Highlights (for review)

Examining the Knowledge Work of Person-Centred Care: Towards Epistemic Reciprocity

Highlights

- Qualitative study to explore the knowledge work of person-centred primary care
- Consultations need broad exploration, reflexive listening and reciprocal inquiry
- Epistemic reciprocity is needed for clinical consultations to be person-centred
- Healthcare redesign needs to allow for patient and doctor reflexive knowledge work

Title page

Examining the Knowledge Work of Person-Centred Care: Towards Epistemic Reciprocity

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Abstract

Objective – It is increasingly recognized that when healthcare staff fails to give adequate credence to patients' illness-related knowledge work, this epistemic injustice undermines person-centered care. Therefore, we set out to examine the experiences of people with long-term conditions with knowledge work in healthcare settings to identify changes needed to strengthen person-centred primary care.

Methods – We designed a qualitative study and recruited people with long-term conditions in the UK. We conducted individual interviews (analysed using interpretive phenomenological analysis) and focus groups (analysed using thematic analysis), then integrated findings from both methods through an approach focused on their complementarity.

Results – Participants described how successful person-centred consultations were characterised by a negotiation between patient and doctor and moments of broad exploration, reflexive listening, and reciprocal inquiry, which allowed for epistemic reciprocity.

Conclusions – Epistemic reciprocity is a core component of person-centred clinical consultations, fostering the co-creation of new knowledge of patient experience and need through the interactive knowledge work of patient and doctor.

Practice Implications – Medical education could benefit from initiatives that develop knowledge use and integration skills across primary care professionals. Accommodating for patient's and doctor's knowledge work during clinical practice requires redesigning the consultation process, including timing, headspace, pre-consultation, and post-consultation work.

Keywords: person-centred care; primary care; chronic conditions; qualitative research; knowledge work; clinical consultations; patient perspective.

1. Introduction

Chronic conditions and their management form the biggest challenge for modern health systems, as one in three adults globally suffers from multiple chronic conditions [1]. A proposed response to this challenge has been for person-centred approaches to clinical care that make patients feel listened and valued as persons [2]. However, patients' complaints about healthcare professionals not listening to them persist [3]. These complaints have been reported alongside experiences of professionals dismissing patients' expertise [4], questions and preferences [5], and have been attributed to clinicians' limited insight into the patient's knowledge work and testimony on their illness experience [6].

Knowledge work refers to the search for, evaluation of, and use of knowledge for everyday work/activity, with the potential for knowledge creation [7]. There has been a growing consensus in the health and social sciences towards the incorporation of patients' voice and knowledge work into clinical encounters, for example through a recognition that patients can be experts [8], or through the development of guidelines for clinicians to facilitate patient involvement and shared decision-making [9].

In the UK, patient knowledge has been recognised as expertise by policymakers [10], yet the limited success of national policies focusing on it was found to be partly due to a reported failure of physicians to give due attention to patients' perspectives and work [11]. In particular, people with chronic conditions reported limited involvement in their own care [12] and decreased satisfaction with aspects of care such as listening, explaining, and decision-making [13], which involve using knowledge or relate to knowledge to some extent. When healthcare professionals discredit patient knowledge, they inhibit person-centred care [14], with the potential to create epistemic injustice [15].

Epistemic injustice describes situations in which a person is wronged in their capacity as a knower, namely being unjustly prevented from receiving or sharing knowledge [16]. According to Fricker [17], epistemic injustice can occur when someone's credibility is discredited because of prejudice and stereotyping (i.e., testimonial injustice, whose stereotypes might be based on different aspects of people's identity, such as gender or ethnicity), or when some people are excluded from activities that shape how their society understands concepts (hermeneutical injustice). Several studies (see supplementary material) have now identified examples of both epistemic and hermeneutical injustice in healthcare settings [18-22].

As Bogaert [23] suggested that rectifying epistemic injustice by focusing on patients' perspectives is paramount for the advancement of person-centred care, we set out to examine the experiences of people with long-term conditions with knowledge work in healthcare settings, in order to identify changes needed to strengthen person-centred primary care.

2. Methods

We designed a qualitative study employing individual interviews and focus groups, and adopted a phenomenological perspective to engage in an in-depth exploration of the participants' experiences with knowledge work during clinical consultations. Phenomenology in health and social research is regarded as "the study of human experience" [24], making it particularly suited to our study aim. In particular, we referred to interpretive phenomenological analysis (IPA) to analyse individual interviews about the participants' experience. To complement this focus on experiences, we conducted focus groups, as their interactive nature allows for the collection of a broader range of opinions and perceptions on clinical consultations.

