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Patient Decision Making

A qualitative study of patient choices in using emergency health care for long-term conditions: The importance of candidacy and recursivity



Cheryl Hunter^{a,*}, Carolyn Chew-Graham^{b,d,1}, Susanne Langer^{c,2}, Alexandra Stenhoff^{c,3}, Jessica Drinkwater^d, Elspeth Guthrie^{e,4}, Peter Salmon^{f,5}

- ^a Nuffield Department of Population Health, University of Oxford, Oxford, UK
- ^b Research Institute, Primary Care and Health Sciences, Keele University, Keele, UK
- ^c Department of Mental and Behavioural Health Sciences, University of Liverpool, Liverpool, UK
- ^d Centre for Primary Care, Institute of Population Health, University of Manchester, Manchester, UK
- ^e Manchester Royal Infirmary, Manchester, UK
- ^f Division of Clinical Psychology, University of Liverpool, Liverpool, UK

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ABSTRACT

Objective: We aimed to explore how patients with long-term conditions choose between available healthcare options during a health crisis.

Methods: Patients in North-West England with one or more of four long-term conditions were invited to take part in a questionnaire cohort study of healthcare use. Semi-structured interviews were conducted with a sub-sample of fifty consenting patients. Data were analysed qualitatively, using a framework approach.

Results: Patients described using emergency care only in response to perceived urgent need. Their judgements about urgency of need, and their choices about what services to use were guided by previous experiences of care, particularly how accessible services were and the perceived expertise of practitioners.

Conclusion: Recursivity and candidacy provide a framework for understanding patient decision-making around emergency care use. Patients were knowledgeable and discriminating users of services, drawing on experiential knowledge of healthcare to choose between services. Their sense of 'candidacy' for specific emergency care services, was recursively shaped by previous experiences.

Practice implications: Strategies that emphasise the need to educate patients about healthcare services use alone are unlikely to change care-seeking behaviour. Practitioners need to modify care experiences that recursively shape patients' judgements of candidacy and their perceptions of accessible expertise in alternative services.

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E-mail addresses: cheryl.hunter@dph.ox.ac.uk (C. Hunter), c.a.chew-graham@keele.ac.uk (C. Chew-Graham), s.langer@liv.ac.uk (S. Langer), Alexandra.Stenhoff@liverpool.ac.uk (A. Stenhoff), jdrinkwater@doctors.org.uk (J. Drinkwater), Elspeth.a.guthrie@manchester.ac.uk (E. Guthrie), psalmon@liv.ac.uk (P. Salmon).

1. Introduction

Health services in developed countries provide a range of options for healthcare in response to perceived urgent need [1,2]. Alongside a proliferation of care choices, health policy in many countries seeks to constrain and shape patients' care decisions in order to ensure that the service accessed reflects the level of medical need. Specifically, policies seek to reduce use of hospital emergency department care, mainly because of its high cost compared to alternative healthcare options [2–5].

Patients with long-term conditions (LTCs) are particularly frequent users of health care, and account for a large proportion of emergency care (EC) use [6–8]. In the UK and USA, policies have explicitly targeted people with LTCs in the attempt to constrain use of EC [2,8]. In addition to services available for acute illness, many patients with LTCs now have access to

^{*} Corresponding author at: Health Services Research Unit, Nuffield Department of Population Health, Rosemary Rue Building, University of Oxford, Oxford, OX3 7LF, UK. Tel.: +44 01865 289393.

¹ Tel.: +44 0178 273 3922; fax: +44 0178 273 3911.

² Tel.: +44 0151 794 4034; fax: +44 0151 794 5537.

³ Tel.: +44 0161 276 5326; fax: +44 0161 273 2135.

⁴ Tel.: +44 0161 276 5391/5331; fax: +44 0161 273 2135.

