What do the healthcare experiences of people with long-term conditions tell us about person-centred care? A systematic review.

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Abstract

Introduction

Growing numbers of people now live with long term conditions. For each person, the challenges are multiple and unique to that individual. In recognition of this, health policy places greater emphasis on the delivery of person-centred care (PCC). However, patients report declining levels of such care. One reason for this may be a mismatch between patient and professional/policy understanding of PCC.

Aim

To understand PCC from the perspectives of people with long-term conditions.

Methods

A systematic review of qualitative literature was conducted. Databases searched included ASSIA, BNI, CINAHL, the Cochrane Library, Embase, Medline, PsycINFO, PubMed, Scopus, Web of Science, and grey literature databases. Two reviewers independently screened and selected the studies, assessed their quality, and extracted data. Fifty-four records were analysed through meta-ethnography.

Results

Four themes emerged: the healthcare system as a battlefield, the healthcare system as a maze, patients' accounts of personhood, and the centrality of patient enablement. A person-centred healthcare system is described by this review as one that values personhood and enables patients to build knowledge with their clinician in order to manage their illness in a safe, caring, and accessible environment.

Conclusion

PCC does not depend on the efforts of the clinician alone, but results from a collaboration with the patient and needs to be enabled by the wider organisational and educational systems. Efforts directed at the implementation of PCC might be bound to fail if the healthcare policy agenda does not address the role of the patient's personhood in clinical practice, and its integration in educational settings.

1 INTRODUCTION

Over the last few decades, the rising numbers of older people and prolonged time living with long-term conditions have put much strain on resource-limited healthcare settings. In such settings, the biomedical model has long been the dominant approach to clinical care, with its focus on treating single diseases and on "discovering the pathology rather than understanding the illness" [1 p1401]. However, such clinical orientation has contributed to the development of a plethora of guidelines that, if applied slavishly, could end up contributing to the patients' treatment burden instead of solving their health problems [2,3]. Therefore, more comprehensive and effective approaches to clinical care are needed in order to deal with the complexity of chronic conditions.

Nowadays, we see a resurgence in healthcare models that take into account not only the person's disease, but also his or her illness experience. A more person-centred approach, which recognizes the biopsychosocial dimensions of health, prioritizes the person's subjective experiences, and involves patients in decision-making processes [4], has been emphasised, as it is considered to be crucial in the management of chronic diseases [5].

Still, patient surveys have reported that healthcare professionals are not delivering or implementing person-centred care (PCC) in a meaningful way [6]. For example, in the United Kingdom, notwithstanding the commitment of successive governments to PCC [7], people with long-term conditions are receiving care that does not meet their perceived needs, with inefficient use of contact time, scarce focus on information and education, and poor outcomes [8,9]. This is even more evident in primary care settings, where a recent survey has found that the indicators for PCC have deteriorated since 2017, and that some groups of people are less likely to report positively on the care they receive, or report scarce involvement in their own care [10]. Whilst possible reasons for this are varied and complex, one explanation is that we do not have a clear, patient-derived view of PCC. Therefore, policy and organisational changes might have attempted to strengthen and improve the delivery of PCC in ways that did not always reflect the patients' own views and priorities.

So far, studies about what patients think of PCC have focused on specific constructs or settings [11,12] or were quantitative in nature [13]. Therefore, we set out to conduct a systematic review of the healthcare experiences of people with long-term conditions in order to get a more encompassing understanding of what PCC is from their perspective. Our review question was:

- What are the essential elements of a person-centred healthcare system as described by the experiences of patients?

Essential elements are those aspects of healthcare that have a positive impact on someone's healthcare experience (e.g., they resulted in positive outcomes, patients or study authors defined them as important or needed, positive feelings/satisfaction were expressed, and so forth).

2 METHODS

We conducted a systematic review of qualitative studies following the steps described in the ENTREQ (Enhancing transparency in reporting the synthesis of qualitative research) guidelines of best practice [14]. We conducted a search of the following databases: ASSIA (Applied Social Sciences Index and Abstracts), BNI (British Nursing Index, now known as British Nursing Database), CINHAL Plus, the Cochrane Library, Embase, PsycINFO, Pubmed and Medline, Scopus, and Web of Science. WorldCat, Grey Literature Report, the INVOLVE

Libraries, and OpenGrey were searched in order to retrieve any relevant grey literature. Additional records were identified through reference lists checking. The search was conducted between February 2018 and March 2018, and was updated in September 2019 (excluding grey literature databases).

The development of the search strategy was informed by the research questions and by other systematic reviews of qualitative studies about the experiences of people with long term conditions; a combination of subject heading and keyword searching was employed depending on the database. A systematic review protocol was developed and registered online on PROSPERO (registration number CRD42018094380), where excerpts of the search strategies are available.

2.1 ELIGIBILITY CRITERIA

The studies' references, titles, and abstracts were transferred to a dedicated EndNote library. Two reviewers (MD and SP) independently screened all the documents against the eligibility criteria, and compared their decisions. Whereas any disagreements or doubts emerged, they were solved through academic discussion, with a third reviewer (JR) being available in case they could not be solved. The eligibility criteria were defined as follows:

Inclusion criteria

- Qualitative studies that involve adults (> 18 years old) with physical and/or mental chronic conditions;
- Studies that acknowledge person or patient-centred care;
- Studies published in English;
- Studies conducted in developed countries;
- Studies with mixed-methods designs whose qualitative component was substantial enough to allow for analysis;
- Studies conducted in primary or secondary care settings;
- Empirical papers (including reviews of qualitative studies).

Exclusion criteria

- Studies presenting exclusively quantitative data and methods;
- Meta-analyses, book reviews, study protocols, conference proceedings, commentaries, and systematic reviews of quantitative studies;
- Studies about:
    - Complementary medicine
    - Illness (not healthcare) experience
    - Other groups (e.g., caregivers, health professionals)
    - Specific groups (e.g. sex workers, veterans)
    - The creation, validation, or assessment of a model, intervention, toolkit, etc.
    - Telecare and home-based care
    - Care delivered by students/trainees
- Studies involving more than two stakeholder categories (e.g., patient, carers, and providers), or presenting the findings in an unclear way (e.g., "the participants said");
- Exclusively methodological and/or theoretical studies.