2.1 Recruitment

Recruitment took place in Yorkshire (UK) and started after receiving ethical clearance (NHS REC reference 19/EM/0056).

We used purposive sampling to recruit the interview participants (twenty participants, table 1), namely heterogeneous sampling seeking participants with specific characteristics (adults with one or more long term conditions, able to speak English, give consent and recollect their healthcare experiences) but also variety across a spectrum of aspects relevant to our topic of study (i.e., time spent with the condition, type of condition, and GP surgery) [25]. To this aim, we approached local patients support groups and community groups that provided healthcare and social support to the community. We told the potential participants about the study, and invited those who met the eligibility criteria to get in touch with her if they wanted to participate.

For the focus groups, we used a combination of purposive and convenience sampling as we recruited participants from both patient support groups (purposive sampling) and two general practices in the area that offered to help with the study (convenience sampling). Inclusion criteria for the focus groups were the same as those for the interviews. FA made sure that the participants identified through convenience sampling also met the eligibility criteria. Twenty-two people participated in four focus groups (table 2).

For both interviews and focus groups, we made a maximum of two contact attempts via letter, e-mail or phone call, depending on which contact details were publicly available.

2.2 Data Collection

We developed the individual interview guide drawing on guidelines for phenomenology-based interviews, exploring three main areas [26]: the participant's life context, details of their healthcare experiences (with a focus on clinical consultations), and the participants' meanings and reflections on such experiences. The interview guide has been made available as supplementary material.

During the interviews, FA took field notes to document contextual information [27]. The interview guide was piloted with a heart disease patient, and was amended to make the questions easier to understand for the participants. Interviews' length ranged from 44 to 106 minutes, averaging to approximately 64 minutes. The site of the interview was always decided by the participants. Most interviews took place at the participants' home, six within the premises of the University, and one in a private, secluded area inside a café. In two cases, participants requested to be interviewed in pairs (with a friend/partner, who was also a participant) rather than individually.

We set the end of recruitment for the interviews by referring to data saturation, defined as the point in which nothing new is apparent [28]. We opted for data saturation because of its association with phenomenology-based studies [29], and defined it as the point in which the answers to an interview did not yield any new topics compared to the previous interviews.

The focus groups' schedule (available as supplementary material) aimed to elicit a variety of opinions and perceptions about clinical consultations. We piloted the focus group guide with a group of three participants. We considered the methodological implications of including data from the pilot focus group in the analysis as they provided relevant information in their own right [30], and decided to include them, as the pilot interview was recorded, and consent for participation was taken regularly before the group interview, with all the participants meeting the inclusion criteria. The duration of the focus groups ranged from to 60 to 114 minutes, averaging to approximately 87 minutes. A focus group assistant (a general practitioner in training) was always present to take field notes and help facilitate the discussion. Two focus groups were conducted within the premises of the University, one at a general practice surgery, and one at a place where the participants used to meet on a regular basis.

We opted for code saturation to set the end point for recruitment in the focus groups, defined as no emergence of new codes during data analysis [31].

Both interviews and focus groups were conducted, recorded (sound only), and transcribed by FA within two days from when they occurred. FA presented the focus of the individual and group interviews to the participants as an investigation of their healthcare experiences aiming to understand how to improve person-centred primary care services. This information was given in person as well as provided in written form on the participant information sheet.

FA did not have any prior relationship with any of the participants. She introduced herself to them as a PhD student doing research as part of her PhD degree. At the time of the interviews, FA had a Master's Degree in Health & Society and research experience in health promotion and qualitative methods. During her PhD, FA received further training in good clinical practice and qualitative data collection and analysis. The authors of this study are a team of academic clinicians and researchers in social and medical sciences, with expertise in qualitative research, (person-centred) primary care, medical generalism and health inequalities.

2.3 Data analysis

We adopted IPA [32] for the analysis of the individual interviews, as it aims to elicit the way in which people make sense of their lived experiences through its ideographic focus and context-rich data [33]. For the focus groups we referred to inductive thematic analysis, with the aim to keep an iterative and reflexive approach throughout the process [34]. We decided to use different analytical approaches because of the interviews' focus on lived experiences (which IPA allows to analyse in-depth) and the focus groups revolving around a range of people's opinions (that in this case would be better investigated through thematic analysis, being particularly suited for cross-comparisons across the dataset from an early stage of data analysis).

From the outset, we designed the data collection tools so that the interviews and focus groups could be mutually informative. We treated the individual interviews' data as the principal dataset, with the focus groups' data adding new perspectives on the phenomenon explored in detail by the interviews. To integrate the findings, we referred to the observations by Lambert and Loiselle [35] on the rigour of the combination of qualitative data. This meant charting (sub-)themes, comparing similar (sub-)themes and data across the two datasets, and investigating how different and similar perspectives contributed to the description of patients' and doctors' knowledge work during clinical consultations.