⁵ Tel.: +44 0151 794 5531; fax: +44 0151 794 5537.

additional types of practitioner, including specialist healthcare practitioners based in primary care or hospital clinics [9,10]. On the assumption that patients lack the knowledge to choose between services [11], or to manage their health needs effectively within the community [12], health policies emphasise shaping patient use of EC through education to address this purported knowledge gap [7].

Health policy thereby implicitly adopts a 'deficit' model of patients, as it asserts that patients require education in order to make effective choices, but this assumption has not been based on clear evidence about how patients with LTCs choose from available healthcare options in response to a health crisis. A recent review of qualitative studies of healthcare use in patients with LTCs found that patients' use of EC was influenced by their previous experiences of healthcare services, and reflected the values patients attributed to the different services [13]. For socially or economically marginalised patients, EC in particular offered access to care that might otherwise be unavailable to them [13]. This review suggests that, by focusing on patient education, policy may oversimplify how patients choose between healthcare services. However, a limitation of this review was that few papers addressed EC use directly. Moreover, none asked about instances where patients chose to avoid EC. In the present study, we aimed to elaborate on the processes by which patients with LTCs choose between available options for care in response to a health crisis, to inform the development of future policy and guidance on modifying EC use. Crucially, we explored, with patients, instances of EC use and instances of avoiding EC use.

2. Methods

The study was approved by NHS Research Ethics Committee 09/ $\,$ H1013/81.

2.1. Health system context

This study was based in North-West England. The UK National Health Service (NHS) is a public healthcare system that is free at the point of delivery to all patients [14]. Each patient has the right to choose a primary care practice and to express a preference to see a named general practitioner, and primary care is seen as the main healthcare provider for patients, with a key role in referring patients to other services [2]. However, patients can also access alternate healthcare services, such as emergency departments (EDs), out-of-hours primary care providers, and walk-in centres, without incurring financial cost.

2.2. Sampling and recruitment

The target population was patients, aged over 18, with one or more of four LTCs: chronic obstructive pulmonary disease (COPD); coronary heart disease (CHD); asthma; and diabetes. Patients were identified from Quality and Outcomes Framework (QOF) registers of general practices and invited to take part in the CHOICE cohort study (Choosing Health Options in Chronic Care Emergencies, http://choice.mhsc.nhs.uk/home.aspx). The QOF remunerates practices for providing evidence-based care in line with a series of clinical indicators [14]. Of 939 patients at six general practices within the cohort study, 474 (50%) consented to be contacted further. Out of those, we purposively sampled 212 people to invite for interview, aiming to achieve variation in age, gender, type and number of LTCs, and different levels of self-reported use of routine primary care and EC. Out of this purposive sample, 67 agreed to be interviewed, and a final sample of 50 people participated in semistructured interviews.

2.3. Data collection and analysis

Semi-structured interviews (conducted by CH and SL) in participants' homes (30–90 min duration, mean 46 min) began with discussion of the participant's health and social circumstances, then explored attitudes to, and expectations and specific experiences of, EC, primary care, and other healthcare and community services. During interviews, patients were guided to reflect on specific instances of using EC, the circumstances surrounding these and the factors which influenced these decisions. In addition, respondents were also asked to reflect on times when they did not use EC, and on what influenced decisions not to use EC services. Interviews were audio-recorded with the participant's consent, anonymised and transcribed verbatim.

Analysis used the framework approach [15]. Analysis was an inductive and iterative process, developing through discussions within a multidisciplinary team (with backgrounds in primary care, psychology, social anthropology, and psychiatry). We compared instances of using EC with instances when EC was not used, both across and within cases. A thematic framework was developed and honed through constant comparison of data between and within cases. Each transcript was coded in-depth in QSR NVivo8, using this process to refine and test the thematic framework across the entire data-set. Data collection continued until theoretical saturation was reached, determined through periodic discussion within the research team whose members also read the transcripts [16].

