013 and 2018) were selected by the then Department of Health to better integrate care for their local populations, by prioritising patient-centred care, improving horizontal integration between NHS and social care services, and taking a 'whole system' approach to integration.[8] Pioneers often focused on older people with long-term conditions and/or at risk of hospital admission.[9,10] As in other pilots,[11] community-based multi-disciplinary teams (MDTs) were one of their most widely reported integration initiatives.[9,12] Such MDTs are often based around general practices, focus on older people and bring together professionals - including those from the primary, community and acute health care sectors, adult social services, and community and voluntary services (CVS) - to co-ordinate, and sometimes provide, patient care ('patients' is used hereafter to include social care users and clients).

The current analysis was part of a wider evaluation of community-based MDTs.[13] Eleven MDTs in two contrasting Pioneers participated. Described in detail elsewhere,[13–15] Pioneer 1 (P1), located in a large urban conurbation, involved eight MDTs coordinated by NHS administrators, and operating to one model. Pioneer 2 (P2), a mixed urban-rural area, had three MDTs operating differently: two general practice-based and one led by an NHS acute hospital. In both Pioneers, MDT aims included supporting those discharged from hospital, and preventing hospital admissions.[15,16] While targeting older people, P1's MDTs also responded to other adults with complex needs. P2 MDTs focused more specifically on older people.

Based on the relevant literature and logic models constructed in the early evaluation of the Pioneers,[9] we developed a conceptual framework of MDT functioning[13,14] for the evaluation. The framework was structured as a classic input-process-outcome model, with the MDT as the intervention. It outlined the pathways by which dimensions - including local contextual factors and inputs (e.g. MDT aims, resources, team composition) - in tandem with key MDT intervention processes (individual and group behaviours in the team; collaboration through information exchange, communication and shared decision making) might lead to a range of patient- and staff- related outcomes, including improved patient care experiences. The framework was used to guide data collection and analysis during the MDT evaluation. We report elsewhere on our observations of how staff work together in MDT meetings[14] and strategic leader[15] and frontline staff[16] perspectives on how MDT working enables the delivery of more holistic, patient-centred care.

The aim of this paper is to understand the care experiences of MDT caseload patients. We report the findings of qualitative interviews exploring MDT patients' and informal carers' views about health and care services, including how their needs were being met, and how co-ordinated and patient-centred their care was. We intentionally did not ask about MDT activities specifically. This was to avoid biasing responses about service quality, and as patients may not be aware of, or remember, services' names, instead recalling changes to their care.[17] COVID-19 interrupted data collection in Spring 2020 and, thus, when we resumed our interviews, we also explored the pandemic's perceived impacts on participants' care.

Methods

Participants

We interviewed 44 patients and 15 informal carers. For practical reasons, we could only approach patients participating in the MDT evaluation for whom we had telephone numbers and their informal carers. We interviewed 21 male and 23 female patients, and six male and nine female informal carers. Fourteen patients and four carers were interviewed in P1 and 30 patients and 11 carers in P2.

The average age of P1 patients was 76 (range 60-91) and carers 65 (range 57-77) while that of patients in P2 was 83 (range 68-94) and carers 70 (range 54-92).

Data collection

P1 interviews were conducted between November 2019 and March 2021 and P2 interviews between July 2020 and March 2021. Postal invitations to participate were followed by phone contact. Participants received a £10 shopping voucher. Prior to the pandemic, interviews were conducted in participants' homes. During the pandemic, on account of COVID-19 restrictions, interviews were conducted by phone. Interviews were semi-structured, audio-recorded, and lasted approximately 39 minutes. We undertook one joint P1 patient and carer interview, and a number of P2 patients were helped during phone interviews by a carer (e.g. if hard of hearing). LT, MAH, AP and ND conducted interviews. The interview schedules are given as S1 and S2 in the Supplement C.