Two flow diagrams (Fig. 1 and Fig. 2) documenting the screening process were developed in accordance with the PRISMA guidelines [15].

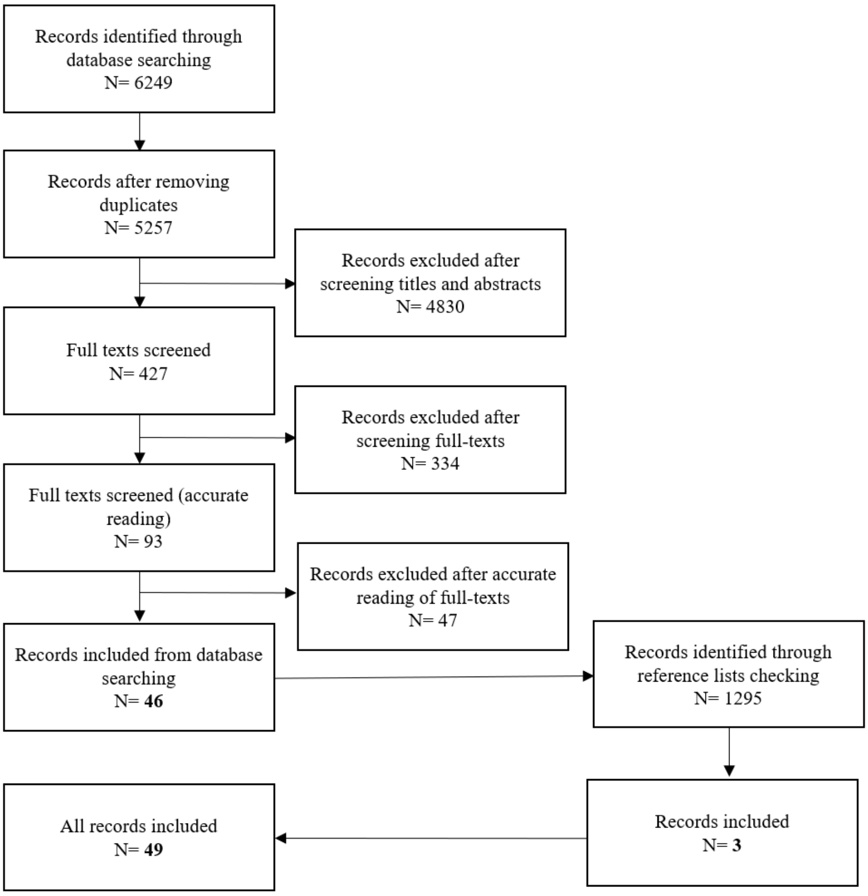

Figure 1. PRISMA flowchart – initial search (February 2018 - March 2018).

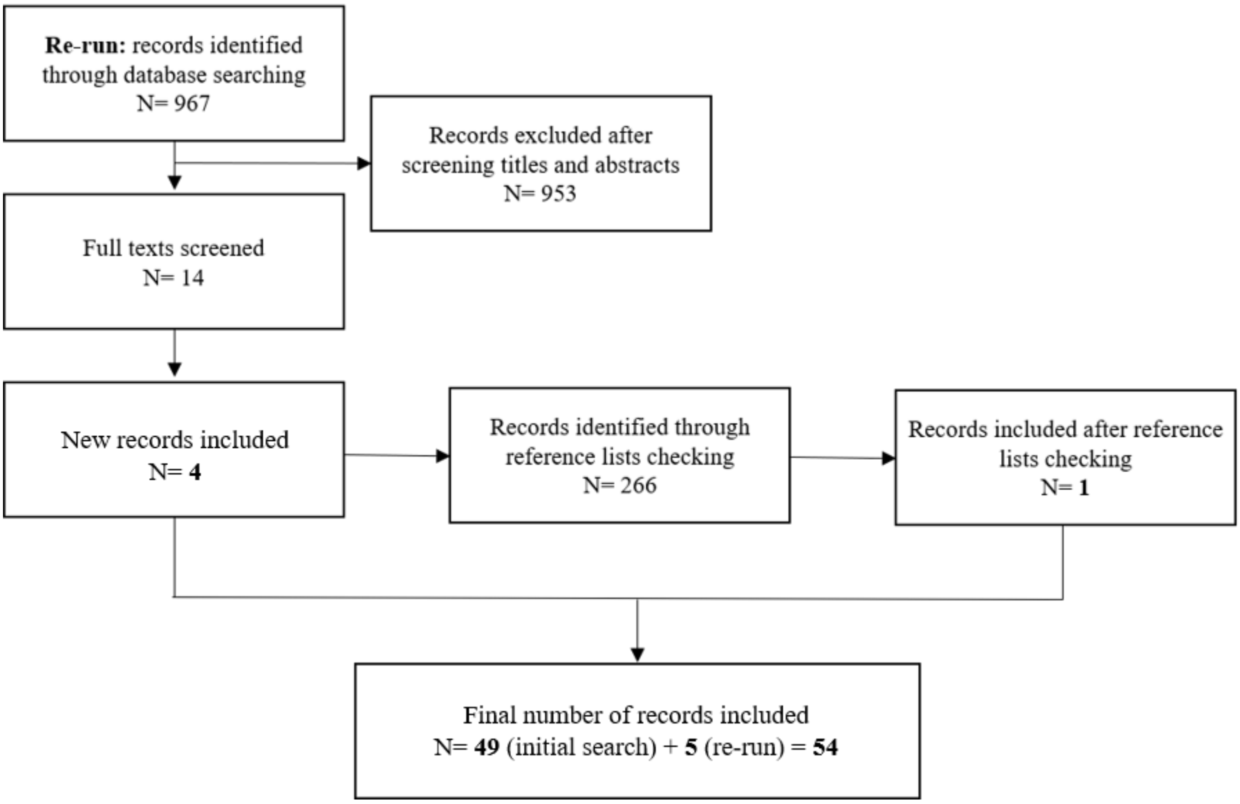

Figure 2. PRISMA flowchart – search update (September 2019).

2.2 DATA EXTRACTION AND ANALYSIS

Two reviewers (MD and SP) employed a data extraction form to independently extract study characteristics, the participants' demographics, quotes, and authors' interpretations. The electronic versions of each record were transferred to NVivo 12 (QSR International, Melbourne, Australia).