3. Results

3.1. Sample characteristics

Fifty patients took part in a semi-structured interview. All patients were registered with a general practitioner, and most were White British (n = 42); 34 were retired or unable to work due to ill-health. Asthma was the most common condition (n = 10), followed by diabetes (n = 9), but almost half (n = 24) reported more than one of the four LTCs of interest. Most patients reported other co-morbidities, such as arthritis (n = 28) and high blood pressure (n = 28). Age ranged from 39 to 86 years (mean 63.6). Thirty-six patients had used EC in the past year. Table 1 summarises participants' socio-demographic characteristics, as well as information on use of EC during the year.

3.2. Findings

Patients described a variety of symptoms prompting them to consider using EC, particularly breathlessness, pain, dizziness, and unusual sensations. They described the use of EC as unavoidable because of the inherent urgency of their need. However, analysis showed that the judgement that need was urgent, and choice of EC provider, were influenced by previous experiences of care. We present illustrative data to characterise these findings, below. The ellipsis in parentheses (...) signifies omitted text. Square brackets denote explanatory text.

3.2.1. Patients framed instances of EC as unavoidable

When patients were asked about EC services, they consistently described reluctance to use them. This reluctance was expressed as a desire not to feel like a "burden" on services:

I'd prefer not to be a nuisance, you know, and I'll phone them [hospital staff] up and take advice, but I'd sooner not go round and bother people (P23, female, 53 yrs, asthma)

Hospital EDs were seen as a "last resort", a service only to be accessed when other options were exhausted:

I kind of think that hospital is the last resort where you'd, where you've been through the doctor, or whatever and that's where you end up when you've got to have something done that the GP can't do (P09, female, 62 yrs, CHD & diabetes)

Patients recognised that need for help had to be unequivocally serious to justify using EC. Consistent with this, patients who used EC described doing so as unavoidable, using language such as "had to", "got to go", "I just knew" or "I needed it". There was no evidence of deliberation or uncertainty:

It's not something, it's not something you think about. I just knew I needed an ambulance there and then, I needed it as soon as possible (P10, male, 64 yrs, CHD)

It's just that painful, you've just got to go [to hospital] (P27, female, 54 yrs, asthma & COPD)

Likewise, when patients talked about instances when they chose not to use EC, they explained that their need was insufficiently urgent to require it, choosing to wait and attend primary care instead:

If it's something that I consider is minor (...) like with getting certain aches and pains [in] my tummy like I have been having or something connected with diabetes, I know I can get it sorted in the proper hours rather than out of hours, you know (...). Besides that, I think I've got in the back of my mind "I'm not getting everyone up for me to go to hospital (...) when I can sort it out tomorrow" type of thing (P33, male, 61, CHD, diabetes)

3.2.2. Previous experiences shape future EC use

Patients described how previous experiences of health crises and of healthcare services shaped their judgments about needing EC and their decisions about which EC service was most appropriate. The key aspects of previous experience were: prior negotiation of urgency with family or friends, or with healthcare practitioners in primary or specialist care; the technological expertise of different healthcare services; and the accessibility of services.

 Table 1

 Socio-demographic characteristics of participants.

	No. (%)
Gender	
Male	26 (52)
Female	24 (48)
LTC	
CHD	5 (10)
Asthma	10 (20)
COPD	2 (4)
Diabetes	9 (18)
More than one of above	24 (48)
Ethnicity	
White British	42 (84)
Black or Black British-Caribbean	3 (6)
Black or Black British-African	2 (4)
White Irish	1 (2)
Other white background	1 (2)
Mixed White and Black Caribbean	1 (2)
Use of emergency care in last 12 months	
None	15 (30)
1–2 times	23 (46)
3 times or more	12 (24)

3.2.2.1. Negotiating and establishing urgency. Patients' understanding of what constitutes urgent need (and thereby justifying EC) was based on previous experiences of exacerbations and the responses of family and friends and healthcare services at those times. These experiences then guided patients' future choices of when to access EC and of which EC service to access.

