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Exploring people-centred healthcare in arthritis care: a qualitative study

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Abstract

Background Arthritis encompasses a group of chronic musculoskeletal conditions that may involve pain, functional limitations, and impacts on quality of life. People-centred care, encompassing both person- and patient centred principles has been recognised by the World Health Organisation as an essential strategy to address the complex needs of individuals with chronic illness. However, existing research remains limited in capturing how people with arthritis perceive and experience people-centred healthcare across different stages of their care experiences. The aim of this study was to explore the experiences of people with arthritis to develop a conceptual framework of people-centred arthritis care.

Methods A qualitative design was employed, informed by principles of design thinking. Seven participants with a confirmed diagnosis of arthritis and at least three years of experience of accessing UK health services were recruited through online arthritis- related support groups and a national charity. Semi-structured interviews were conducted via Microsoft Teams, transcribed verbatim, and anonymised. Data were analysed using a combination of journey mapping, framework analysis, and thematic analysis, guided by an interpretive phenomenological and design thinking orientation.

Results Findings identified participants experienced healthcare journeys as cyclical rather than linear, characterised by four interconnected stages: needs identification, information acquisition, service utilisation, and continuity and coordination of care. Across these stages, six key features of people-centred care were identified: the importance of personalised health management, information access and self-education, the role of community groups in providing support, communication and resource challenges within the healthcare system, the influence of economic factors on service accessibility, and the impact of continuous and timely support on experience. Participants highlighted the value of being recognised as active agents in their care, while also identifying structural and systemic barriers that limited responsiveness and trust.

Conclusions This study demonstrates people-centred healthcare for arthritis requires flexible, iterative approaches that respond to fluctuating symptoms, personal circumstances, and long-term support needs. Incorporating the perspectives of people with arthritis into service design can enhance continuity, equity, and empowerment, with potential implications for wider models of chronic care.

Trial registration Not applicable.

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Keywords People-centred care, Arthritis care, Qualitative research, Care experience

Background

Study aim and rationale

This paper aims to explore how people living with arthritis perceive and experience healthcare services. By exploring participants' accounts of their interactions and emotional responses across different stages of care, the study seeks to understand which aspects of healthcare services are perceived as meaningful and people-centred from their perspective. Through this approach and analysis, the study also sought to develop an integrative analytic structure to organise participant-defined elements of people-centred arthritis care across the healthcare journey.

Global and national context

The International Classification of Diseases, 11th Revision (ICD-11) of the World Health Organization (WHO) defines arthritis as a group of conditions primarily affecting the joints, characterised by common features such as pain, swelling, and stiffness [1]. With population ageing and the increasing burden of chronic illness, the global prevalence of arthritis continues to rise [2]. Both osteoarthritis and rheumatoid arthritis present significant public health and socioeconomic challenges, disproportionately affecting older adults and women [3, 4]. As chronic conditions, they are often associated with long-term functional limitations and diminished quality of life, necessitating interdisciplinary, continuous, and people-centred models of care to support self-management and social participation [5].

In the United Kingdom, the management of arthritis follows an evidence-based and integrated approach, guided by the recommendations of the National Institute for Health and Care Excellence (NICE), with care typically involving general practitioners in primary care, specialist rheumatology services, allied health professionals, and support from voluntary and charitable organisations [6]. Treatment strategies typically combine pharmacological and non-pharmacological interventions, including physiotherapy, hydrotherapy, dietary interventions, and education programmes [6]. Patient education and sustained multidisciplinary support are regarded as key measures for improving outcomes [7]. Care experiences may also differ across arthritis types. Osteoarthritis is often managed primarily in primary and community care settings, whereas inflammatory arthritis commonly requires early specialist assessment and long-term rheumatology follow-up, shaping the intensity and continuity of care received [6].

Nonetheless, significant challenges persist in practice: people living with multimorbidity frequently encounter

insufficient care coordination within primary care [8]. Workforce and financial pressures within the National Health Service (NHS) contribute to uneven service provision and prolonged waiting times, thereby impacting on patient's experience of care [9]. These difficulties have been further exacerbated by the COVID-19 pandemic, which exposed shortcomings in inter-organisational collaboration, data sharing, and health equity [10]. While telemedicine has played a role in sustaining access to services, its long-term implications for continuity and equity of care remain to be evaluated [11].

Frameworks of people-centred care

Against this backdrop of multi-actor and condition-specific care pathways, people-centred care has gradually emerged as a key direction for global health reform. People-centred care underscores the recognition of the values and preferences of individuals, carers, and communities, positioning them as active participants and co-creators within health systems [12]. Evidence indicates that people-centred care not only enhances people's satisfaction with health services but also strengthens the sense of professional fulfilment among healthcare providers [5]. The call for such a transformation is closely linked to the major challenges confronting health systems worldwide, including population ageing, the rising prevalence of chronic conditions, lifestyle changes, and increasing care fragmentation [13].

In healthcare literature, the terms patient-centred, person-centred, and people-centred care are sometimes used interchangeably, but they reflect different emphases. Patient-centred care focuses on respecting individual patients' preferences and values within clinical encounters [14], while person-centred care emphasises individuals as whole persons beyond their medical conditions [15]. People-centred care adopts a broader system-level perspective that includes individuals, families, carers, and communities, and emphasises organising services around people's comprehensive needs rather than specific diseases [12]. In this study, the term people-centred is used consistently to reflect this broader focus.

The World Health Organisation [5] has outlined five interdependent strategic directions to advance the implementation of people-centred and integrated care: (1) empowering and engaging individuals and communities by strengthening their capacity to participate in health decision-making and service co-creation; (2) strengthening governance and accountability through transparent decision-making and shared responsibility to ensure equity within health systems; (3) reorienting models of care by reinforcing primary and community-based

services and fostering cross-sector collaboration; (4) coordinating services by integrating provision across levels and sectors to reduce fragmentation, enhance continuity, and improve responsiveness to emergencies; and (5) creating an enabling environment by driving system reform through legislation, financing, and workforce development.