For the analysis, we opted for meta-ethnography [16] in consideration of its suitability for the exploration of people's experiences, and because it aims at developing a conceptual understanding of a phenomenon [17], as we wanted to understand the phenomenon of person-centred care. The phases of meta-ethnography are seven, namely (1) getting started, (2) deciding what is relevant, (3) reading the studies, (4) determining how the studies are related, (5) translating studies into one another, (6) synthesizing translations, and (7) expressing the synthesis. These phases have been described elsewhere [18,19]. More specifically, the analysis (steps 5 and 6) was carried out in two steps: reciprocal and refutational translation, and line of argument synthesis. During the reciprocal and refutational translation the studies' key concepts and themes were translated into each other (reciprocal translation), while any differences and inconsistencies between the studies were explored (refutational translation). Then, the line of argument synthesis was carried out to achieve an overarching interpretation by synthesising the findings that emerged throughout the dataset.

In particular, the translation was facilitated by dividing the studies in three groups according to their setting (primary care, secondary care, and mixed). The records within each group were analysed in chronological order, using thematic analysis. The themes that emerged from each group were synthesised together by drawing relationships between them. This process was informed by the authors' individual interpretation and academic discussion with the wider team, as well as by previous knowledge of the literature on person or patient -centred care.

Quality Appraisal

MD and SP carried out quality assessment independently, using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for qualitative research and for systematic reviews, as we considered its focus on congruence [20], and emphasis on the participants' voices compatible with the principles of meta-ethnography. Exclusion was contemplated only if a qualitative methodology was deemed incompatible with the aim of the study. Otherwise, studies were not excluded based on their quality, as our priority was that of capturing a wide range of people's experiences. Results of quality appraisal have been reported in Appendix A. Differences in scores were usually related to incomplete reporting (i.e., “unclear” answers on the JBI checklist).

3 RESULTS

Fifty-four records were analysed. This number includes 46 qualitative studies, six mixed-methods studies, and two literature reviews (of which one was systematic). The studies presenting primary data brought together the views of 1882 adults with long-term conditions, plus an ethnographic study in which the number of participants was not reported. Most of the studies (22) were about a variety of chronic conditions, followed by chronic pain (9), mental illness (5), diabetes (4), cancer (4), stroke and/or brain injury (3), degenerative disorders (3), heart failure (2), chronic kidney disease (1), and frailty (1).

Four main themes emerged from the analysis: (1) the perception of the healthcare system as a battlefield, (2) the perception of the healthcare system as a maze, (3) the patients' accounts of personhood, and (4) the importance of processes of patient enablement.

In general, studies conducted in primary care settings tended to focus more on the clinician-patient relationship, whereas studies conducted in secondary care settings mentioned more often service efficiency and identification of patients' needs. On the other hand, the communication of relevant information was a common topic across all study groups.

Theme 1: The perception of the healthcare system as a battlefield

The perception of the healthcare system as a battlefield emerged through the participants' feelings of anger and fear to speak up when something was wrong, the occasional perception of health professionals' aggressiveness, and the appearance of war metaphors (e.g., "battle", "fight") across the dataset. For example, one participant used the word "army" to refer to a group of medical students accompanying their care team during clinical visits [21].

These data hinted at a perceived power struggle, for example when patients said they were afraid the doctor would "punish" them if they disagreed with them; in other instances, they believed that they had to fight to be believed [22], to defy paternalistic attitudes [23], and to access medical resources [24]. Such perception led some patients to believe that clinicians were unwilling to share information with them [25], or would actively get in their way to prevent them from getting information [26]. Several participants were afraid to be seen as a "bother", and thus refrained from asking for help [27,28].

> "I sensed that I was troublesome to her and she didn't like me . . . this made me upset. I dare not communicate and talk anymore with her in the future" [29]

Contrasts were present also when role expectations differed between patients and clinicians. Whereas some patients (usually a minority) thought that clinicians were "the experts" [30,31], and should decide for them [32], in other instances people believed that nobody could understand their illness better than themselves, and wanted to be viewed as proactive patients with their own skills and expertise [22,33-35]. Reasons behind such different attitudes were investigated during the analysis. For example, patients tended to think that clinicians were the experts because they thought clinicians "trained for years" or "have the degrees" [31,32]; patients accepted most of the clinicians' decisions also when such decisions were communicated and explained clearly [30]. On the other hand, other patients thought of themselves as experts because they "know their body" [34], as well as the social, mental and physical consequences of their symptoms, which clinicians do not know [22].

When the healthcare staff's and the patients' goals differed, patients either accepted the situation [36,37], did not adhere to the treatment (or made their own medical decisions) [30,32,38], looked for a second opinion [38], or stopped using healthcare services altogether [39]. In other instances, patients would take the initiative differently, for example by trying to educate their physicians about their illness [40,41], or demanding to see "someone higher up" [32]. Still, for some authors, even seemingly "passive" behaviours like non-adherence or the adoption of unhealthy lifestyles in spite of the doctors' advice could be seen as "powerful statements of self-determination" [39 p40].

Theme 2: The perception of the healthcare system as a maze

Patients had a hard time finding out which services were available, trying to access services and information, and coordinating the information collected across different services. These people received care that did not meet their needs, in particular concerning information exchange and retrieval, and identification of/access to health services. For example, even when the clinician was valued as an expert and a source of knowledge, organisational issues such as lack of time meant that patients were unable to find a way to get information from them [42].

In general, hospital settings were perceived to be less accessible than primary care settings, with longer waiting times, less flexibility, and scarce continuity [43]. Still, getting in touch with the health centre's staff was difficult in primary care settings as well [31]. In this context, the participants emphasised the importance of relational continuity (i.e., seeing the same clinician every time) as it contributed to feelings of security and consistency [44,45]. Flexible continuity, namely timely access to care, and the practice staff's ability to make and change appointments efficiently [43] was also mentioned by the participants as a desirable aspect of care.

Patients also made recommendations to help them "navigate the maze"; examples are the presence of a care coordinator [27], availability of online and offline resources that people can access after discharge [21], and centralised information systems that could facilitate provider access to patient data [46].