Data analysis

Interviews were transcribed verbatim, and data managed using NVivo 12.[18] Following familiarisation with transcripts, an initial coding frame was constructed (AP, MAH, LT, MAD). Coding was largely deductive in nature, based on the interview schedules and the results of our observing MDT meetings,[14] and interviewing strategic leaders and frontline staff.[15,16] Data were coded by AP, LR, LT and MAH. The thematic analysis[19] was led by MAD, with emerging themes discussed in team meetings. We sought to capture similarities and differences in views between participants in the two Pioneers, given the different contexts and MDT operating models in the two Pioneers,[15,16] and between patients and carers, and to ensure that both positive and negative perspectives were captured.

Results

Patients' needs and types of help received

Patients reported a wide range of physical, age- or frailty-related conditions and acute events or illnesses that had necessitated contact with services, as well as daily living and personal care needs, mental health problems, and social challenges. Carers too reported their own health problems. The three main sources of support with health and care needs were: NHS and local authority (often referred to as 'council') services or self-funded social care; CVSs and illness-specific support organisations (e.g. for dementia); and informal care (e.g. from family).

Experiences of hospital stays, post-discharge care, outpatient and general practice consultations and home visits from community-based NHS or care professionals were commonly reported, but many patients did not specifically mention an MDT's role in their care. A number were uncertain about which services or professionals delivered aspects of their care. Very few patients or carers reported receiving a care plan - where one had been received this was almost always in P2.

Participants faced challenges with navigating systems, uncertainties about entitlements, and difficulties in completing complex forms. Where they paid, or considered paying, for domiciliary care or home modifications, it was generally because of not qualifying for local authority funding. However, a number of participants had organised equipment or domiciliary care privately for reasons such as greater personal control, poor past experiences, long waiting times, or not wanting local authority involvement. Indirect care costs included transport to appointments, which could be considerable, and personal alarms. Some expressed resentment about having to pay when entitlements were means-tested:

> I did ring the council about it [having a shower fitted] and they did say, 'Oh, well, sometimes it's because if you have too much money in the bank'… We've worked all our lives, we've saved up and put money aside. It's detrimental because it goes against you, so you have to pay for these things yourself. (Carer 02, P2)

In both Pioneers, some participants had been offered or received information and help with navigating health and care systems through to limited forms of patient befriending and carer respite from CVSs or condition-specific organisations/charities. CVSs were occasionally contrasted positively with social services:

> The social services, in all their wisdom, have cut me down to one hour once a week now, which is absolutely useless, and that's for domestic work. … [The CVS organisation] send people round to do shopping for me and that sort of stuff. In fact, I'm waiting for someone to come round today because I've got to get some money out of the bank, and they'll do that. Social workers aren't allowed to do that, or carers I should say, whatever they are. (Patient 03, P1)

However, some participants would also reject CVS support for fear of strangers visiting their homes, not providing the help needed, or because payment was required.

Most patients relied to at least some extent on family and friends for informal care. Some expressed gratitude and good fortune for having people who provided companionship and help with household tasks, shopping and, in some cases, personal care (e.g. showering) and medical needs. Carers echoed patients' descriptions of their informal caring activities. A few alluded to providing almost 24-hour support:

> I do all the housework, I do all the cooking and the shopping, practically the lot. Actually, she can wash herself and dress herself, although she gets a bit confused at times. … If she dirties herself, incontinence, I have to help clean her up. And I have to give her reassurance when she gets depressed. I'm 92, so it's quite hard work. (Carer 03, P2)

Carers also acted as contacts and information sources for services, arranged appointments, and advocated for patients:

> So, you feel like sometimes you have to contact all the services to say, 'This is what I've been asking for/requiring.'… At least they're all going to say, 'This person has called.' (Carer 01, P1)

Participants occasionally mentioned having a personal history of self-reliance, resilience, coping, and not wanting to be beholden to others. Some also voiced a perceived expectation that families could cope with little or no professional input. For some, providing care was 'what families do' or was driven by the patient's preference:

> Yes, it was pretty bad, but we were coping best we could, as you do, because Mum doesn't like people in. It's very hard for her to accept help from anybody. She's a bit old school: 'Family should do it.' (Carer 04, P2)

However, participants also expressed the belief that patients only managed because of the informal support they received:

> I'm managing because I've got my daughter. I couldn't do it without her (Patient 02, P2)

> I don't know what the situation would be if I was not here to actually help her and do like we do now. (Carer 05, P2)

The negative impacts of caring included stress, worry, risk-holding, juggling multiple responsibilities, self-neglect, limited social lives, and, for a few, having to take early retirement or reduce paid work.