In rheumatology, patient-centred and person-centred principles have been implemented in both research and clinical practice. For example, the 2021 EULAR recommendations for the management of inflammatory arthritis explicitly emphasise the inclusion of self-management advice and resources in routine care, with the aim of empowering patients and promoting a more holistic, patient-centred approach to improve care experiences and outcomes [16]. However, while such recommendations reflect patient- and person-centred principles primarily within clinical encounters, the extent to which broader people-centred care principles are enacted and experienced across arthritis healthcare services and care pathways is lacking from contemporary literature and policy.

Beyond policy-oriented frameworks, recent scholarship highlights people-centred care as a relational and experiential approach, while also identifying persistent barriers in practice, including inadequate communication, rigid organisational routines, and misaligned incentive structures [17]. Existing literature further suggests that biomedical and system-level priorities continue to overshadow people's lived experiences, leaving the relational and experiential dimensions of care underexplored [18].

Nevertheless, the promotion of people-centred care faces considerable obstacles worldwide. Studies have highlighted that inadequate communication, informational asymmetries, rigid institutional cultures, insufficient clinical training, and misaligned incentive structures all serve to undermine trust and collaboration between people receiving care and professionals [17, 19]. Within efficiency-driven institutional contexts, people are frequently reduced to carriers of disease, while their social circumstances, emotional needs, and lived realities are overlooked [20]. Existing research continues to focus predominantly on biomedical indicators and clinical outcomes, paying insufficient attention to people's everyday experiences within complex systems [18]. As a result, the relational, contextual, and experiential dimensions of people-centred care remain underexplored.

Methodological orientation and contribution

To address these limitations, this study focuses on the everyday experiences of people living with arthritis, aiming to explore how healthcare services are perceived and understood from their perspective. The study explores

participants' retrospective accounts of their interactions and emotional responses across different stages of care, with the aim to understand which aspects of healthcare services are perceived as meaningful and people-centred.

An interdisciplinary methodological framework was adopted, informed by principles of design thinking, qualitative health research, and interpretative phenomenology. Design thinking contributed an emphasis on empathy and problem reframing, which was supported by framework analysis and incorporating journey mapping. Finally, thematic analysis contributed to the identification of recurring patterns across participants' accounts, identifying themes and organising these themes across stages of care and to support systematic comparison within and across cases. This combined approach enabled both inductive insight generation and structured interpretation of complex healthcare experiences, while remaining grounded in participants' lived experiences.

Methods

Research design

This study aimed to identify and understand the elements of people-centred care in arthritis-related healthcare services accessed across a range of public (NHS), private, and third-sector providers within the UK healthcare system, from the perspective of people with arthritis. A qualitative design was employed within an interdisciplinary methodological framework, focusing on the perspectives of people with arthritis to explore their day-to-day interactions with health services and to identify participant-defined features of people-centred care. The study adopted an interpretive orientation, emphasising how participants made sense of and attributed meaning to their healthcare experiences.

An interdisciplinary framework was adopted to integrate perspectives from design research, qualitative health services research, and interpretative phenomenology, in order to address the complexity of arthritis care pathways. Design thinking contributed principles of empathy and problem framing, supporting engagement with participants' experiences and helping to surface service-related challenges from a people-centred perspective. Qualitative health services research provided conceptual and analytical grounding in service organisation and care delivery, ensuring relevance to healthcare practice. Interpretative phenomenology informed the focus on lived experience and meaning making, enabling attention to both shared patterns and individual variation. Such integration supports engagement with the complexity of healthcare services and care experiences [21].

The study adopted an interpretative phenomenological orientation, emphasising the dual interpretation of experience - meaning [24] to reveal both common patterns

and individual differences. In line with design thinking principles, journey mapping was employed not only to visualise care pathways but also to trace recurring patterns and feedback loops, revealing the cyclical nature of people's healthcare experiences. The process of mapping participants' experiences helped to identify key touchpoints and potential "bottlenecks" along the care pathway, offering a structured means to locate where people-centredness was reinforced or compromised. In practice, user journey mapping was employed to visualise care pathways and emotional fluctuations, in combination with framework analysis and thematic analysis: the former to systematically organise and compare the data, and the latter to inductively identify participant-defined elements of people-centred care. This design ensured that the analysis remained both people-centred and empathetic, while also producing findings relevant to service improvement and policy debate.

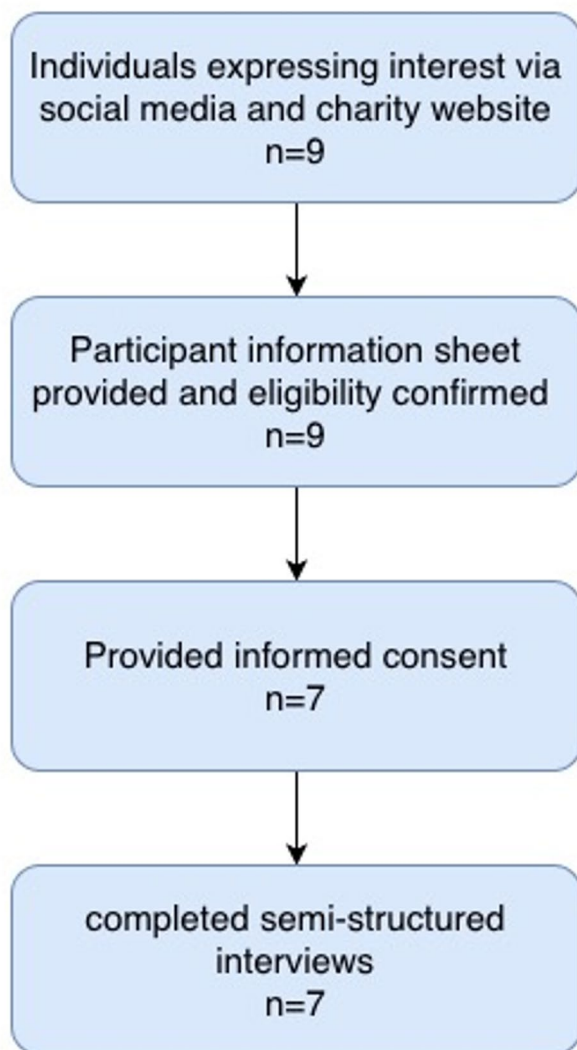


Fig. 1 Participant recruitment flowchart

Participants

This study employed purposive sampling, selecting participants on the basis of the research objectives [22].