We have reported the steps we followed for data analysis and integration on table 3. Coding was carried out by FA, with SA and TA engaging in double coding on a portion of the transcripts (one and two transcripts respectively). FA kept sharing data and interpretations iteratively with SA and TA throughout the data analysis process.

As this study was carried out in the context of a larger PhD project, this paper reports the most salient findings about patients' and doctors' knowledge work during clinical consultations, namely the theme 'shared negotiation of knowledge', and its three sub-themes broad exploration, reflexive listening, and reciprocal inquiry.

3. Results

The findings describe a shared negotiation of knowledge, namely a process whereby patient and doctor interactively use their knowledge as they negotiate a shared understanding of the patients' illness experience and treatment plan. This negotiation consists of three elements: broad exploration, reflexive listening, and reciprocal inquiry.

3.1 Broad exploration

Broad exploration describes the patient's and the doctor's search for and identification of multiple types of information relevant to the patient's health problem. An example of doctors engaging in broad exploration was given by Emma, who had had two contrasting experiences when she got sick (table 4, quote A1). Her experience shows the difference between a narrow inquiry and a broader one (i.e., one that takes into account multiple types of information). In her story, one doctor was narrowing their focus on one specific set of data, namely the blood tests results, which were inconclusive (hence the decision to repeat them). The other doctor, on the other hand, did not focus solely on Emma's blood test results, but also on her exhaustion, thin face, and Emma being "quite gone" (hence the decision to refer her to an endocrinologist). Other participants described how patients themselves engage in broad exploration. For instance, Eva said it is important to be able to talk to the doctor about multiple problems (table 4, quote A2). Her account shows how her knowledge work in this case consisted in engaging in broad exploration by identifying several health problems related to her respiratory condition (i.e., sleeping and ankle swelling), and eventually constructing a story for the doctor by taking all these elements into account ("an accumulation of things to ask him about").

3.2 Reflexive listening

Reflexive listening refers to moments in which the doctor listens to the patient and the patient listens to themselves, bringing about further reflection and awareness. This sub-theme was derived from the analysis of the experiences that the participants had with the practitioner's listening attitude, and of their reactions to such experiences.

Jane described how being listened to prompted reflexive knowledge work as she was explaining why it is important to listen to patients during clinical consultations (table 4, quote B1). In her quote, Jane said that the information one is sharing "comes back". She describes a reflexive exercise in which what is told to the doctor, and comes from the patient, also returns to the patient in the form of "flashes of a way forward", hence giving a hint to advance in her journey with a long-term condition. Jane's choice of words such as "almost" and "flashes" indicates that what comes back during a consultation (which can be a realisation, an idea, a hunch, and so forth) needs to be integrated with other "little flashes". According to Jane, these hunches develop during the clinical consultation when the GP gives the patient time to talk.

Ann offered another perspective as she explained that thinking about her own condition and circumstances would have benefitted from the involvement of her doctor (table 4, quote B2). Her account highlights the importance of the doctor's role in supporting the patient's knowledge work when it comes to reflective (i.e., "think about it") and learning ("tell me about it") activities. When she went home to "think about" her own condition, she realised that she needed somebody "there" – not necessarily physically at home, but in her reflexive moment. This example echoes Jane's account in that the patient's reflexive moment is best experienced with a health professional rather than on one's own, and highlights how the moment of listening does not belong to the doctor alone, but to the patient as well, who listens (to themselves and to the doctor) as well as being listened to.

3.3 Reciprocal inquiry

During moments of 'reciprocal inquiry' patient and doctor work together to integrate their perspectives in constructing a plan to move forward grounded in mutual understanding.

According to the participants, the doctor's engagement in reciprocal inquiry was characterised by flexible integration of different types of knowledge. An example was given by Victoria, who was recalling a time in which she negotiated with her GP to stop taking some of her medication, as she thought she did not need it and that it was needlessly expensive (table 4, quote C1). In this example, Victoria's GP did not accept her request immediately. Firstly, he set a condition (i.e., that Victoria knew that her body was ready to come off that medication); then, he offered Victoria to meet halfway, by reaching a compromise: Victoria would stop taking the stronger and more expensive medication, but would still keep the other one in case of need. Therefore, the outcome of this consultation was a flexible plan that supported Victoria's aims and knowledge work, as it gave her the opportunity to reflect on her body's readiness to stop taking that medication and understand and decide when to take the backup medication.