Perceptions of care

There was considerable variation in participants' expectations and experiences of the extent to which formal services could, or did, meet their specific needs. While some were positive about their experiences - sometimes singling out specific services and professionals for praise, or expressing gratitude to the NHS in general - others were less satisfied. Valued aspects of care were sometimes best illustrated in narratives of their absence.

Care that enables independence, is timely, and provides continuity. Among the components of care most valued by participants were those that helped maintain patients' independence. Formal needs assessments were sometimes viewed as 'tick-box exercises' that led to false promises, no follow-up, or to paying for care inputs, and caused disappointment or frustration. Far more frequently, however, they resulted in interventions - including equipment or home modifications - that enabled patients and their carers to cope more effectively with the patient's often considerable daily living challenges and improved their quality of life. Interventions that facilitated mobility or helped patients to better undertake their own personal care, and engendered a sense of safety and capability were particularly welcomed:

> I finished up with equipment round the toilet so I could get up, if you see what I mean, with my hands, because my legs are getting weaker. And then I had a Zimmer Frame downstairs. … They were very helpful. (Patient 04, P2)

> That bed made a profound difference because it was higher and it had a means whereby I could pull myself up or guard myself as I sat down, so that was extremely helpful (Patient 03, P2)

Timely and easy access to the type and amount of health and social care participants believed they needed also appeared key to satisfaction. General practice care was central to accounts of interaction with professionals. Some patients and carers expressed satisfaction with GP services. Others were dissatisfied as a result of difficulties in obtaining appointments and GP home visits, problems exacerbated by COVID-19:

> It is actually very difficult to talk to the GP, although they are quite helpful when you finally get to talk to them, … because the receptionist do their very best not to let you speak to the GP. Once I needed an appointment, and I wanted someone to come here, because I was not in a good way, and then I was told to go there, and I couldn't get a taxi, so I missed the appointment, and they will not give me another one. I had to phone [an] emergency number, and they then phoned my GP and I think told them off, because suddenly I got an appointment, but no one will come to my house, I have to go there. It costs me £14 each time I have to go to the GP in taxi fares. (Patient 6, P1)

While GPs, when eventually seen, were viewed by some as helpful, others were disappointed by brief consultations or GPs' seeming lack of engagement with their health concerns. Community professionals' and carers' home visits were also occasionally described as rushed, and post-discharge care packages deemed to be limited in scope or too short in duration. However, time pressures on staff were sometimes attributed to an overstretched system within which busy professionals did their best.

Continuity in general practice care was also seen as important. Patients who consistently saw the same GP believed they benefitted from the GP's knowledge of their personal and family history and circumstances. Where continuity was lacking, patients could feel unknown:

> For many, many years I had the same GP, and you felt a lot happier then. … They knew everything about you and about your family. … Nowadays, you get decent enough service, but there's no continuity. … They're looking at a computer and reading it off. (Patient 5, P2)

Consistency and continuity in domiciliary care was similarly seen as important. Knowing who would visit and that they would arrive regularly, and at convenient times, was not just about practicalities, it also facilitated the development of trusting relationships:

> When I think about the carer that Mum has three mornings a week and three lunchtimes, she's built up a relationship with that person, that person isn't hurrying in, shoving some food down and hurrying out, which is the experience with the council-provided six-week stepdown care. … Through having the consistent carer … [Mum] feels there's somebody who understands her needs and is going to respond to them, and therefore she feels safe and confident to stay at home. (Assisted interview 01, P2)

A number of participants wanted more flexibility or responsiveness from services. Where, for example, a needs assessment had resulted in a decision that a patient could cope alone or with family support, or where there was inflexibility about the timing of care packages, carers suggested that their needs, as well as those of the patient, were being negated. A carer explained:

> We got in touch with [the service provider] and said, 'Right, we've had no care for the last 12 weeks, we could just do with a little bit of help.' 'Well, no, sorry, you're out of time.' A bit more give and take at that point: 'Well, oh yes, you were okay with us, you were sound with us when your wife first came out, you've done all the caring.' I did all the washing, I had to wash her daily, I had to feed her, I had to do everything for her. But as soon as I turned round to them, and all I wanted somebody to do was knock on the door and just make sure everything was all right: 'Sorry we can't do that. You'd have to go back to your specialist and your specialist would have to refer her to us.' (Carer 01, P2)

Effective communication. Participants viewed effective communication and information-sharing both with patients and between the services involved in their care as central to expectations about how services should be delivered as well as to the perceived patient-centredness of care. However, opinion was divided as to whether or not this was occurring in practice. Quite a number of participants suggested that professionals and services did communicate and share information with one another. Crucially, some participants cited examples of shared information being acted upon in a manner that suggested services were working in an integrated fashion:

> I'm quite surprised that they've been in touch with each other for different things. You know, like this team contacted the other people. And, yes, I think they've worked well together. They've passed information on to each other. (Patient 07, P2)

Having a named professional contact (e.g. a nurse) was believed to facilitate good communication, leading to timely assessments, and better care co-ordination. Other participants reported as the benefits of good communication everyone being kept informed about the patient's condition, needs, and ongoing care (e.g. appointments), as well as patients and carers feeling that their views were being taken into account, or not having to repeat their stories.

Community-based MDT care was only mentioned specifically by some of those on two P2 MDT caseloads, although a few other P2 and P1 participants described what might potentially have been MDT input. Where MDT input was mentioned, participants reported having clinical or other care from MDT members, a named MDT professional, or the team's phone number. They said contact with MDT professionals facilitated rapid responses to emerging needs, and expedited care co-ordination between relevant professionals and services to deliver help needed:

> We rang a central number and then we'd say, 'Look, my mum's leg's broken out again, we need it dressing.' So she'd say, 'Well, I'll contact the district nurses and then the organiser will send somebody this week.' Often it was the same day or the next day, depending. So it was very good. (Carer 07, P2)

> We also have the services of a nurse from the [MDT name] team. She's like a go-between between my husband as a patient and the doctor. And if we need anything, she can arrange it - get the doctor to call us, all sorts of things.. (Assisted interview 02, P2)

Other participants, however, viewed communication as sometimes poor or lacking, even where professionals and services were individually seen as effective or patient-centred. Examples included perceived insufficient information-sharing with patients and carers about their health condition and care planning, failure to follow up, and information getting lost or ignored. This sometimes led to adverse consequences (e.g. potential misdiagnoses). Two participants expressed surprise that there seemed to be so little patient record sharing. Where poor communication was experienced, the suggestion was that patients' needs were not being considered holistically or acted on in a co-ordinated way:

> It seemed to be both when I was in the rehabilitation hospital and when I came home that one of the things that was wrong was communication. … Even if things *were* communicated, they didn't read them. (Patient 08, P2)

> Each part of the system looks at their little bit, but doesn't look at the entirety. … It just, to be honest, feels like an endless battle. (Assisted interview 01, P2)

A small number of patients and carers viewed themselves, by necessity, as care co-ordinators, undertaking tasks such as ensuring information was shared between professionals:

> Working together? Not at all, completely not connected, unless they're brought together by voluntary agencies or me complaining. (Patient 01, P1)

> I've got to tell the doctor about that [new symptom], how he's feeling. And I want to know if the doctor's been told about his eyes, because I don't know if he's been told about his eyes yet. … But it seems weird to have to write to a doctor to tell him things and find out things. (Carer 02, P1)

Feeling like they matter. Participants praised those professionals and others who treated them as not just another 'case', but rather listened to them, championed their needs, and could be relied on to get things done or were perceived as going beyond what might usually be expected of them. These included GPs who proactively checked on patients or made home visits, CVS staff who navigated complex systems on their behalf, and pharmacists who delivered medications. Participants perceived such actions as indicators that their needs mattered to those providing their care:

> She asks me how I am, and if I say, 'I'm not very well' or anything she tells the doctor, and then the doctor will ring me if he thinks it's helpful. ... If I need any medication, she'll get it for me. … She's really nice and I really do appreciate that. (Patient 02, P2)

> If at any time I need help I must ring them [community nurses] and tell them, and they will organise things for me. So, yes, they are very good. They don't leave you on your own. (Carer 02, P2)

Other challenges, gaps, failings and harm

A number of participants described examples where they had repeatedly to chase up elements of care, were unable to get what they believed they needed despite repeated requests, or experienced poor or unprofessional care. In such cases, participants felt angry, unheard, neglected, or abandoned:

> [GPs] never ask to see me, and I can't keep chasing them. … I had a very good doctor years ago, who would ask to see me if he hadn't seen me for a while. But the care that you get these days is not as good because they've got too many patients. … I get a bit neglected sometimes because they haven't got time for me. (Patient 07, P1)

> [Formal carers] would try and mock [my husband] and I by doing things, like [my husband] would say to them, 'Please, as you come into the kitchen, close the back door, don't leave it wide open' because moths would come in. So they would leave it deliberately open and laugh about [my husband] and I, and leave mess everywhere, in the kitchen, or things like that. (Carer 06, P2)

A few carers reported feeling undervalued. A carer whose husband was the focus of professional input explained how she was made to feel invisible:

> Yes, it's lost in the information of what am I, who am I? You know? And I can see me being on a list as carer, but that's my whack, isn't it, because no one actually comes to see who [interviewee] is. I mean, when they phone me, a lot of these people, they say, 'Oh, are you [interviewee]?' And I think, 'You've got my phone number, you're phoning me.' (Carer 02, P1)

While dissatisfaction with professionals or services was sometimes couched in general terms, a number of participants recounted episodes where potential or actual harm had occurred - wrong medications were administered or misdiagnoses made:

> I went to see a GP who decided I probably had a urinary infection. Well, I didn't think I had, but if you've gone there you don't start arguing. He put me on antibiotics over the weekend and, of course, on the Monday, I think it was, my appendix ruptured, so then there was a lot of consequences from that. (Patient 05, P2)

Such errors were generally attributed to communication gaps, miscommunication, professionals being too busy, or human error. A few participants had made formal complaints about their care. However, others were reluctant to do so. They did not wish to question professional expertise and judgement, or believed professionals were doing their best in difficult circumstances where services were overstretched and COVID-19 was taking its toll.

Participants also suggested that complaining would not achieve anything, that future care might be negatively affected, and/or that complaining was too challenging alongside dealing with existing health problems. As one participant said:

> 'If you grumble about something, youre not going to get the help, are you? (Patient 10, P2)

Perceived impacts of COVID-19

COVID-19 impacts on patient and carer wellbeing. Only four participants reported having contracted COVID-19. Some patients had only rarely left their homes pre-pandemic or

were used to being alone. As such, they were not unduly concerned by the enforced isolation of the initial lockdown.

However, the majority of patients felt the pandemic's broader effects in changes to their routines. Lockdowns meant they missed meeting family and friends, could not socialise at home or elsewhere, and felt bored, frustrated, lonely or more depressed. Carers suffered similarly, and went without respite from their caring duties:

> Not being allowed to even go past the front door or down the path to speak to somebody. And you see people going past and they give you a wave. And it does bring your mood down because it makes you tearful because you desperately want somebody to stop, come to the window and have a chat. (Carer 06, P2)

Participants took stringent precautions to avoid catching COVID-19, including not having visitors, going out only for exercise or shopping, wearing facemasks when out, socially distancing, or avoiding crowds. Patients' dependence on carers appeared to increase following the start of the pandemic, especially for help with activities such as shopping. Some, however, started online shopping and socialising. Additional offers of help from neighbours, community organisations and churches were reported, and a few received council food parcels. For carers, COVID-19 brought increased responsibilities for protecting patients:

> No, we don't let people come into the house and visit like [during] what I call 'the good old days.' They either stay at the door or a distance away from me. (Patient 11, P2)

> [My patient] carries antibac [antibacterial hand gel], he wears a mask. I just couldn't risk him picking something up. So, if he goes out, he only goes out once a week with me. (Carer 03, P1)

COVID-19's impacts on services. Many participants reported receiving NHS or local authority information about COVID-19. This was generally deemed useful, although some felt sufficiently informed by, for example, television broadcasts. A number received COVID-19 vaccines at home, and local authority carers and NHS professionals continued making home visits to some patients throughout the first lockdown. Professionals were described as wearing personal protective equipment and taking precautions to prevent the spread of COVID-19. Nonetheless, a few patients and carers did not want home visits or cancelled routine hospital appointments, for fear of catching the virus:

> When she [the patient] came home, … they got in touch with us and asked us what support we would need. Obviously, the COVID had just started then, and I didn't want to involve as many people. I wanted as few people as possible coming to the house - for our wellbeing and our safety, as well as the people that were coming. (Carer 01, P2)

One widely experienced change was that contact with health care professionals was largely by phone rather than in person. Where routine hospital appointments were cancelled, a few patients described having positive phone or online consultations instead. Some viewed the changes as necessary to control the spread of COVID-19 or believed that new ways of communicating with their general practices benefited them. A couple described measures put in place by their general practices to ensure that 'shielding' patients (i.e. those individuals who were deemed extremely vulnerable clinically and therefore most at risk of contracting COVID-19 and who had been advised by the NHS not to leave home and to avoid face-to-face contact with others where possible) could be seen in person.

Others found the lack of in-person consultations with their GPs challenging, suggesting, for instance, that their health complaints could not be properly diagnosed or managed:

> Any issues which she [the patient - the carer's mother] did have, we could just use a photograph and telephone interview with the GP. And that worked really, really well. The same with the specialist with mother's legs. Again, that worked well - where I was just sending them photographs via email and telephone interviews. (Carer 07, P2)

> How can they [GPs] examine you over the phone? They can't. They can only take your word for it, and then they give you some antibiotics. So, in other words, they could give those antibiotics to anybody, couldn't they? Just talking over the phone and say, 'I'm poorly,' and what have you. You should be seen by the doctor. (Patient 12, P2)

Improving health and social care services

The desired improvements in care often mentioned by participants were better access to GPs, improved communication, and increased checking on patients and their carers:

> If we could get a few more house visits. … This virus thing has set everything back, hasn't it, and we have to be careful what's happening. But I think when that's over there should be more doctors prepared to go and visit people. (Patient 13, P2)

Some carers suggested that having more time with professional services or respite from caring would improve their overall wellbeing.

Discussion

Our results are in line with previous studies, which have found patients and carers value being treated as an individual, receiving adequate information, and trusting/having

confidence in professionals.[20–22] GPs were central to our participants' accounts, with perspectives ranging from positivity about GP services and novel approaches to consultations during COVID-19, to frustration and distress associated with difficulties obtaining desired GP services. Registered patients are expected to have a named, accountable GP,[23] and seeing the same GP a greater proportion of the time is associated with fewer hospital admissions for conditions manageable in general practice in those aged 62 to 82 years.[24] However, this does not mean patients get to see the same GP. Continuity of GP care is a component of access often overlooked by policymakers in favour of number or timeliness of appointments offered.[22] With data suggesting that 8.4% of permanent GPs left general practice in England in the year ended December 2021[25] and unknown long-term impacts of COVID-19 on services, GPs' capacity to meet older peoples' expectations is unclear.

Patients found managing health conditions, daily living activities, and interactions with services challenging, and expressed gratitude for the informal support they received. Even where MDT-led community case management is in place, family and friends have been viewed as essential to filling formal social care services' gaps.[17] While such non-medical services are not easily obtainable, and informal carers are filling the gaps, it is questionable whether care can ever be experienced as truly integrated.