Recruitment information was disseminated through arthritis-focused groups on LinkedIn, X (formerly Twitter), and Facebook, as well as via a notice on the website of the UK charity Arthritis Action. Individuals expressing interest contacted the researcher by email to obtain the participant information sheet and consent form, and interviews were arranged following confirmation of participation. Inclusion criteria required participants to be aged 18 years or older, to have a clinical diagnosis of arthritis for at least three years, to be able to communicate in English, and to consent to a remote interview conducted via Microsoft Teams. To ensure alignment with the UK healthcare context, individuals who had not accessed UK health services were excluded.

A total of nine individuals initially expressed interest in participation, of whom seven provided written informed consent and were interviewed. The recruitment process from initial expressions of interest to the final sample is summarised in Fig. 1.

Participants were adults living with arthritis affecting different joints and body areas, with disease duration ranging from approximately 7 years to over 65 years. The sample included four women and three men. Among participants who disclosed age, ages ranged from 57 to 88 years. All participants had experience of accessing UK healthcare services for arthritis-related care across one or more settings, including NHS primary care, specialist outpatient services, and, in some cases, private or third-sector support.

All interviews were conducted remotely via Microsoft Teams, with participants joining from quiet and private settings, ensuring accessibility and the protection of confidentiality.

Data collection

The primary data source for this study consisted of one-to-one semi-structured interviews. All interviews were conducted remotely via Microsoft Teams, scheduled at times convenient for the participants, and carried out in English. Interviews were conducted by the first author, who had prior training and experience in qualitative interviewing and qualitative health research. The interviewer did not have any prior clinical or therapeutic relationship with participants.

Interviews were conducted between February 2023 and March 2023 and lasted approximately 30–60 min. With participants' consent, each session was audio- and video-recorded. Video recording was enabled to support rapport-building in the remote interview context and to facilitate conversational flow, allowing the interviewer to attend to participants' emotional expression and

engagement during the interview [23]. However, visual data were not treated as analytic material and were not formally analysed.

The recordings were subsequently transcribed verbatim by the researcher, with follow-up clarification sought where necessary to ensure accuracy of meaning and expression. This process was limited to clarification and did not constitute formal member checking or participant validation of analytic interpretations.

The interview guide was developed on the basis of the literature review and publicly available NHS resources and informed by informal input from individuals with lived experience of arthritis and familiarity with arthritis-related services, which was used only to support question development rather than as a data source. The interview guide was informed by an interpretative phenomenological orientation, with questions designed to elicit participants' lived experiences and the meanings they attributed to their interactions with healthcare services. Accordingly, the guide prioritised open-ended, non-directive questions that encouraged participants to describe experiences in their own terms and to reflect on how they made sense of care encounters over time. Probing was used flexibly to support depth and clarification, guided by participants' accounts. It comprised open-ended questions addressing themes such as care pathways and key touchpoints, service experiences and emotional fluctuations, needs and expectations, and understandings of care relationships and communication, with the aim of eliciting in-depth experiential narratives (see Fig. 2 and Supplementary File 1). Following a small-scale pilot, minor adjustments were made to the wording and sequencing of questions in response to feedback, in order to enhance clarity and answerability. The pilot interviews were not included in the final dataset. The interpretative

phenomenological orientation, contemporary review, and the pilot study provided a coherent basis for the development of the interview guide and its suitability to address the study aims. The guide supported in-depth exploration of lived experience and meaning making, with flexibility achieved through follow-up prompts to clarify meanings and deepen narratives, which were not rigid or pre-designed.

To ensure data security and confidentiality, audio recordings and transcripts were stored in an encrypted, access-restricted space. Transcripts were anonymised and pseudonyms were assigned immediately after transcription. In terms of ethics, the study received approval from the relevant institutional ethics committee.

Data analysis

An integrated analytical strategy was developed to address the complexity of arthritis care experiences and the multi-layered nature of people-centred care. No single analytic method was considered sufficient to capture both the structural organisation of care pathways and the subjective meaning-making of participants' lived experiences. Journey mapping was therefore used as the overarching organisational framework, combined with framework analysis and reflexive thematic analysis from an interpretative phenomenological perspective was applied to support meaning-oriented interpretation [24]. As illustrated in Fig. 3, framework analysis was used as the primary method for data organisation and familiarisation, with user journey mapping incorporated as an analytic structuring device during this stage, followed by reflexive thematic analysis and interpretative meaning-making. While the literature review informed the development of the interview guide and sensitised the researchers to relevant areas of inquiry, the analytical

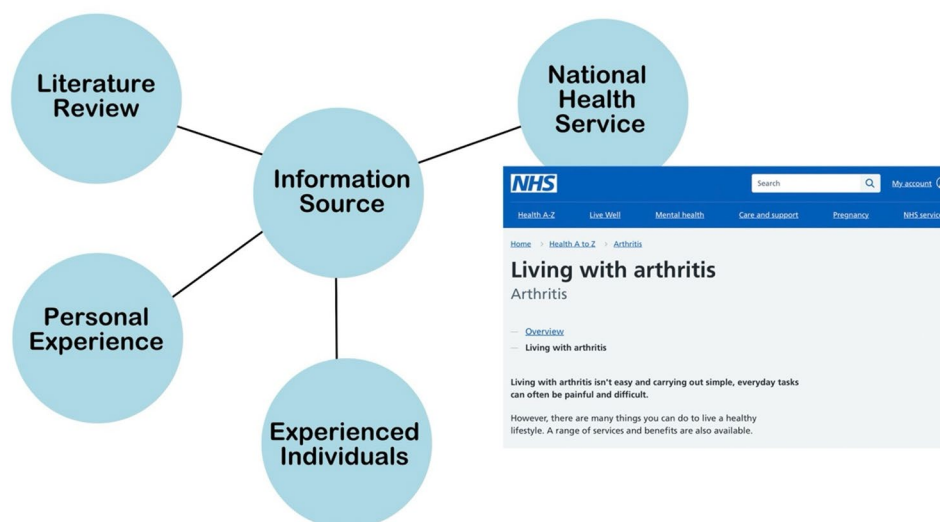


Fig. 2 Preliminary information sources informing the development of the interview guide