Theme 3: The patients' accounts of personhood

The participants' perception of the healthcare system as a battlefield and/or a maze had a negative impact on their healthcare experience: feelings of frustration, humiliation, and isolation led some of them to lose faith in the system or in their doctor [31,47,48]. Such reactions indicated that the patients were affected on a personal level by what happened within the clinic's walls. Some of them, in fact, complained about not being seen as "persons". The importance of personhood was also highlighted in a positive way when some participants admitted that being seen as a person allowed them to "show the true reflection of self", giving them more confidence in the clinical environment [49 p15].

Nonetheless, negative feelings affecting patients on a personal level were common. For example, patients with long-term conditions have to deal with the fluctuating nature of their illness, and the feelings of uncertainty and anxiety that accompanied the most unpredictable or degenerative diseases could be exacerbated when these people did not manage to communicate effectively with the staff [28]. The lack of information and feedback left them with feelings of being met with nonchalance and being ignored, which caused them a degree of unnecessary concern and anxiety [34,45]. Feelings of anxiety were also associated with other aspects of the care process, such as receiving the diagnosis [50], accessing a saturated care system [51], or asking for help while fearing rejection [52].

Another feeling described by some participants was that of being neglected, or of their health problems being downplayed by health professionals. This was particularly true for older people, people with chronic pain, and residents of nursing homes [37]. The participants' sense of self-worth could be affected by this, as exemplified by the following quotes.

> "Is it because I'm over 65, they're not doing anything about it?" [28]

> "It is not until you sit in a doctor's chair yourself and live through the experience of telling them how much pain you are in […] that you can understand how worthless a patient with fibromyalgia feels in their eyes." [40]

Some patients also reported feeling labelled as hypochondriacs or drug seekers [53], or complained that their physical symptoms (e.g., pain and fatigue) were attributed to mental disorders [54], laziness, and stereotyping [22]. In such situations, some of them reported feeling dehumanised [54]. Examples of this were numerous, as the participants said that the healthcare staff made them feel like numbers [41, 55], objects (e.g., "a rock", a "piece of the furniture") [25,35,39], or animals [21,56].

Theme 4: The centrality of processes of patient enablement

A series of aspects that improved the participants' healthcare experiences have also been identified. For example, access to tailored information was valued because it enabled patients to better understand the circumstances around their disease, and act accordingly. Information exchange usually took place when the patient was "enabled" to engage in such activity, for example when a good relationship with the doctor, and a favourable organisational culture [46,49], allowed them to "ask and talk freely" [57 p4].

Whereas most of the participants wanted to know a variety of things, from illness progression, to possible illness trajectories, alternative treatments, and treatments' side effects, a minority did not want to receive too much information, as they considered knowledge to be a source of distress [42,58]. On the other hand, information helped the participants take decisions, manage their condition with awareness, and cope with the stigma associated with some health problems [59].

Participants also cherished a positive relationship with the staff, as it made them feel safe and comfortable. Such positive relationship was built on mutual respect, legitimization of their illness experience, friendliness, care, trust, empathy, emotional support, and openness. It was also characterised by the clinicians taking time to listen to what patients had to say, and patients being known or remembered by their doctors [60]. Being known not only made patients feel valued as individuals, but also saved them the work of repeating their medical histories to healthcare professionals that did not know them, or that did not read their medical records [61]. Furthermore, the participants believed that the opportunity to share their knowledge and experiences should be considered valuable from a clinical point of view. In fact, patients' accounts also hinted at a wish for clinicians to adopt more holistic approaches to their care, and to be seen as "a whole person" [22,40,62,63].

Finally, a good relationship with the doctor, though valuable in itself, was still instrumental to knowledge building. Therefore, the clinician's competence and ability to understand and address the complexity of the participants' illnesses, and to refer them to community or specialist services when applicable, was considered to be complementary to a good relationship.

> Simply being ''nice'', however, was not welcomed if ineffective: "All the doctors are very nice, but they don't take any notice…They don't do anything." [28]

In turn, knowledge-building was also considered to improve the patient-clinician relationship [64]. Still, whereas some patients are already enabled to be proactive agents in their own care because of many and varied circumstances (e.g., the way in which they have been socialised, education, and life experiences among others), others lack knowledge of their own condition, hence being prevented from engaging in effective decision-making and self-management [50]. For example, language issues (e.g., not speaking the local language fluently) could represent a barrier to patient enablement [33,54], as well as a low socio-economic status (SES) and low levels of health literacy [31,50].

Line of argument synthesis: Aspects of person-centred care that matter to people with long-term conditions

After identifying these four themes, we engaged in meta-ethnography's line of argument synthesis by listing the themes, along with their sub-themes, on a blank piece of paper. Then, we linked inter-related concepts by connecting and clustering them, hence creating a mind-map. Relationships drawn were informed by the author's knowledge of the literature, but were mainly grounded in the data. An excerpt of the themes and sub-themes is presented in table 1.

Table 1. Themes and sub-themes. For simplicity, for each theme, only five sub-themes are presented.

Themes →	**Theme 1 – The battlefield**	**Theme 2 – The maze**	**Theme 3 - Personhood**	**Theme 4 - Enablement**
Sub-themes →	- Perceived power imbalance - Feelings of fear - Feelings of anger - Perception of fighting a battle - Clinician's negative attitudes …	- Difficulties identifying services - Difficulties accessing services - Difficulties getting information - Difficulties understanding information - Navigating the system …	- Patient feels dehumanised - Healthcare experience's impact on patient's self-worth - Patient's unique characteristics - Feelings of humiliation - Patient vs Person …	- Tailored information - Clear communication - Positive relationship (care, trust, etc.) - Listening to the patient - Knowledgeable and competent healthcare professional …

For example, "feeling cared for" and able to "trust the doctor" (theme 4) were considered to improve the relational aspect of someone's healthcare experience, because it made communication easier. On the contrary, when patients were afraid to speak freely, and did not feel safe (theme 1), it could result in the clinician being unaware of important information, hence being unable to offer proper care. Therefore, the "relationship domain" (which includes aspects of healthcare such as trust, safety, respect, etc.) was identified as one of the components of person-centred care from the patient's perspective.