Not all the participants described examples of successful reciprocal inquiry. However, they would still assess the doctor's behaviour as well as the thought process that led a doctor to a certain conclusion. For instance, while suffering from a chest infection, Emily called her practice to ask for a nebuliser, namely a machine that can help people breathe by turning liquid medicine into a mist. Whereas a doctor told her that she could not have one, she explained that what the GP told her was not credible enough for her to follow his advice (table 4, quote C2). In this example, Emily refers to her own knowledge: she knew that a nebuliser could not heal her, but could only relieve her symptoms. On the other hand, the doctor had not visited her, hence she believed that he did not have sufficient grounds for his conclusions. Furthermore, Emily did not like the doctor's attitude (the way in which he conveyed his message), challenging the legitimacy of the GP's warning as she conveyed it felt more like a threat ("I must warn you: if you don't, you might die") and felt "horrible". Finally, for Emily, the doctor's advice was not relevant to her own preference (i.e., to die at home). This story thus provides an example of how the patient's engagement in reciprocal inquiry involves an assessment of the negotiation process that affects their decision.

A key characteristic of reciprocal inquiry therefore lies in the patient's and doctor's interactive insight into each other's ideas, as one-sided discussions were criticised by the study participants. Lorna, for example, said that her husband was not asked any relevant questions when he was hospitalised for breathing difficulties (table 4, quote C3). In Lorna's story, the doctors were busy making sense of what happened to her husband, but they were doing so among each other, and without involving him. In her example, there is no reciprocity between doctor and patient. According to Lorna, this led the doctors to the wrong conclusion (i.e., that her husband was a smoker). According to Jack, however, this was not only about misdiagnosing or being wrong: it also meant that Lorna's husband, the patient, was invisible, hence not a valuable party in the clinical investigation.

4. Discussion and Conclusion

Whilst it is widely recognised that there is a long-standing expectation that good doctors should be good listeners [36,37], our analysis demonstrates that patients also listen critically to their doctors, and take decisions accordingly. Therefore, whereas healthcare professionals are encouraged to engage with patients with "skill, curiosity and wonder" [38], perhaps we also need to recognise that patients can also be encouraged to engage with doctors with their own skills, curiosity and wonder. Within our data, we highlighted examples of patient and doctor working together to create a mutual understanding of a problem, and so define treatment options. We propose that this interactive work can be described through the lens of epistemic reciprocity, a core component of person-centred care that encompasses activities and processes that foster the co-creation of new knowledge of patient experience and need through the interactive knowledge work of both patient and doctor.

Epistemic reciprocity builds on the concept of epistemic injustice, stemming from a reflection on ways to prevent it through constructive interactions between doctor and patient characterised by broad exploration, reflexive listening and reciprocal inquiry. Such interactions aim to foster epistemic justice, which Geuskens [39] defined as “the proper inclusion and balancing of all epistemic sources”, the emphasis being on the virtues of the hearer [17,40]. However, epistemic reciprocity differs from epistemic justice in that it does not focus on the hearer’s virtues, but on reciprocal knowledge integration and co-creation, and on an epistemic effort of both doctor and patient that, along with the virtuous conditions described above, can foster epistemic justice.

Epistemic reciprocity also ties in with the concept of shared decision-making (SDM), which has been recognised to foster epistemic justice by breaking down hierarchies [41]. SDM has been defined as the process whereby patients and doctors reach a mutual agreement by taking into account patient preferences and outcomes probabilities [42]. Some elements of SDM (e.g., the focus on mutual interaction and information sharing [43]) overlap with reciprocal inquiry as defined by this study. However, reciprocal inquiry focuses more narrowly on the strictly epistemic processes that facilitate such interaction, such as the doctor’s interpretive and generalist skills (i.e., knowledge integration and complexity management) [44], and the patient's critical assessment of the doctor's messages.

This study has some limitations. Firstly, we are aware that we focused exclusively on the patient’s perspective, because our starting point was a need to examine patient-derived concepts to understand how to rectify epistemic injustices. Nevertheless, clinicians are at the centre of the clinical consultation together with patients. Further research is needed to investigate the learning and knowledge work of clinicians, to understand their perspective on and the interactive knowledge work of the clinical consultation. This might warrant the use of different methods (e.g., observations) to also investigate the epistemic interactions of both patients and clinicians during clinical consultations.

Furthermore, this study involved a group of relatively active participants, who belonged to either a patient support group or a patient participation group. This is important for interpreting the findings, as it is possible that patients that engage less (if at all) with health or community services have different epistemic priorities throughout their illness experiences. Along the same lines, people with moderate to advanced dementia or cognitive impairment (who have been excluded from this study) may have a different way to learn and develop knowledge about their conditions, or to engage with clinicians.