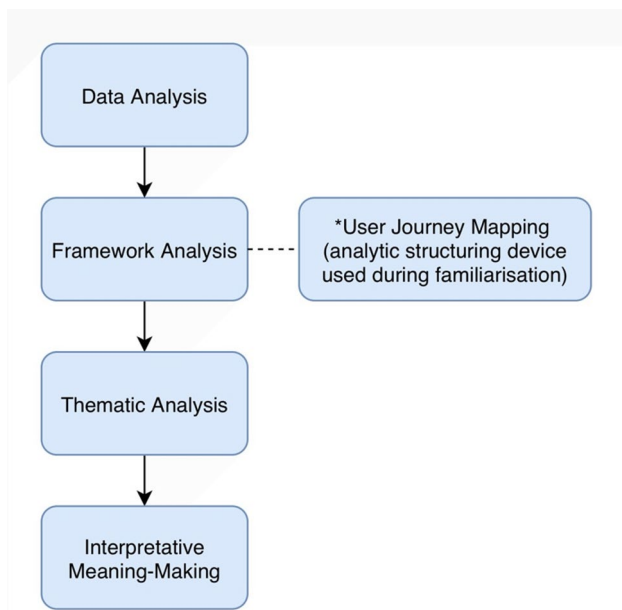


Fig. 3 Overview of the data analysis process

process was conducted inductively, with categories and relationships emerging from participants' accounts rather than being imposed a priori. Data analysis was conducted by the first author, drawing on training and experience in qualitative health research.

These approaches were mutually reinforcing as journey mapping offered a structured view of care pathways and touchpoints; framework analysis ensured systematic organisation of the data and cross-case comparison; and thematic analysis inductively identified participant-defined elements of people-centred care from participants' narratives.

Following transcription and de-identification, the analysis advanced through a structured sequence: initial familiarisation and inductive coding; subsequent mapping of key information onto journey stages and touchpoints, supported by framework-based organisation and cross-case comparison; and, on this basis, the development and labelling of themes, which were then cross-checked and integrated with the analytical framework generated through framework analysis.

Framework analysis followed the established five-stage process of familiarisation, identifying a framework, indexing, charting, and mapping and interpretation. During familiarisation, user journey mapping was used as an analytic structuring process, after which data were indexed and charted into a framework matrix organised by journey stages and participants to support comparison across cases. During familiarisation, key touchpoints across participants' journey were identified. For example, accounts relating to participants' early interactions with healthcare services were coded inductively and

then organised and mapped onto key stages of the care journey using a framework-based structure. The final touch points were symptom recognition, entry into services, initial treatment, and long-term management. An exemplar journey map illustrating key touchpoints, events, and emotional responses across the care journey is provided in the Supplementary Material. In parallel, inductive thematic analysis was undertaken to examine participants' narratives in greater depth, focusing on recurring experiential meanings across cases rather than predefined categories. Codes and candidate themes were developed through iterative engagement with the data and were subsequently compared and refined in relation to the framework-based organisation. This process supported cross-case comparison and the identification of recurring patterns, which were subsequently refined into themes representing participant-defined elements of people-centred care.

This integrative approach facilitated the simultaneous illumination of shared experiences and individual differences, highlighting how participants perceived and ascribed meaning to their healthcare encounters within the context of their lifeworlds, thereby providing a robust interpretive foundation for identifying elements of people-centred care.

Rigour and reflexivity

The rigour of this study was ensured in accordance with Lincoln and Guba's [25] four criteria: credibility, dependability, transferability, and confirmability. With regard to credibility, semi-structured interviews were used to obtain rich narratives, clarifications were sought in real time, transcripts were repeatedly reviewed, and cross-case comparisons were undertaken; moreover, triangulation was achieved through the combined use of journey mapping, framework analysis, and thematic analysis. All stages of triangulation and analytical integration were conducted by the first author. Data collection and analysis were conducted independently by the first author, with methodological guidance and critical review provided by two academic supervisors with complementary expertise in qualitative design and health research. For dependability, an audit trail was maintained, documenting key decisions and version changes, and retaining revisions of the interview guide and coding notes to ensure traceability. The researcher did not have a clinical role, and participants were informed that the interviews were not intended to provide medical advice. If participants expressed a need for support, the researcher would respond appropriately and provide assistance within the boundaries of the research role. In terms of transferability, details of the UK healthcare context and participant characteristics were provided, and representative quotations were included in the findings to enable readers to