This led to the development of two more domains (Fig. 3): the "epistemic domain" (including information availability, tailored information, knowledge exchange and creation, etc.) and the "organisational domain" (including flexibility, continuity, timely appointments, etc.). However, we considered that some of the sub-themes had a boundary-spanning nature, laying at the interface between two domains. For example, listening skills fostered both relationship building (relationship domain) and knowledge sharing (epistemic domain), whereas the clinician's access to patient information contributed to both continuity of care (organisational domain) and to the patient's feeling of "being known" by the doctor (relationship domain). This indicates that the boundaries between these domains are not clearly demarcated, and that all the elements interact to contribute to the whole, with each aspect being necessary, but not sufficient, to the achievement of person-centred care.

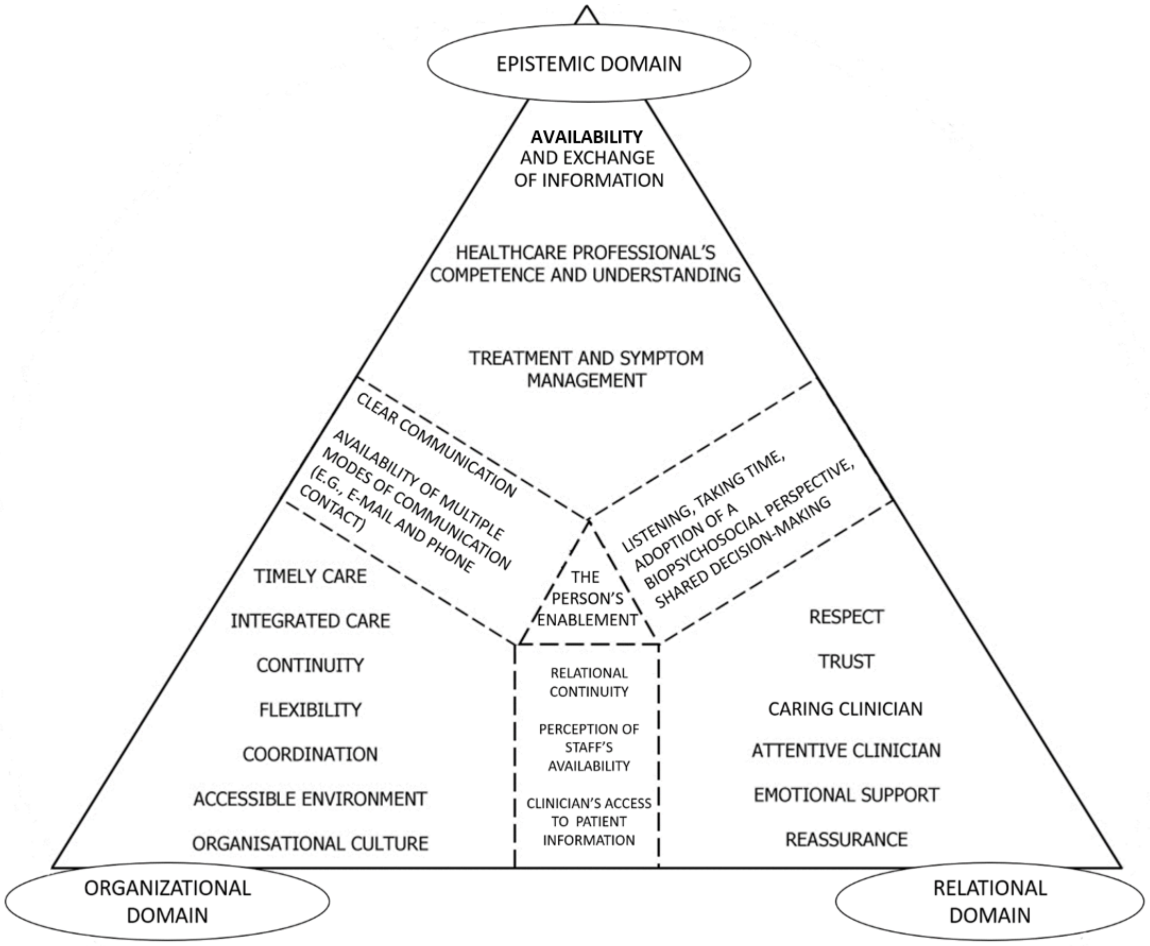

Figure 3. Diagram presenting the components of person-centred healthcare as described by the experiences of people with long-term conditions.

At the centre of this diagram lays the person's enablement, as the patient/person inevitably interacts with all of these domains while attending healthcare services, but also needs to be enabled to engage with such domains proactively and successfully. It is important to specify that "enabling" is not a synonym of "helping", but refers to the achievement of a balance between offering help and respecting the patient's independence, which requires a cognitive effort as well as effective communication and sensitivity on the side of the practitioner [65], who has to adopt a flexible consultation style between (and sometimes within) consultations [66]. In fact, paternalism, under the guise of "too much help", was often contrasted by patients, and ended up contributing to the "battlefield" theme instead than to the "enablement" theme.

4 DISCUSSION

As person-centred care is still not being achieved in practice, we set out to identify how people describe it, by interpreting their healthcare experiences through a person-centred care lens in order to consider whether a new person-centred understanding of PCC offers insight into why reported PCC is declining. According to this systematic review, the elements of person-centred care that matter to people with long-term conditions can be traced back to three main domains: epistemic, relational, and organisational.

As regards the epistemic domain, it is important to note that there is not just one form of knowledge. Russel Ackoff [67] was the first to posit a hierarchy of knowledge, at the top of which lay wisdom, followed by knowledge, information, and data. As Bernstein explained [68], the synthesis and compound of different types of knowledge (e.g., the patient's knowledge of illness experience, and the clinical knowledge of the doctor) can lead to wisdom that, according to Ackoff, is essential for the pursuit of valued goals. Yet, if a patient perceives the healthcare system as a battlefield, this has potentially negative implications for the achievement of wisdom, since knowledge sharing is supported by trust [69] and by a collaborative culture [70].