The participants were also quite homogeneous in terms of ethnicity and sexual orientation, with a majority (n= 14) of the participants in the interviews being female. However, epistemic positioning is an important aspect of epistemic injustice, as it uncovers how social inequalities affect the evaluation of knowledge claims [45]. Whereas we tried to recruit participants of varied backgrounds, we did not manage to reach them. This might be mitigated in the future by referring to more appropriate strategies to recruit hard-to-reach groups in qualitative studies, such as engagement with gatekeepers [46] or multiple contact attempts [47]. We also suggest this could open further areas of inquiry focusing on patients of more varied social and ethnic backgrounds. Nonetheless, we managed to include a variety of other characteristics, such as type of conditions, socioeconomic status, and being registered to different surgeries.

We addressed potential limitations of our sampling strategies by conducting a prior literature review to inform recruitment choices [48], and making sure that the sampling judgements stemmed from a clear framework (for example, we recruited people with long-term conditions because they were found to experience epistemic injustices) [49]. Furthermore, during the analysis, we made sure to look at contrasting examples (e.g., positive and negative healthcare experiences; presence or lack of knowledge work; and so forth) and explore a variety of circumstances.

5. Conclusions

At the start of this study, we set out to investigate what an analysis of the knowledge work done by adults with chronic conditions during clinical consultations could tell us about changes needed to strengthen person-centred primary care. We identified epistemic reciprocity as a core component of person-centred care, guiding the clinical consultation and fostering the co-creation of new knowledge of patient experience and need through the interactive knowledge work of patient and doctor.

In the previous section, we suggested that exploring the knowledge work of different groups of people and with different methods could open new research avenues. However, future research could also support the development, implementation, and evaluation of guidance and interventions to integrate epistemic reciprocity in medical education and clinical practice, and to identify barriers and enablers to its implementation to guide the redesign of healthcare and support person-centred approaches.

5.1 Practice implications

Regarding medical education, it is important to frame person-centred care not only as the ethical thing to do, but also as the wise and competent thing to do. A step in this direction has been done in the field of health professions education, where a shift in culture has been called for, promoting new skills, knowledge and dispositions [50] and greater focus on patient knowledge and narratives [41]. Along these lines, we suggest that medical education curricula would benefit from training in the robust and safe construction of knowledge-in-practice-in-context [51], and in subjects such as interpretive medicine, which consists in the use of a range of different types of knowledge through the practitioner's reflective judgement [52].

For clinical practice, it is important for clinicians to allow for the patients' reflexivity. However, this means addressing the realities of primary care practice in the UK. The short time reserved to each consultation, along with the significant workload that GPs experience in their daily work, prevent both patients and doctors to engage in an in-depth exploration of the patient's circumstances [53]. It is paramount to address these issues if we are to achieve epistemic reciprocity and enable both patients and doctors to engage in meaningful person-centred knowledge work during clinical consultations.

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Tables

Table 1. Characteristics of study participants (individual interviews). Not all the characteristics have been disclosed because of ethical reasons. For every participant, only the type of their primary health condition, as indicated by each participant, has been reported. If the participant also reported having at least another long-term health problem, this has been indicated with the expression "multiple long-term conditions". Participants have been listed below based on interview (chronological) order.

#	**Pseudonym**	**Sex**	**Age range**	**Type of long-term condition(s)**
1	Mark	Male	50s	Neurological condition, multiple long-term conditions
2	Emma	Female	50s	Endocrine condition
3	Mary	Female	60s	Kidney disease, multiple long-term conditions
4	Jane	Female	70s	Neurological condition, multiple long-term conditions
5	Kyle	Male	70s	Heart condition
6	Victoria	Female	70s	Endocrine condition, multiple long-term conditions
7	Owen	Male	60s	Heart condition
8	Angela	Female	60s	Sleep disorder, multiple long-term conditions
9	Ada	Female	70s	Respiratory condition
10	Eva	Female	70s	Respiratory condition
11	Claire	Female	40s	Endocrine condition
12	Martha	Female	70s	Heart condition, multiple long-term conditions
13	Charlotte	Female	70s	Joint disease, multiple long-term conditions
14	William	Male	40s	Neuromuscular condition, multiple long-term conditions
15	Emily	Female	60s	Respiratory condition
16	Oliver	Male	60s	Respiratory condition, multiple long-term conditions

17	Patty	Female	70s	Respiratory condition, multiple long-term conditions
18	Tessa	Female	60s	Respiratory condition, multiple long-term conditions
19	Ann	Female	60s	Respiratory condition, multiple long-term conditions
20	Thomas	Male	60s	Respiratory condition

Table 2. Characteristics of the study participants (focus groups). As for the participants in the individual interviews, not all characteristics have been disclosed because of ethical reasons. Some participants have not indicated one primary health problem, but a series of health problems. In this case, the expression “multiple long-term conditions” has been reported on the table. Focus groups have been listed in chronological order.