Some patients talked about other people as the key decisionmakers in their use of EC. These were often family or friends, but there were instances of healthcare practitioners fulfilling this role:

I said "oh I'm not bad". Anyhow I was going worse, obviously, and I couldn't get my breath and you know, I tried to get up and I felt really ill. And um, [my nephew] said "I'm sorry [aunt], but I'm going to have to get an ambulance" (P25, female, 80 yrs, diabetes & COPD)

The GPs have said that to me, "don't come, don't come here [to the GP surgery]. If you've got something, if it's your chest, go to hospital, because I'm just gonna send you to hospital anyway" (P02, male, 57 yrs, CHD & asthma)

In these circumstances, the patient was no longer making the judgement to use EC alone: this decision was sanctioned or made by another trusted decision-maker.

Judgements of urgency emerging from previous encounters with healthcare providers were then applied in future instances of help-seeking. Box 1 illustrates how practitioners reinforced one patient's concerns about his health. A specialist judged his initial choice of primary care to be inappropriate, and the patient inferred that he should access hospital emergency services in future. The care from healthcare practitioners at hospital thus established a pattern that favoured future use of EC.

3.2.2.2. Prioritising technological expertise over established relationships in times of crisis. Patients differentiated between routine primary care and EC services according to what they offered. Patients valued routine primary care as a source of personal relationships with practitioners:

I generally stick to one [GP] because he like gets to know your background and all your history and everything else, you know (...) but sometimes, like I said to you I just think what else can they do for me? (P27, female, 54 yrs, asthma & COPD)

Conversely, they valued EC services for their technological expertise, perceiving this to be unavailable in primary care:

They won't do x-ray there [at the GP surgery], they won't do, they'll give you tablets. If I go to A&E they get everything there, everything to take blood, to take wee [urine], and then it's sort me out there (P07, female, 44 yrs, diabetes)

At times of urgent need, patients preferentially sought technological expertise. This often resulted in using EDs, but a few patients valued – and used – other services because of their perceived technological, and often disease-specific, expertise, as established in prior instances of help-seeking:

Researcher: [If] you were getting really bad, um what do you think's the first thing you would do?

Patient: Um I'd probably phone [diabetic nurse at hospital] (...) just because I know she knows how to advise me on the [insulin] pump (...) That'd probably be first point of call (P11, female, 39, diabetes)

Previous experiences of services established this belief that routine primary care was not the best site for disease-specific care:

Box 1. Patient case – How practitioner responses shape patient's future judgements of urgency and need for EC

P33, male patient, 61 yrs, CHD and diabetes

This patient described how, before knowing he had a heart condition, he experienced palpitations. He chose to attend primary care, and his GP referred him to hospital. During the time between the GP's referral and the hospital appointment, he experienced pains between his shoulder blades and saw the GP again. The GP explained he might be having a heart attack. He was immediately directed to hospital, where he saw a cardiac surgeon. The surgeon insisted that he should have attended hospital earlier:

[The surgeon] was quite, you know, explicit, but he was being, he was being genuine about the way he felt. From all the angiogram and the tests I'd had, he couldn't understand how I was, how the blood was getting through at all (...) so he said, "I, I'd have expected you to be dead by now."

The cardiologist and the staff at hospital reinforced the importance of attending as soon as possible, and, since this incident a decade ago (which resulted in a bypass), the patient felt that "as far as my heart's concerned, there never is any hesitation anymore":

You realise that the support is there and you must use it to put your mind at rest because there's nothing worse than something festering and you sit here and you worry about it and you think about it, when you know for a fact that the support's there, so don't hesitate, just [go to hospital], that's what the people [at the hospital] are there for.

An episode in the six months prior to interview illustrated this point. He experienced palpitations which he described as "quite concerning. It wasn't necessarily painful, but because of this pounding in my chest I, I was a bit concerned about it". He called an ambulance immediately:

Because of the previous heart [problems], I know it was ten, eleven years ago, but, I get very anxious when things start to happen with my heart and I like to get it seen to straightaway.