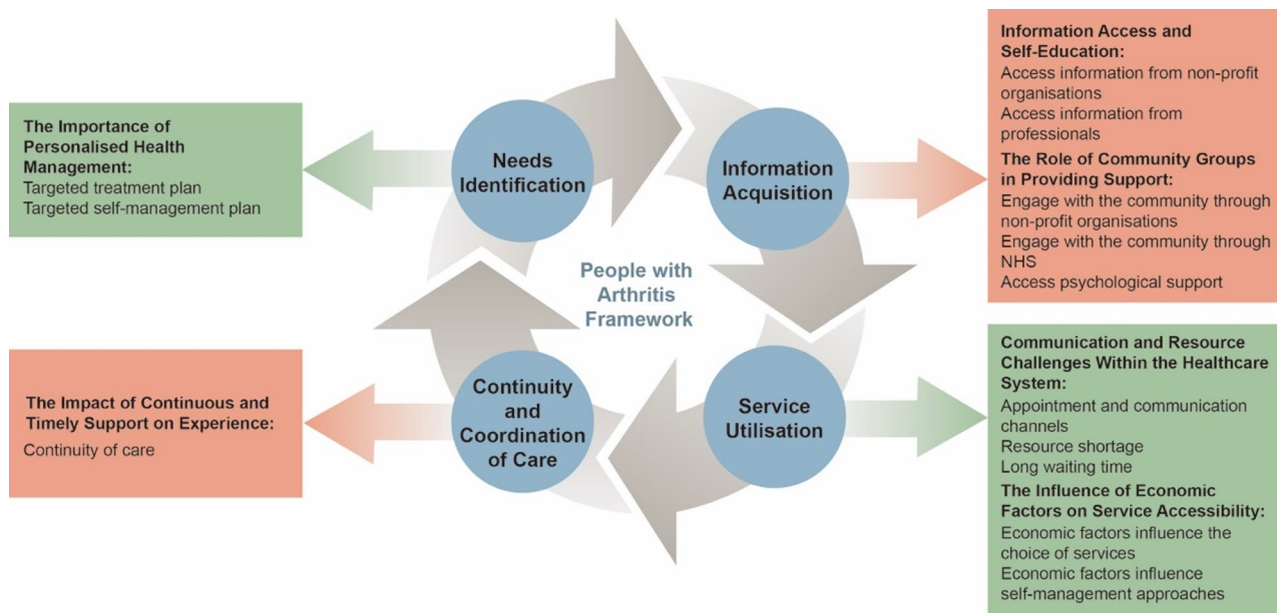


Fig. 4 The circular framework of arthritis care experience incorporating people-centred elements

judge applicability. With respect to confirmability, all data were de-identified and an explicit evidence chain linking quotations, codes, and themes was preserved, while triangulation across methods was employed to minimise researcher bias. The study aimed to develop an in-depth, interpretive account of people-centred care experiences rather than to exhaustively capture all possible perspectives. Data saturation was assessed iteratively based on the recurrence of experiential patterns relevant to the study aims, and methodological triangulation across analytical approaches supported analytical depth. In line with an interpretative phenomenological orientation, saturation was approached as the point at which recurring experiential meanings relevant to people-centred care were identified across cases, rather than as exhaustive coverage of all arthritis diagnoses or care pathways [26]. Saturation was assessed iteratively through cross-case comparison, with recurring themes indicating sufficient depth to address the study aims.

The researcher entered the study with prior familiarity with people-centred care, service design, and qualitative health research. This pre-understanding was treated reflexively as both a resource and a potential source of bias, with reflexive memoing and iterative engagement used to question assumptions and prioritise participants' own meanings. Throughout data collection and analysis, the study emphasised the researcher's reflexive awareness, seeking to minimise the influence of prior assumptions on questioning, probing, and the labelling of codes. During the stages of analysis and writing, a people-centred perspective was consistently maintained, with priority given to presenting participants' original

expressions and contexts, rather than imposing pre-defined frameworks that might obscure their processes of meaning-making.

Results

Framework analysis overview: a circular framework

The analysis resulted in a circular framework comprising four interrelated stages: needs identification, information acquisition, service utilisation, and continuity and coordination of care (Fig. 4). The framework not only depicts the main stages of participants' healthcare journeys but also integrates a number of themes relating to people-centred elements. It reflects the lived experiences of people with arthritis, whose health trajectories are seldom linear but instead characterised by recurrent cycles of help-seeking, adjustment of management, and re-engagement with services.

For instance, Participant A described seeking medical help in response to multiple arthritis-related symptoms affecting both her fingers and toes:

I initially noticed my hands on my 2 fingers...my fingers look a little bit misshapen. I think I need to do something about that...so I went to my doctors. [later] I've noticed that my toes were really, really swollen. And there were really chunky and quite sore. And so, I went to my doctors with my toes and obviously it have been before my finger. (Participant A)

This cyclical structure illustrates the ongoing and recurrent nature of arthritis care, authentically reflecting the

lived realities of people with arthritis in the process of managing their condition.

Stage 1: Needs identification

The first stage of the circular framework - needs identification - corresponds to the initial phase of the care journey, during which individuals begin to recognise changes in their health and their need for medical support. This stage is characterised by participants' reflections on bodily symptoms, the disruptions to everyday life, and moments of awareness that prompted them to seek help or reassess their self-management strategies. Within these accounts, personalised approaches to health management emerged as a central element.

The importance of personalised health management

The findings highlighted the central role of personalised health management in addressing the diverse needs of people with arthritis. A core principle of people-centred healthcare is the provision of tailored support that takes into account individuals' preferences, everyday contexts, and health needs. In the data from this study, personalised health management was defined, drawing on participants' accounts, as the adaptation of health-related plans, recommendations, or services to align with personal preferences, daily routines, symptom patterns, or social contexts.

Participant B described how, within NHS care, taking into account his doctor's advice and considerations relating to his stage of life, he chose to postpone surgery and instead pursue a less invasive option:

The long term, it's gonna be knee replacements, but the specialist suggested I'm a little too young... So I'm holding out with steroid injections for the time being. (Participant B)

Participant A, within NHS care, after experiencing side effects, was advised to adjust her medication. For example, following adverse effects with a previous treatment, she was allowed to choose the mode of administration for a new therapy:

They consulted me... they asked me if I wanted to do my injection weekly or two weeklies. They consulted me through the plan, because obviously there's a plan for me. (Participant A)

Participants' accounts indicate that personalisation was experienced as important, as this approach supported joint decision-making regarding care, incorporating individual circumstances such as stage of life, treatment tolerance, and daily routines. In particular, being consulted about treatment options and having choices incorporated

into care plans enabled participants to align medical recommendations with their own preferences and capacities, rather than having standardised decisions imposed upon them. Personalised health management constitutes a core element of people-centred care precisely because it respects individual differences and, through interaction, incorporates people's health status, daily routines, and preferences into the decision-making process. Participants not only articulated their choices, but these preferences were also acknowledged and translated into concrete plans, thereby realising shared decision-making. Through such contextualised adjustments, care pathways became more closely aligned with individual needs, reflecting the flexibility and participatory nature of people-centred care.