	Pseudonym, sex, and age range	***Long-term conditions***
1	1) Jack, male, 70s 2) Fiona, female, 70s 3) Lorna, female, 70s	1) Endocrine condition 2) Endocrine condition 3) Multiple long-term conditions
2	1) Daniel, male, 60s 2) Liam, male, 70s 3) Laura, female, 70s 4) Lily, female, 70s 5) Nora, female, 80s 6) Alex, male, 60s	1) Multiple long-term conditions 2) Multiple long-term conditions 3) Multiple long-term conditions 4) Joint disease 5) Multiple long-term conditions 6) Multiple long-term conditions
3	1) Adrian, male, 70s + carer (carer was not a participant) 2) Erin, female, 60s 3) Samuel, male, 60s 4) Lucy, female, 70s 5) Julia, female, 60s 6) Nathan, male, 70s	1) Multiple long-term conditions 2) Multiple long-term conditions 3) Multiple long-term conditions 4) Multiple long-term conditions 5) Respiratory condition 6) Multiple long-term conditions
4	1) Lena, female, 70s 2) Cindy, female, 70s 3) Colton, male, 70s 4) Matt, male, 60s 5) Michelle, female, 60s 6) Simon, male, 70s 7) Evan, male, 60s	1) Multiple long-term conditions 2) Multiple long-term conditions 3) Multiple long-term conditions 4) Multiple long-term conditions 5) Multiple long-term conditions 6) Multiple long-term conditions 7) Multiple long-term conditions

Table 3. Steps we took for data analysis and integration of the findings.

Data analysis steps - Individual interviews; informed by Smith [32]	**Steps Data analysis steps - Focus groups; informed by Braun and Clarke [34]**
Become familiar with the data	Become familiar with the data
Preliminary inductive coding	Generate initial codes (inductively)
Deciding on a topic to investigate through further in-depth analysis	Search for themes
Creating excerpts including all instances of the chosen topic	Review themes
In-depth coding of the excerpts and writing thematic summaries	Define themes
Developing and refining themes	Producing the report
Producing the report	.
Integration of interviews and focus groups findings; informed by Lambert and Loiselle [35]	
Listing themes derived from the interviews and focus groups separately	
Group together comparable themes from different datasets (e.g., themes with similar focus, topic, and so forth)	
Charting similar sub-themes and comparing interviews' and focus groups quotes' (reflecting on how they informed each other)	
Refine themes (e.g., the sub-theme "eliciting information", initially derived from the individual interviews, became "reciprocal inquiry" upon noticing how focus groups data on the elicitation of information were characterized by a wish for reciprocity).	
Checking and reviewing themes (e.g., in the case of the example above, this meant going back to the interview dataset to look for any instances of reciprocity to further clarify the theme's scope and definition)	
Defining themes and producing the report	

Table 4. Participants’ quotes (results’ section). Focus groups’ quotes present the abbreviation “FG” right after the quote.

Theme	**Participants’ quotes**	
Broad exploration	**A1**	I was very ill, before diagnosis, and I kept going back, and the female doctor that I had there, […] [pushed] for me to have an endocrine appointment, and the other doctor in the surgery […] thought “I’ll give her another month or so, and have another blood test” […]. [The female doctor] kind of persevered instead of just thinking “oh well, it might be a viral problem”… you know, the blood tests weren’t conclusive, but she could see that I was totally exhausted and I was quite gone as well, my face was thin and I had varied symptoms. *– Emma, F, 50s, endocrine condition*
	A2	When you go to the doctor, it’s not just about your [respiratory condition], [your respiratory condition] causes other problems as well. […] I was sleeping too much, and me ankles are swelling as well, so by the time I’ve gone to the doctor I’ve got an accumulation of things to ask him about. *– Eva, F, 70s, respiratory condition*
Reflexive listening	**B1**	[Being listened to is important] because you can hear yourself. […] So [what you say] comes back, and you see it, you just see flashes of a way forward. And so, to me, the journey has been by degrees with a long term [condition], and it’s like little flashes that add up, and add up, and add up, and add up, that just give you that… bring you to where you are now. So there’s no one thing – it’s always more things that bring you to this whole thing for me, and being listened to [does that]. *– Jane, F, 70s, neurological condition, multiple long-term conditions*