My GP is a wonderful GP, but he's not geared to look after diabetics (...) The GP's a general practitioner, he knows an awful lot about a lot of things, but the diabetic clinic are specialists for that disease (P44, female, 54 yrs, diabetes)

Conversely, experience of services that were responsive and technologically capable informed future help-seeking, as illustrated by Box 2. This patient's prior experience of a severe exacerbation, and the safety afforded by the hospital's equipment and facilities, ensured his choice of this service in future.

In recent years, several services similar to routine primary care have been established in the UK to meet increasing demand, including walk-in centres and out-of-hours primary care providers. Patients only rarely talked about using these services. When patients did mention them, it was as less preferred and often ineffective alternatives that lacked both the technological expertise offered by hospitals and specialist clinics and the trusted relationships offered by routine primary care:

[Walk-in centre] don't do nothing to you, you just walk in and they look at you and they say go to your doctor, everything like that (P17, male, 77 yrs, CHD & COPD)

We go to A&E or I go and see my GP. It's very rare I use the emergency doctor (...) Because, again, the emergency doctors, 'cos they're restricted to what they can do as well, a lot of them'll say to you 'Well, you know, go to A&E', because I have a bad heart and I'm diabetic and everything else (P45, female, 41 yrs, CHD & diabetes & COPD)

Box 2. Patient case – How previous experiences of technological expertise and accessibility shape future choice of service

P43, male patient, 62 yrs, asthma

Several years ago, this patient experienced a severe episode of asthma, where he was taken to the hospital and admitted for over a week. The experience of this severe episode meant that the patient saw his asthma as potentially "life threatening" and himself as being "given a second chance" to look after himself. He praised the care in the hospital during this episode as being immediately responsive and without fault, and his experiences of hospital services since that episode had reinforced this praise. His belief in the hospital's technological expertise even extended to being treated in the emergency department without being admitted:

I mean I've spent, on one or two occasions when, not for a long time, er, when I've had, er, felt an attack coming on, I've probably spent seven hours on a trolley in a cubicle. But I'm quite happy to do that because I know it's not where you are, as regards being in a cubicle, it's where you are as regards being in a hospital. You would still get the same treatment in the cubicle as you would on a ward

He reflected that he would now rely on the emergency department of the hospital if he experienced another asthma exacerbation in the future:

If [the hospital staff] know you're having any sort of attack or symptoms related to your asthma, they, they are good. I think they realise that it is asthma and it's an attack coming on and they can get you in there quick. Whereas if you go to a doctor and he starts having, even though a doctor is qualified to know that it's an asthma attack, they probably haven't got the equipment and the facilities to, to bring you round if anything should happen very quickly. Where in hospital they've got everything there. they've got the ventilators, the drips, they've got everything, they can resuscitate you, if need be (...) I feel safe going in a hospital. He contrasted his certainty that the hospital was equipped to look after him when he suffered from asthma exacerbations with his experience of primary care as lacking in the expertise to recognise and respond to asthma exacerbations as a potential emergency: "You seem to get rebuffed every time you go [to the general practice]". "They don't seem to think that [asthma] is a priority"

3.2.2.3. Judging accessibility of services. Patients experienced numerous barriers to unscheduled access to primary care at their general practices. Barriers were mainly organisational, including limited opening hours, poor or delayed availability of named practitioners, gate-keeping practices by reception staff, and restrictive appointment systems.

Sometimes I don't have the money to go up to see my doctors, and to see my doctor you have to be there at, like, 8 o'clock, half past eight because there's a queue (...) It doesn't open on 9 o'clock but there could be (...) 15 people stood outside waiting to go in to see [the doctor] (P40, male, 57 yrs, COPD)

Some patients, like P40, found travelling to primary care practices difficult, due to a combination of ill-health, inability to afford taxis, and poor public transport. When patients talked about walk-in centres and out-of-hours primary care providers, they were described as more accessible than routine primary care, as the barriers around appointment systems and travel tended to be reduced:

Very, very rare have I phoned up the doctor and been able to get in, you know what I mean, like, you know, to see my GP within two or three days. It's nearly always next week, or the week after or whatever, so you need the err, you need the out of hours doctors really to help you out for them situations (P24, male, 59 yrs, asthma)

Out-of-hours doctors who could perform home visits, and walk-in centres based in central locations with good transport links (in city centres or at hospitals) reduced the resources required for access.