Actually, a positive relationship with the healthcare staff is important not only for knowledge-building purposes, but also because of the impact it has on the patient on a personal level. This systematic review showed that healthcare services can still cause unnecessary suffering to people [71], not just by contributing to their treatment burden [3,72], but also affecting them psychologically, with possible consequences being anxiety, hopelessness, and fear. Lian and Robson [22 p10] observed that "decades of debate and research emphasising person-centred clinical methods, [are] not traceable in the expressed experiences of … [the] study participants". In this context, a further question should be raised, namely what is the extent (if any) to which such debates around PCC have been incorporated in the education curricula of medical students and healthcare professionals.

However, the achievement of a good relationship between the patient and the clinician needs to be enabled by organisational aspects of care such as care coordination and integration, flexibility, and continuity. Some of these can be subsumed under the broader umbrella of the concept of access, previously defined as "the degree of "fit" between the clients and the system" [73 p128]. Access has also been defined in other ways, such as the potential to enter the healthcare system [74], or as people's *ability* to obtain available health services [75]. The use of the term "ability" in the definition of access assumes an interesting meaning in the light of the fact that access seems to be one of the aspects of care that are usually beyond the patients' control. Therefore, there might be a mismatch between what patients can do, and what the healthcare system assumes they can do. Over the last few years, research studies in the health sciences have acknowledged this mismatch, and found that people with long-term conditions nowadays deal with a significant workload, and need a certain capacity to do so [3,72].

4.1 AT THE "CENTRE" OF PERSON-CENTRED CARE

Our synthesis shows that the doctor alone cannot achieve person-centred care. According to the experiences of the patients included in this systematic review, person-centred care is not something that can be delivered, provided, or administered (e.g., like a drug, or a rehabilitation technique). Person-centred care is rather a process that can be achieved only collaboratively. Therefore, the challenge for the healthcare professional is not only that of understanding what kind of treatment the patient needs, but also that of enabling the patient to engage in a combined, collaborative effort in order to reduce, instead of increasing, the burden that they already carry [76]. The presence of organisational aspects in our diagram indicates that clinicians also need to be enabled to engage in person-centred clinical encounters, by the healthcare system organisational setup and, before then, by the very educational system that trains them to become healthcare professionals.

Yet, it seems that person-centred care is being increasingly reified by policies and guidelines, hence running the risk of reducing it to a checklist of behaviours, values, and principles that a healthcare provider has to follow – if they do, they can say that they deliver person-centred care. This is reflected by those cases in which some services guaranteed they offered person-centred care, whereas people using such services disagreed [52].

4.2 COMPARISON WITH OTHER DEFINITIONS OF PERSON-CENTRED CARE

The findings of our systematic review are compatible with other definitions previously reported, such as that of Kitson and colleagues, who conducted a narrative review of the literature from health policy, medicine, and nursing in order to operationalise patient-centred care [77]. The elements of patient-centred care that they identified were (1) patient participation and involvement, (2) the relationship between the patient and the health professional, and (3) the context where care is delivered. Similarly, Scholl carried out a content analysis of 417 records, in an attempt to develop a conceptual definition of patient-centred care [78].

Kitson's and Scholl's definitions share both differences and similarities with our findings. For example, a positive relationship between the clinician and the patient has been found to be an important aspect of care by our systematic review as well as by Kitson's and Scholl's reviews. However, compared to both, our review emphasised the importance that person-centred healthcare should place on the patient's personhood. The idea of personhood is indeed acquiring increasing acknowledgement in studies around person-centred care, as it has been pointed out that primary care practice needs to be underpinned by theories of the self that could allow health professionals to understand the patient "as a self with intrinsic worth" [79 p135]. The fact that these aspects of care are not as emphasised in Kitson's and Scholl's reviews might be attributed to Scholl's analysis being based on a series of conceptual definitions of patient-centred care, Kitson's review being based on the views of different stakeholders (patients, policy makers, and professionals), and our review being based exclusively on patients' experiences.

4.3 STRENGTHS AND LIMITATIONS

A strength of this review is that screening, data extraction, and quality appraisal were done independently by two authors on all the records. A limitation is that types of care such as telecare and home care were excluded from the review. However, this was done to keep the review as focused as possible, as there was a large number of studies about telecare and homecare, which could warrant a separate review.

Another strength is that we have updated our search prior to submission. The update resulted in five more papers being added to the systematic review. Still, although these papers contributed to the quality of the discussion by offering further insights to the interpretation of the studies, theoretical saturation (no emergence of new themes) was reached, hence the addition of the extra records did not change the findings significantly.

Also, this study allowed for the synthesis of the views of a large number of people, which is a strength as qualitative studies do rarely involve high numbers of participants. However, along these lines, a limitation is that fifty-five studies might challenge the interpretative nature of a meta-ethnographic approach [80]. Yet, the use of meta-ethnography with a relatively large number of studies has been documented in several instances [19,81]. We addressed this challenge by considering the guidelines reported on methodological studies on the use of meta-ethnography with large numbers of studies [82], using a computer assisted analysis software to facilitate the synthesis, and dividing the studies in three groups instead of pooling them together, so that each group could be analysed in-depth.

Finally, it is important to note that this review focused on people's healthcare experiences, hence other relevant aspects that lay outside of the healthcare realm have not being identified, yet are part of what enables patients achieve person-centred care. Examples of such aspects are biographical reframing processes and realization of life work [83].

5 CONCLUSIONS

In its attempts to move closer to the patients, it could be suggested that the healthcare system has ended up moving away from them. However, this trend is not sustainable: today's patients have complex problems, and the disconnection between patients and healthcare services could end up increasing the workload for both patients and practices in the long term. In fact, for an approach to be achieved and persist over time, it needs to make sense to the people involved [76], yet it seems that the way person-centred care has been implemented so far has not always made sense to the people who are supposed to be at its very centre.

We conducted a systematic review of qualitative studies, and found that people with long-term conditions describe a person-centred healthcare system as one that values and respect their personhood, and enables them to build knowledge together with the clinician in order to manage their illness in a safe, caring, and accessible environment. Moving forward, further research might explain the relationships between the aspects of our diagram, or validate it through quantitative studies. Moreover, our systematic review suggests the need to review the direction of travel of person-centred care policies, interventions, and education, as the mismatch between patients' and other stakeholders' views around PCC might be partly attributed to differences in their views on what personhood is, and in the value and consideration that they attach to it. Therefore, it is important to engage in further theoretical reflection on the meaning of this concept in healthcare settings: how it is being defined, how it is impacted by healthcare experiences, and how (and if) it is being properly incorporated in current clinical practice and education. As policy and organisational changes take time [84], and the students that are starting medical school today will be doctors in ten years or more [85], it is important to act now, so that patients in the future have more opportunities to be enabled to become pro-active agents in the management of their long-term conditions.