	B2	It does take time to get it into your brain, [and] to know what you’ve got as well. […] I think some doctors leave you too long and not tell you about [the condition]. I think they say “go home and think about it” – yeah, you’re going home thinking about it, but you need somebody there… to, you know… I’m a knowing person, I need to know […] tell me, do you know what I mean? Tell me what I’ve got, tell me about it, tell me! – *Ann, F, 60s, respiratory condition, multiple long-term conditions*
Reciprocal inquiry	**C1**	I said “I want to come off some of my meds, can I come off?”, […] and he said “yeah, if you feel your body is ready to come off, and you’re ok, let’s take you off […], but I want [one of the drugs] as a backup for you to keep”. […] Well, it was two meds I wanted to come off, one was […] a drug for the more serious times, and it had a lot of side effects. Not that I was experiencing them, but I thought that I could have a tendency, and so I said “I really don’t need a very expensive drug”. He said “ok, I’ll take you off then. […] But the other one, what I want you to do, is keep what you’ve got […] and then you’ve got a backup, just in case”. – *Victoria, F, 70s, respiratory condition, multiple long-term conditions*
	C2	[The GP] said “we do not let patients have nebulisers at home. If you need a [nebuliser], you need to be in hospital”. I said “no, I ain’t going in hospital”, so he said “well, I must warn you: if you don’t, you might die”. [...] Oh, it was horrible […]. The [nebuliser] would have just relieved my symptoms and helped me breathe a bit better. […] But [this GP] hadn’t even seen me […]

		I: If he had said that in a different way, would you have gone to the hospital? Emily: I would have maybe considered it, yeah. But, when somebody’s telling me that... well, if I’m gonna die, I’m gonna die at home, you know? – *Emily, F, 60s, respiratory condition*
	C3	Lorna: When they took him in, it was the three doctors arguing… three doctors came to see him and were arguing whether it was COPD [chronic obstructive pulmonary disease], asthma, and all three of them came to the same conclusion he’d been a smoker. And he never ever had. Jack: But did they ask [him], “have you smoked?” Lorna: Well, one of the things… No. Jack: Exactly! And that would have cleared that up completely! […] Lorna: They just assumed he’d been smoking. Jack: If they went back to the room, they would never notice if he was missing. – FG, *Lorna, F, 70s, endocrine condition, multiple long-term conditions; Jack, M, 70s, endocrine condition*

Declaration of competing interests for the paper entitled "Examining the Knowledge Work of Person-Centred Care: Towards Epistemic Reciprocity"

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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List of studies on epistemic injustice (was previously table 1)

Examples of studies about epistemic injustice in healthcare settings. References on the original manuscript.

Study title	**Application of epistemic injustice**
Epistemic injustice in healthcare encounters: evidence from chronic fatigue syndrome [18].	Epistemic injustice is used to explain how the healthcare experiences of people with chronic fatigue syndrome might result in ethical concerns such as marginalisation.
The Legitimacy of User Knowledge in Decision-Making Processes in Mental Health Care: An Analysis of Epistemic Injustice [19].	Epistemic injustice is used as a framework to understand barriers involved in legitimizing user knowledge in decision-making processes.
Epistemic injustices in clinical communication: the example of narrative elicitation in person-centred care [20].	Epistemic injustice is used as a theoretical framework for the analysis of narrative elicitation during clinical consultations.
Language barriers and epistemic injustice in healthcare settings [21].	Epistemic injustice is used to describe the ethical issues that stem from the impact of language barriers on healthcare provision.
Epistemic Injustice in Health Care Professionals and Male Breast Cancer Patients Encounters [22].	Epistemic injustice is used to demonstrate how male breast cancer patients experience systemic stigmatisation and marginalisation in healthcare settings.

Individual interviews guide

The interview guide for the individual interviews is reported below. Arrows (→) indicate follow-up questions.

Welcome and introduction:

The interviewer introduces herself, the study aims, and reminds the interviewee about the ethical arrangements of the interview (e.g., the interviewee does not need to say anything that makes them uncomfortable, they can stop the interview or have a break whenever they want to, and so forth).

Interview questions:

1) Can you tell me how is it to live with a long-term condition?
→ Has your life changed since then?

2) Can you describe your typical day at a GP surgery? From the moment in which you decide to schedule an appointment to the moment you leave the clinic.
→ Probing with examples (e.g., detailed description of the clinical encounter, scheduling appointment, etc.) and extensions (i.e., can you tell me more about that? What happened exactly?)