[The out of hours service have] come out and seen me [at home] (P23, female, 53 yrs, asthma)

However, whilst some patients described these services as accessible, we saw above that they were thought unable to meet patients' needs. The hospital ED, by contrast, was seen as both readily accessible and providing technological expertise:

[At the hospital ED] I always get seen to straightaway, no matter what (...) Once when I'm there, I know I'm alright, because I know they can pinpoint what it is and what's doing it (P02, male, 57 yrs, CHD & asthma)

The accessibility of a service therefore influenced patients' use of healthcare both in the event of non-urgent need, and in the event of urgent need. Routine primary care was typically least accessible, requiring the most effort to use, whereas the hospital ED was the most accessible, with the additional benefit of readily available technological expertise.

4. Discussion and conclusion

4.1. Discussion

Patients draw on previous experiences of services and practitioners when choosing how to respond to illness exacerbations. The choice of EC vs routine primary care was shaped by patients' perceptions of urgency, which were in turn influenced by previous responses from healthcare practitioners, and by involvement of friends or family. Choosing between different EC providers was also shaped by perceptions of those services, formed by previous experiences of their accessibility, and technological expertise.

Two theoretical concepts from the healthcare access literature, hitherto unapplied to the problem of EC use in people with LTCs, provide an interpretive framework for these findings [17,18]. The first, 'candidacy', describes how access to healthcare is framed as often requiring work for patients to achieve, and eligibility to access care is continuously negotiated in patient-practitioner interactions [17]. Developed from interpretive synthesis of literature on access to healthcare in socio-economically disadvantaged groups [17], the concept has been applied to healthcare use in other vulnerable populations [19,20]. The second concept, 'recursivity', describes how future demand for services, and the process of help-seeking, is determined by a patient's previous experiences [18]. When considered together, the concepts of candidacy and recursivity highlight that the key determinants of patient choice of healthcare are social and diachronic, with future healthcare use contingent on prior service responses to patients' requests for care, and on previous experiences of the social process of care [17,18,21]. Patients rely on experiential knowledge of services and practitioners to choose between services and to establish their candidacy for accessing services.

The establishment of candidacy was evident in patients' accounts of interactions with practitioners in both primary and secondary care services. Box 1 describes a pivotal instance of healthcare in response to palpitations (perceived fast or irregular heart beat) wherein the specialist and hospital staff ratified the patient's decision to use EC. Negotiations of candidacy were sometimes bypassed by family and friends who acted on behalf of patients. Patients were sensitive both to practitioners' responses to a request for help, and to the responses of family and friends; both recursively shaped patients' candidacy when making future

healthcare decisions, demonstrating that help-seeking is a social process involving more than just patients' decisions.

Recursivity was seen in patient accounts of how they chose between healthcare services, particularly in the choice to use EC. They framed these choices by drawing on previous experiences of help-seeking. Although patients described using EC as inevitable, their judgements of urgency and their understanding of why EC was 'inevitable' were socially conditioned, arising out of previous encounters with healthcare practitioners, family and friends, and particular services. Box 1 illustrates recursivity in how judgement of urgency, and ultimately candidacy for accessing care, is established through previous encounters. Similarly, Box 2 illustrates how previous experience of particular qualities in a healthcare service (in this case, easy accessibility and technologically capability) ensures future reliance on that service for similar problems. That is, previous experiences of a service can build a foundation of trust which strengthens patients' confidence in choosing that service in future [22].