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APPENDIX A – STUDY CHARACTERISTICS AND QUALITY APPRAISAL SCORES

Table A1. Study characteristics.

	Authors and year	Title	Country of setting	Data collection technique	JBI scores
1	Johansson, et al., 1996.	"I've been crying my way"—qualitative analysis of a group of female patients' consultation experiences	Sweden	Semi-structured interviews	**YES: 7** NO: 1 UNCLEAR: 2 N/A: /
2	Gilmore and Hargie, 2000	Quality issues in the treatment of depression in general practice	UK	Semi-standardised interviews	**YES: 3** NO: 3 UNCLEAR: 4 N/A: –
3	Cott, 2004	Client-centred rehabilitation: client perspectives	Canada	Focus groups	**YES: 8** NO: 2 UNCLEAR: – N/A: –
4	Harding, et al., 2005	“It Struck Me That They Didn’t Understand Pain”: The Specialist Pain Clinic Experience of Patients With Chronic Musculoskeletal Pain	England	In-depth interviews	**YES: 9** NO: 1 UNCLEAR: – N/A: –
5	Naithani, et al., 2006	Patients’ perceptions and experiences of continuity of care in diabetes.	England	Semi-structured interviews	**YES: 6** NO: 2 UNCLEAR: 2 N/A: –
6	Abdulhadi, et a., 2007	Patient-provider interaction from the perspectives of type 2 diabetes patients in Muscat, Oman: a qualitative study	Oman	Focus groups	**YES: 9** NO: – UNCLEAR: 1 N/A: /

7	Saver, et al., 2007	A qualitative study of depression in primary care: missed opportunities for diagnosis and education	United States	Interviews	**YES: 6** NO: 3 UNCLEAR: 1 N/A: –
8	Bayliss, et al., 2008	Processes of care desired by elderly patients with multimorbidities	United States	Semi-structured interviews	**YES: 5** NO: 3 UNCLEAR: 2 N/A: –
9	Cooper, et al., 2008	Patient-centredness in physiotherapy from the perspective of the chronic low back pain patient.	Scotland	Semi-structured interviews	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
10	Egeli, et al., 2008	Patients’ views: improving care for people with fibromyalgia	Canada, the United States, and the United Kingdom	Online open-ended questionnaire	**YES: 7** NO: 3 UNCLEAR: – N/A: –
11	Wilkes, et al., 2008	Clients with chronic and complex conditions: their experiences of community nursing services	Australia	Interviews	**YES: 7** NO: 3 UNCLEAR: – N/A: –
12	White, et al., 2009	Stroke patients’ experience with the Australian health system: A qualitative study	Australia	Interviews (mixed methods study)	**YES: 7** NO: 1 UNCLEAR: 2 N/A: –
13	Teh, et al., 2009	Older People's Experiences of Patient-Centered Treatment for Chronic Pain: A Qualitative Study	United States	In-depth interviews	**YES: 8** NO: – UNCLEAR: 2 N/A: –
14	Upshur, et al., 2010	They don't want anything to do with you”: Patient views of primary care management of chronic pain.	United States	Focus groups	**YES: 8** NO: 2 UNCLEAR: – N/A: –

15	Cocksedge, et al., 2011	Holding relationships in primary care: a qualitative exploration of doctors' and patients' perceptions	England	Semi-structured interviews	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
16	Hartley, et al., 2011	Experiences of attendance at a neuromuscular centre: perceptions of adults with neuromuscular disorders	England	In-depth interviews	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
17	Jowsey, et al., 2011	Effective communication is crucial to self-management: the experiences of immigrants to Australia living with diabetes.	Australia	Semi-structured in-depth interviews	**YES: 7** NO: 1 UNCLEAR: 2 N/A: –
18	Nakrem, et al., 2011	Residents’ experiences of interpersonal factors in nursing home care: a qualitative study	Norway	In-depth interviews	**YES: 8** NO: 1 UNCLEAR: 1 N/A: –
19	Raven, et al., 2012	Vulnerable patients’ perceptions of health care quality and quality data.	United States	Focus groups (mixed methods)	**YES: 5** NO: 3 UNCLEAR: 2 N/A: –
20	Toles, et al., 2012	Transitions in care among older adults receiving long-term services and supports	United States	Semi-structured interviews	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
21*	Hancock, et al., (2012)	‘If you listen to me properly, I feel good’: a qualitative examination of patient experiences of dietetic consultations	United Kingdom	Individual interviews and focus groups	**YES: 8** NO: 2 UNCLEAR: – N/A: –
22	Bergman, et al., 2013	Contrasting tensions between patients and PCPs in chronic pain management: a qualitative study.	United States	In-depth interviews	**YES: 6** NO: 2 UNCLEAR: 2 N/A: –

23	Cabassa, et al., 2014	Primary health care experiences of Hispanics with serious mental illness: a mixed-methods study.	United States	Focus groups (mixed methods)	**YES: 5** NO: 2 UNCLEAR: 3 N/A: –
24	Hudon, et al., 2013	Family physician enabling attitudes: a qualitative study of patient perceptions	Canada	In-depth interviews	**YES: 7** NO: 1 UNCLEAR: 2 N/A: –
25	Kuluski, et al., 2013	The care delivery experience of hospitalized patients with complex chronic disease	Canada	Semi-structured interviews (mixed methods)	**YES: 7** NO: 1 UNCLEAR: 2 N/A: –
26	Morton, et al., 2013	Patients’ perspectives of long-term follow-up for localised cutaneous melanoma	Australia	In-depth interviews	**YES: 5** NO: 3 UNCLEAR: 2 N/A: –
27	Protheroe, et al., 2013	‘Permission to participate?’A qualitative study of participation in patients from differing socio-economic backgrounds.	England	Semi-structured interviews	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
28	Winsor, et al., 2013	Experiences of patient-centredness with specialized community-based care: a systematic review and qualitative meta-synthesis.	Canada (settings of the studies included in this systematic review are North America, Europe, Australia, and New Zealand)	Systematic review and qualitative meta-synthesis	**YES: 5** NO: – UNCLEAR: 6 N/A: –
29	Clarke, et al., 2014	“I Try and Smile, I Try and Be Cheery, I Try Not to Be Pushy. I Try to Say ‘I'm Here for Help’but I Leave Feeling… Worried”: A	Scotland	Two in-depth interviews with each participant	**YES: 8** NO: 1 UNCLEAR: 1