***3)** Think back to the times you went to the GP. Do you remember a time in which you've left feeling particularly good? → What happened?
***3a)** Think back to the times you went to the GP. Do you remember a time in which you've left feeling particularly bad? What happened?
→ How did that make you feel?
→ Have your feelings and thoughts changed since then? (Why?/How?)
→ What did you do (when things went wrong)? // Did you talk to anyone about this? (Who?)

* *If participant can't think of an example, ask about the last time they went to the GP, or about a memorable thing that happened when they went to the GP.*

4) If your experience had been different, do you think it would have made a difference? Why/how? [example: "if your doctor had/hadn't listened to you, do you think it would have made a difference?", "Why?", "How?"]

5) Managing a long-term condition is a complex job. What do you do to manage yours on a daily basis?

→ Why/what motivates you to manage your long-term condition?

→ Is there anyone who helps you manage it? (who and how/why)

→ Is there anyone, or anything, who you think could help you manage it better? (who and how/why)

6) Do you think GPs can help you manage your long-term conditions (or should they)?
→ Why?/How?

7) If you met someone today, with the same condition(s) and circumstances as you, and they asked you for advice - what advice would you give them?

8) Before we end the interview, there is one last question I would like to ask you. [Summarise briefly the main topics discussed so far]. So, based on your experience, what is person-centred care for you?

9) The interview is almost over. Is there anything you would like to add, or that you would have liked me to ask you? Anything at all.

Conclusion

- Asking if there is anything about the interview that the participant would change or improve;
- Thanking the participant for their participation and stop recording/ending the interview.

Probing techniques examples: Clarification (can you explain…), extension (can you tell me more about…), evaluation (that's interesting/that must be challenging), intentional silence.

Focus groups guide

The interview guide for the focus groups is reported below. Arrows (→) indicate follow-up questions.

Welcome and introduction:

The interviewer and focus group assistant introduce themselves. The interviewer then gives an overview of the study aims. The participants will be told about the rules of a focus group (e.g., trying not to talk over each other, there are no right or wrong answers, participation is voluntary, and so forth.), and will be asked to introduce themselves (i.e., saying their names to facilitate the transcription).

Focus groups questions:

1) If you could rate your GP surgery using a traffic light, where “green” means great, “amber” means you’re not sure, and “red” means bad, how would you rate it? (*ice-breaker question*)
→ Probe on the scores (e.g., “why green?”).

2) Are there any things you like about the GP surgeries you are (or have been) registered to?
→ If yes, which ones and why? If not, why none?
2a) Are there any things you don’t like?
→ If yes, which ones and why?

3) When you visit your GP surgery, do you think all of your needs are met?
→ Do you leave the practice feeling better?
→ Can you give me an example of when your needs were (not) met/you left the GP surgery feeling better/worse?

4) Do you think that going to the GP helps you manage your daily life?
→ If yes, how?
→ If not, why? (→ Should/can they help more? Do you expect anyone else (who?) to do so?)

5) The interviewer introduces and reads a scenario in which the participants will pretend to be a GP:

Edith is 70 years old, she has several chronic diseases and is in persistent pain, as she has recently been to the hospital with a chest infection. The specialists have prescribed her some water tablets to relieve pressure on her heart, but she doesn't want to take them because she won't be able to leave her house for fear of needing the toilet. She fears that the hospital doctors didn't listen to her properly, and she is worried about losing her independence.

6a) Now, try to put yourself in Edith's shoes for a moment. Then, try to put yourself in her GP's shoes: If you were Edith's GP, what would you recommend she do about the water tablets?

6b) What do you think Edith's main problem is?

→ What would you suggest Edith does in order to deal with this problem?

→ Have you had the same or a similar issue before? → What did you do/how did you react?

7) Suppose that you were in charge and money wasn't an issue. You can make one change that would make general practice better. What would you do? → Why?

8) We have discussed for some time now about primary care and its characteristics. Now, I would like to ask you one final thing: What is patient (or person) -centred care to you? (If you could define it, how would you define it?)

9) The interview is almost over. Is there anything you would like to add, or that you would have wanted me to ask you? Any final comments you would like to make? (Making rounds – checking with each participant)

Wrapping up

- Summarizing the main points of the discussion;
- Asking if there is anything about the focus group process that the participants enjoyed or that needs improving;
- Thanking the members of the focus group for their participation and stop recording/ending the interview.

Probing techniques: Clarification (can you explain…), extension (can you tell me more about/can you give me an example…), evaluation (that is unexpected/that must be challenging), *intentional silence; exploring strong agreement or disagreement between the members, or strong feelings associated with one specific topic.*