Stage 2: Information acquisition

The second stage of the circular framework - information acquisition - corresponds to the phase of the care journey in which, having recognised their health needs, individuals actively or passively seek relevant information. This stage is characterised by participants' efforts to explore areas such as disease diagnosis, treatment options, and advice on daily management. It also reflects their lived experiences of accessing, understanding, and evaluating information. Following the recognition of needs, participants obtained information through healthcare professionals, non-profit organisations, online platforms, and peer groups. The study identified two people-centred elements at this stage: information access and self-education, and the role of community groups in providing support.

Information access and self-education

The study revealed a variety of pathways and methods through which information was accessed and self-education was pursued. In managing their condition, participants engaged with diverse sources of information, which they used to deepen their understanding, evaluate potential interventions, and support their everyday management practices. The principal sources of information included healthcare professionals, non-profit organisations, and online platforms.

Participant A recalled that, within NHS care, at the time of diagnosis, she was provided with explanatory materials on an ongoing basis:

When I first got diagnosed, they gave me leaflets. I was kept informed and also with the medication as well... my rheumatologist explained everything to me. (Participant A)

Participant D described receiving practical advice from a non-profit organisation:

Here are some things you could do... including things you can get for free or reduced cost. Try those rather than just sitting there feeling sorry for yourself. (Participant D)

By obtaining and understanding information pertinent to their own circumstances, individuals not only enhanced their confidence and autonomy but were also able to make informed choices in managing their health. Such informational support positioned individuals in an active role, realising the participatory and empowering dimensions of people-centred care.

The role of community groups in providing support

Participant E's experience illustrates that people-centred care can be expressed through support at both the informational and relational levels. His engagement with multiple non-profit resources and NHS-led group activities demonstrated how individuals draw on knowledge acquisition and social connection to navigate health-related challenges.

Participant E described accessing a wide range of arthritis-related informational resources through a non-profit organisation:

I did find it helpful because it does give you quite a lot of useful information, like tips on how to maybe do things or not overdo things... I get the magazine as well... there's a lot of information booklets... there's a helpline aswell... if you've got any questions or if you need any help... (Participant E)

Participant E, valued not only information materials but also emphasised the importance of group activities from NHS care, noting that peer interaction helped to reduce feelings of isolation:

these people that are in these groups, they've ended up becoming friends...but I have actually kept in touch with a few of them, so it is nice that I can still comment of keeping talks and you know I'm not the only person. (Participant E)

Community support constitutes an essential element of people-centred care because it not only provides information but also responds to individuals' emotional and social needs. Participant E's experience illustrates that when information is both accessible and personally relevant, and is accompanied by meaningful interaction and recognition, he feels understood and supported in the process of learning to manage his condition. By fostering shared understanding and empathetic relationships, community groups enabled individuals to access

sustained support beyond formal services, thereby realising the principles of people-centred care.

Stage 3: Service utilisation

The third stage of the circular framework - service utilisation - corresponds to the phase of the care journey in which individuals move from recognising their health needs and acquiring information to actively engaging with and making use of healthcare services. At this stage, participants began to establish concrete connections with the health system, taking part in processes such as diagnosis, treatment, follow-up, or other forms of supportive intervention. Their accounts commonly addressed the processes of accessing services, the modes of communication with professionals, and the influence of external factors on service utilisation.

Communication and resource challenges

During the stage of service utilisation, modes of communication and the availability of resources had a significant impact on individuals' care experiences. Participants' narratives highlighted several aspects closely linked to people-centred care, particularly the adequacy of consultation time, the availability and configuration of personnel, and the clarity and consistency of service processes. These factors were closely related to the extent to which services were able to recognise and respond to individual needs.

Participant E noted that the brevity of consultation time made it difficult for him to fully articulate his thoughts:

I think I feel NHS appointments can be rushed. And I don't feel like I'm getting my point across enough. So, it can be a little bit frustrating. (Participant E)

Participant A described experiencing frequent delays in reaching the NHS care team due to staff shortages:

They're very short staffed and you do have to leave messages sometimes because there's so busy. (Participant A)

System-level procedures could also present obstacles. Participant A noted that general practitioners acted as "gatekeepers" in the process of obtaining referrals:

It's got to start at the GP, that's the initial point... If you've got a doctor that's not listening or you know, just a stopping you off, you're not gonna get past the first hurdle to see a rheumatologist. (Participant A)

Challenges relating to communication and resources constitute key elements of people-centred care because

they directly affect whether individuals are able to fully articulate their concerns and receive timely responses. Participants' experiences indicated that limited consultation time, staff shortages, and procedural constraints diminished their sense of participation and being understood.

The influence of economic factors on service accessibility

During the stage of service utilisation, some participants noted that financial factors had a tangible influence on their decisions regarding approaches to health management and choices of services. This theme, "the impact of financial factors on service accessibility," is centred on two interrelated dimensions: first, how economic circumstances shaped self-management practices; and second, the role of financial considerations in decision-making when choosing between available services.

In describing her experiences of service utilisation, Participant A referred to the influence of financial factors on her choice of services:

My twin sister was living in the UK and she got her feet done on the NHS because obviously, it's free here. (Participant A)

Participant F explained that some of the recommended activities were financially difficult to afford:

Because I'm not working, I'm finding them a little bit expensive. (Participant F)

Economic factors are an essential element of people-centred care, as they directly influence both the accessibility and sustainability of services. Participants' experiences indicated that perceived affordability and alignment with personal circumstances determined whether services could be taken up and integrated into everyday health management. Attending to economic realities and ensuring that services are both available and affordable reflects the responsiveness of people-centred care to individuals' lived circumstances.