Patients experienced barriers to using primary care in times of urgent need, and this recursively shaped future choices between services. 'Permeability' offers a way to conceptualise the impact of these barriers [17]. Highly permeable services require less work and fewer resources from patients who access them – for example, EDs in the UK which are open at all times. A service that seems accessible may in fact be impermeable to particular patient groups [19]. For example, despite general practices being locally available, with designated systems for urgent access, patients in our study described that they were, in fact, impermeable because of factors such as receptionists' gate-keeping, and travel cost or mobility problems. In our study, the combination of high permeability and technological expertise led most patients to choose the hospital ED in times of perceived urgent need.

In seeking to reduce EC use, healthcare policy defines patients as in need of education to use services effectively, or suggests the need for reorganisation of healthcare systems to reduce use of costly emergency care services, especially the ED [2,7,23]. This 'deficit' model also dominates previous research investigating EC use, with research focusing on characteristics of the patient [3,24–26] or the healthcare system [11,27,28] that increase EC use. In contrast, this qualitative study demonstrates that patients understood the array of EC services available and were discriminating in their use of them, influenced primarily by previous experiences of services which recursively shaped their future healthcare choices. It contributes to a growing body of research which emphasises the social processes of help-seeking, and the expertise patients bring to decision-making around healthcare use [19,21,29,30].

4.1.1. Strengths and limitations

Our participant sample was large and heterogeneous with respect to age, gender, level of healthcare use (routine care and EC) and types of LTCs. We also probed in-depth about instances when they used EC and instances when they did not use EC, and prompted participants to reflect on their decision-making processes about what healthcare options to use and when to use them.

This study has several limitations. First, it is possible that patients recounted previous use of EC in what they believed to be publicly defensible ways [31]. The use of serial qualitative interviews [32] examining patients' healthcare use over time, might enable access to more private accounts, whereby patient's decision-making can be discussed more openly with a familiar researcher. This approach would enable further insights into the establishment of patterns of healthcare use and how these patterns might be changed.

Second, the study was limited to one geographical region, which may limit the transferability of the specific findings to other

settings. For instance, in our study, hospital EDs were perceived to be most permeable and to offer technological expertise; this is likely to vary across different health care systems [13,33]. However, the theoretical development the study enabled may be transferable to other locations. Finally, most participants were White British patients who spoke English as their first language (n = 42) and some ethnic minority groups were not represented (e.g. South Asian patients). The method of recruitment (via a questionnaire study) is likely to have influenced the recruitment rates of different ethnic groups.

4.2. Conclusion

Previous research has applied the concepts of candidacy and recursivity to understand healthcare use of patients who are vulnerable for socioeconomic reasons [20,21]. In this study, these concepts help to understand healthcare decisions of a different patient group when they are vulnerable because of health crises. In contrast to the 'deficit' model that underlies the view that patients need education to reduce their EC use, our findings demonstrate that patients with LTCs are highly knowledgeable and discriminating in their healthcare choices. They prioritise experiential knowledge when choosing between services. Relying on experience makes sense, given that previous research indicates advice from different healthcare services can contradict, for instance with different professionals giving conflicting messages about using EC [34]. When patients with LTCs feel vulnerable in health crises, it is their previous experience of services that shapes their perception of candidacy and thus their choice of service to access, with patterns of under- or over-use of services becoming established recursively based on these responses.

4.3. Practice implications

We found that patients are discriminating and knowledgeable, relying on experiential knowledge to guide future behaviour. Therefore, to change the way such patients use health care services, a policy shift is needed which accounts for the role of patient–practitioner relationships, family and friends, and past service responses in shaping future healthcare decisions.

Patients prioritise services, particularly the ED, which prior experience has taught them offer technological expertise and easy access. These patterns are unlikely to be changed except by changing patients' experiences. This would require a consistent response from healthcare professionals that indicates to patients what different services can offer. The emphasis of policy should be on shaping those patient–practitioner interactions within which candidacy for healthcare use is recursively established, and on intervening in the experiences of services, as these frame patients' future healthcare choices.

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