		Qualitative Study of Perceptions of Interactions with Health Professionals by Community-Based Older Adults with Chronic Pain.			N/A: –
30	McMillan, et al., 2014	How to attract them and keep them: the pharmacy attributes that matter to Australian residents with chronic conditions	Australia	Semi-structured interviews	**YES: 7** NO: – UNCLEAR: 3 N/A: –
31	Zimmermann, et al., 2014 Aim is the evaluation and implementation of indicators	Patient perspectives of patient-centeredness in medical rehabilitation	Germany	Focus groups (mixed methods)	**YES: 5** NO: 4 UNCLEAR: 1 N/A: –
32	Baudendistel, et al., 2015	Bridging the gap between patient needs and quality indicators: a qualitative study with chronic heart failure patients	Germany	Semi-structured interviews	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
33	Brown, et al., 2015	Exploring the patient and staff experience with the process of primary care.	United States	Open-ended, semi-structured interviews with clinic staff and high-risk patients	**YES: 6** NO: 3 UNCLEAR: 1 N/A: –
34	Deslandes, et al., 2015	An exploratory study of the patient experience of pharmacist supplementary prescribing in a secondary care mental health setting.	Wales	Semi-structured interviews and self-completion diaries	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
35	Murphy, et al., 2015	A qualitative study of the experiences of care and motivation for effective self-management among diabetic and hypertensive patients attending public sector primary health care services in South Africa.	South Africa	In-depth interviews	**YES: 7** NO: 1 UNCLEAR: 2 N/A: –

36	Östman, et al., 2015	Health-care encounters create both discontinuity and continuity in daily life when living with chronic heart failure—A grounded theory study	Sweden	Individual and group interviews	**YES: 9** NO: 1 UNCLEAR: – N/A: –
37	Sav, et al., 2015	The ideal healthcare: priorities of people with chronic conditions and their carers.	Australia	Nominal group technique (focus groups)	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
38	Sheridan, et al., 2015	Patients’ engagement in primary care: powerlessness and compounding jeopardy	New Zealand	In-depth interviews	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
39	Donnelly & MacEntee, 2016	Care perceptions among residents of LTC facilities purporting to offer person-centred care	Canada	Interviews and observations	**YES: 8** NO: 1 UNCLEAR: 1 N/A: –
40	Nygren Zotterman, 2016	Being in togetherness: meanings of encounters within primary healtcare setting for patients living with long-term illness	Sweden	Personal narrative interviews	**YES: 10** NO: – UNCLEAR: – N/A: –
41	Wright, et al., 2016	Narratives of acquired brain injury patients: Their experience of healthcare relationships and medical decision-making	Canada	Semi-structured interviews	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
42	Benham-Hutchins, et al., 2017	“I want to know everything”: a qualitative study of perspectives from patients with chronic diseases on sharing health information during hospitalization	United States	Online survey with limited choice and open-ended questions	**YES: 7** NO: 1 UNCLEAR: 2 N/A: –
43	Chiu, et al., 2017	Barriers to the Accessibility and Continuity of Health-Care Services in People with Multiple Sclerosis: A Literature Review	United States (literature review)	Literature review of qualitative studies	**YES: 5** NO: 2 UNCLEAR: 4 N/A: –

44	Duthie, et al., 2017	Living with cancer and other chronic conditions: Patients' perceptions of their healthcare experience	Canada	Semi-structured interviews	**YES: 5** NO: 2 UNCLEAR: 3 N/A: –
45	Harrison & Frampton, 2017	Resident-Centered Care in 10 US Nursing Homes: Residents' Perspectives.	United States	Focus groups	**YES: 9** NO: 1 UNCLEAR: – N/A: –
46	Ho, et al., 2017	It's a fight to get anything you need"—Accessing care in the community from the perspectives of people with multimorbidity	Canada	Secondary analysis of qualitative data was conducted on semi-structured interviews (see Kuluski et al., 2013, #25)	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
47	Lian & Robson, 2017	"It´ s incredible how much I´ ve had to fight." Negotiating medical uncertainty in clinical encounters.	Norway	Online survey with closed and open ended questions	**YES: 4** NO: 3 UNCLEAR: 3 N/A: –
48	Melhem & Daneault, 2017	Needs of cancer patients in palliative care during medical visits: Qualitative study.	United States	Semi-structured interviews	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
49	Zizzo, et al., 2017	Examining chronic care patient preferences for involvement in health-care decision making: the case of Parkinson's disease patients in a patient-centred clinic.	Canada	Semi-structured in-depth interviews (mixed methods)	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
50	Dams O'Connor, et al., 2018	Patient perspectives on quality and access to healthcare after brain injury.	United States	Focus groups	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
51*	Laitila, et al., 2018	Service users' views regarding user involvement in mental health services: A qualitative study	Finland	Focus groups	**YES: 9** NO: – UNCLEAR: 1

					N/A: –
52*	Morris, et al., 2018	A qualitative examination of patients experiences of dietitians' consultation engagement styles within nephrology	United Kingdom	Semi-structured individual interviews	**YES: 10** NO: – UNCLEAR: – N/A: –
53*	Fu, et al., 2018	The Management of Chronic Back Pain in Primary Care Settings: Exploring Perceived Facilitators and Barriers to the Development of Patient–Professional Partnerships	United Kingdom	Semi-structured individual interviews	**YES: 9** NO: 1 UNCLEAR: – N/A: –
54*	Chan, et al., 2018	Patients' perceptions of their experiences with nurse-patient communication in oncology settings: A focused ethnographic study	Hong Kong	Focused ethnographic study including observations and semi-structured interviews	**YES: 8** NO: 1 UNCLEAR: 1 N/A: –

*Included after re-run