Stage 4: Continuity and coordination of care

The framework then entered the stage of continuity and coordination of care, which reflected the ongoing relationships and support arrangements established between individuals and the healthcare system following the initial consultation. At this stage, service interactions extended beyond one-off appointments to include follow-up care, continuity of information, and ongoing responsiveness to changes in health status.

The importance of continuous and timely support on experience

The following example illustrates the importance of continuity and proactive follow-up as core elements of people-centred care. Participant F, within NHS care, noted:

They don't check back, and I think they should. I think they should ask me how it's going. Because if they don't ask again, how are they going to know if things are going well? (Participant F)

Participant A emphasised that frequent changes of doctor undermined continuity:

If you don't see the same doctor twice or you've got a locum doctor then there, that's where the issues arise because you've no continuity of care. (Participant A)

Participant B described his experience of becoming disconnected from the care system following his GP's retirement and the disruptions caused by the pandemic:

The GP that I did have is actually retired now, but I've not really been to a GP for well really since the pandemic. (Participant B)

Continuity of care and timely support constitute essential elements of people-centred care, as they ensure that individuals feel attended to and understood throughout long-term engagement with services. Participants' experiences indicated that the absence of follow-up, frequent changes of professionals, or disruptions in care undermined trust and a sense of involvement. In contrast, sustained contact and coordination fostered feelings of security and coherence. By guaranteeing ongoing support and timely responsiveness, services were better able to align with individual needs, thereby embodying the responsibility and compassion inherent in people-centred care.

Discussion

Interpretation of findings in the context of arthritis care

This study addressed the research question: What are the people-centred care elements in arthritis healthcare services from the perspective of people with arthritis? The research question was closely aligned with the study aim and the interview guide, which explored perceived needs of people with arthritis, information-seeking behaviours, service access, and experiences of continuity across care settings. The resulting framework therefore reflects not only emergent themes from the data but also the experiential domains explicitly probed during data collection. This study reconceptualised the trajectory of arthritis care as a cyclical and iterative process, proposing a people-centred circular framework comprising

four interrelated stages: needs identification, information acquisition, service utilisation, and continuity and coordination of care. The framework did not derive from predetermined assumptions but was instead grounded in inductive analysis of the experiences of people with arthritis, highlighting the dynamic and cyclical nature of care needs.

In existing research, user journey mapping has become an essential method for capturing experiences [27]. It is commonly represented through linear diagrams, mind maps, or service blueprints, which help to identify key touchpoints and potential “bottlenecks” [28]. May et al. [29] divided the experiences of people with arthritis into the stages of “pre-diagnosis - diagnosis - post-diagnosis - current treatment”. Although these studies effectively illustrate sequentiality, their analyses largely remain within linear narratives and do not sufficiently uncover the dynamic mechanisms of interaction between people with arthritis and the health system. These approaches primarily emphasise planned or normative sequences of care and provide limited analytical attention to re-engagement with healthcare professionals, the re-emergence of information needs, or the ways individuals navigate discontinuities when services are delayed, inaccessible, or misaligned with changing needs.

By contrast, the circular framework developed in this study extends existing journey-based approaches by offering a more accurate reflection of the realities faced by people with arthritis as they navigate multiple systems, engage in iterative decision-making, and confront uncertainties in resources. Its contribution lies in foregrounding people with arthritis as active agents rather than passive recipients. Participants described repeatedly reassessing needs, returning to healthcare professionals for clarification or renegotiation of care plans, and seeking alternative sources of information and support when continuity was disrupted. They not only continually assess needs, seek information, and utilise healthcare and community resources, but also move back and forth across different stages of care. Accordingly, the framework provides a complementary conceptual lens [29, 30] for examining people with arthritis agency, transitional support mechanisms, and the responsiveness of healthcare systems. These elements have been discussed in existing chronic care, self-management and health literacy models; however, this study situates them within the lived service experiences of people with arthritis across multiple care contexts.

Elaborating the six elements as operational features of people-centred care

Conventional systems have largely been shaped by biomedical logic, often neglecting the uniqueness of people [31]. In the context of this study, these observations

reflect the services experienced and interpreted by participants, rather than a general characterisation of all arthritis or rheumatology care models. While people-centred care, shared decision-making and patient and public involvement are widely endorsed aims within contemporary arthritis care, participants in this study reported that these principles were not consistently reflected in their lived service experiences. Beyond failing to recognise personhood, this logic can also drive low-value care, characterised by overuse of procedures, tests and medicines that increase burden and risk while straining healthcare systems [32]. In Ireland, such pressures are evident in extensive orthopaedic waiting lists, with more than 84,000 people waiting for outpatient appointments in July 2021 and 45% waiting for over a year, a situation further exacerbated by COVID-19 disruptions [33]. Outcomes are not guaranteed by intervention alone, as up to 30% of total knee replacement recipients remain dissatisfied one year after surgery [34]. These trends question the sustainability of procedure-centred models and highlight the need to reorient towards a people-centred approach that is both holistic and dynamic, responding to evolving needs from identification to long-term support while promoting participation, continuity and interdisciplinary collaboration.

Emerging initiatives illustrate this shift in practice through needs-based referral pathways, shared decision-making and coordinated navigation between clinical and community settings supported by appropriate data infrastructure [35]. In Ireland, such approaches align with national reforms such as *Sláintecare*, which advocates “the right care, at the right place, at the right time” [33, 36]. Achieving this vision requires not only structural redesign but also informational equity, including broader provider education for complex arthritis care and knowledgeable, early-stage support that strengthens self-management and people’s agency [37]. These developments align closely with the circular model proposed in this study, particularly in their emphasis on early needs identification, shared decision-making as an ongoing process, and coordinated support across care stages rather than linear progression through services.

Building on these systemic and conceptual insights, this study identified six interrelated elements that operationalise people-centred care in arthritis services. These elements represent both practical and relational features through which care becomes responsive, participatory and sustainable within complex healthcare contexts.