Overstretched health care services placing responsibilities on patients and their social networks to be active 'partners' in or 'co-workers' in 'health care work'[(17, p3)] may eventually lead to poorer outcomes and increased stress for patients and carers.[26] Furthermore, in 2022, Carers UK[27] reported that 41% of carers surveyed had not had a break from caring in the previous year, with some reporting burnout. Carers UK argued that the Government should invest an additional £1.5 billion in carers' breaks. Acknowledging the key roles played by informal carers, Darzi[28] suggested that they constitute 'a provider of care who should be treated as an equal partner.'[(28, p70)] Further research, however, is required to explore not only issues around people's preparedness for taking on caring roles, often in middle- or older age, but also to understand the hidden work of care coordination currently undertaken by informal carers.

Given some of our participants' concerns regarding poor communication and information sharing, it does not bode well that MDT staff experienced information governance and IT interoperability-related barriers to information sharing.[14–16] Although shared health and care records are fundamental to the Department for Health and Social Care's integrated care vision and new information governance frameworks have been published,[29] better information sharing remains largely still an intention. Indeed, rather than ensuring that shared records, essential for not only for day-to-day patient care but also performance improvement, were in place, the Hewitt review of Integrated Care Systems[30] focused on what should be shared between such systems, NHS England, Department for Health and Social Care and the Care Quality Commission. In the MDT context, prioritising information sharing through shared records would facilitate front-line staff's patient-related communication and reassure patients that professionals have access to all of the relevant information required to provide them with the best possible care. This would also address National Voices'[20] argument that although people do not necessarily want to know that organisations involved in their care are 'integrated', they are concerned to know that someone is coordinating their care.

It is not uncommon for patients with long-term conditions, despite having care planning discussions, to report not having a formal care plan.[31] It is, though, surprising that so few patients on the caseloads of MDTs designed to coordinate and plan their care reported having one. Although some staff view patients' presence at MDT meetings as infeasible, including for practical reasons, their absence, and therefore their ability to participate in care decision-making, has been said to potentially constrain professionals' ability to provide patient-centred care.[16] New approaches to consultations (such as by phone or online, which have become routine since the COVID-19 pandemic) may facilitate the involvement of patients and their carers in MDT discussions. This could raise awareness among patients about the involvement of an MDT in planning and coordinating their care, and potentially lead to more patients having a named contact, maybe not on the MDT itself if its role is primarily coordination of care but on a related team delivering their care. Increasing patients' (and carers') awareness of, and involvement with, MDTs might also foster opportunities for developing MDT-specific performance assessment tools, and thereby address a staff concern - namely, their inability accurately to assess the effectiveness of MDTs.[15,16] Research is required to explore stakeholders' view of the feasibility and value of such approaches.

Limitation

There is one main limitation with our study. By not asking specifically about MDTs, as explained above, it is difficult to relate participants' views and experiences directly to the features of different MDTs. This raises the wider question for future research as to how to evaluate interventions from the users' perspective that are designed to operate largely 'behind the scenes'.

Conclusions

Our findings highlighted those aspects of care valued by patients and their informal carers. However, as long as the challenges our participants identified - such as timely access

to services - persist, patients and carers are unlikely to experience truly patient-centred care. Further, our findings indicate that the impacts on informal carers of providing informal care require greater attention from those co-ordinating patient care through MDTs.

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Ethical statement

Ethical approval

Research approvals and those for subsequent amendments were obtained from NHS Ethics (17/LO/0421) and the Health Research Authority (HRA) (IRAS 209623), the LSHTM research ethics committee (Ref: 14474) and the relevant Research and Development (R&D) Offices at the evaluation sites. Informed consent was obtained from all participants.

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Data availability statement

The datasets generated and analysed during the current study are not publicly available because they contain information that would identify the research sites, individuals, and/or case-material and it would not be feasible to redact or otherwise anonymise them. The data custodian is Professor Nicholas Mays, London School of Hygiene & Tropical Medicine.

Supplemental material

Supplemental material for this article is available online.

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