The importance of personalised health management

Personalisation entails flexible adaptation within clinical, psychological, and social contexts rather than a “one-size-fits-all” approach. People with arthritis differ markedly in terms of symptom fluctuation, treatment response, and

life priorities [38]. Previous studies have underscored the importance of personalisation and respect in healthcare interactions [39]. Consistently, patients emphasise that care should reflect their lived experiences and individual needs, and that they wish to participate actively in decisions about treatment options [40]. The findings suggest the early stage of needs identification plays an important role in shaping care experiences, as the failure to recognise and respond to individuals' situations at this point was described as particularly distressing and undermining subsequent engagement with care. As one participant described: "I kind of went nearly two years of not knowing what's going on. So it wasn't. It was pretty dreadful." (Participant E). The contribution of this study lies in demonstrating that personalisation is not an abstract ideal but exerts a concrete influence on the quality of care from the earliest stages of the care journey.

Information access and self-education

Information is derived not only from healthcare professionals but also from online resources and peer groups. Education has been shown to improve outcomes [41, 42] and should strike a balance between empowerment and the avoidance of overload [43]. People seek education to strengthen autonomy and plan for the future [44], while also sharing knowledge with professional teams [45]. This study found that *information acquisition* represented the foundational stage of the circular framework, reflecting both the agency and health literacy of people with arthritis. Importantly, the findings suggest health literacy operates not merely as access to information, but as a capability enabling patients to interpret, appraise, and apply information when navigating services and making care related decisions [46]. Participants' experiences indicated that variations in health literacy influenced how effectively information translated into service use and continuity of care, positioning health literacy as a key mechanism shaping people centred care in practice [46]. Moreover, the study revealed that information acquisition is not merely the transfer of knowledge but a key mechanism for activating people's agency.

The role of community groups in providing support

Community groups play an important role in psychological adjustment, decision-making, and daily management, and are often perceived as more empathetic than formal healthcare settings [43]. Existing research has shown that self-management relies on social networks [47], and people with long-term conditions demonstrate strong interest in peer support [48]. This study found that community interaction not only provided emotional support but also facilitated knowledge co-construction and identity reconstruction [49]. This finding extends the literature by indicating that community spaces play a more

central role in continuity of care and the empowerment of people with arthritis than previously recognised.

Communication and resource challenges within healthcare system

People often find it difficult to articulate their needs and build trust due to limited consultation time and fragmented processes [50]. Although telemedicine has become increasingly widespread [51], patients' primary concern was the quality of communication rather than its mode of delivery. Previous research has emphasised *listening* as central [52], yet this study found that its practice was constrained by structural factors, highlighting the need for appropriate triage and improved resource allocation to safeguard space for interaction. The study further contributes a new perspective: communication barriers stem not only from individual interactions but are also profoundly shaped by institutional arrangements.

The influence of economic factors on service accessibility

WHO [12] has noted that financial barriers limit access to healthcare. This study found that people with arthritis continued to take affordability into account within a publicly funded system, considering, for instance, the costs of private treatment and self-management. This indicates that financial considerations remain an important reference point in decision-making. Beyond access, the findings suggest the economic impact of arthritis shaped how individuals prioritised services, balanced formal and informal care, and sustained engagement over time [53]. These findings indicate that economic factors actively informed patients' care related choices and strategies, rather than functioning solely as structural constraints. The finding extends existing discussions by demonstrating that, even within public systems, economic reasoning continues to shape service use.

The importance of continuous and timely support on experience

Continuity has been regarded as a cornerstone of people-centred care [17]. However, this study found that many participants experienced episodic contact rather than long-term support. This finding should be interpreted in the context of evolving care models in rheumatology, such as Patient-Initiated Follow-Up (PIFU) supported by NHS England, which aims to personalise outpatient care and reduce unnecessary routine appointments but may also change how continuity is experienced in practice [54]. The absence of a stable point of contact undermined trust and a sense of security [55]. Within the circular framework, continuity is conceptualised as a stage requiring active maintenance, yet in practice it was often constrained by the lack of follow-up and feedback mechanisms [56]. The contribution of this study lies in

showing that continuity of care does not occur naturally, but instead requires institutional support and deliberate design.

Implications

The circular framework of arthritis care experiences proposed in this study, together with its six people-centred elements, offers a contextualised synthesis for understanding and improving arthritis services. The findings suggest that service providers should move away from predominantly linear care pathways and develop cyclical models of care that are responsive to fluctuating symptoms and life contexts. Previous studies have represented care journeys in linear or sequential terms, typically progressing from symptom onset to diagnosis, treatment and outcomes [27, 28]. For instance, Haldeman et al. [30] proposed an evidence-based, person-centred pathway for spine-related conditions that follows a stepwise progression from initial awareness through clinical assessment to intervention and outcomes. Similarly, May et al. [29] illustrated the experiences of people with arthritis across distinct chronological stages, including “before diagnosis”, “diagnosis”, “after diagnosis” and “current treatment”. While these linear models help structure service delivery and identify key transition points, they often fail to capture the fluid and adaptive nature of care experiences in chronic conditions such as arthritis. In contrast, the circular framework proposed here foregrounds the iterative and interdependent nature of people’s needs, emphasising flexible re-entry, equitable access to information and sustained support across boundaries, thereby enhancing people’s agency and satisfaction.

Limitations

Several limitations should be considered when interpreting the findings of this study. First, the sample was drawn from a single region, with a relatively homogeneous cultural and service context, which restricts the applicability of the framework and its elements across more diverse settings. In addition, the study involved a limited number of participants, and interview lengths varied depending on participants’ experiences and engagement, which may have influenced the depth and breadth of the data generated. Recruitment through arthritis support groups and the use of remote interviews via Microsoft Teams may have influenced the characteristics of participants, potentially limiting representativeness. Second, the circular framework and elements proposed remain at the level of theoretical construction and have yet to be systematically tested in practice. Finally, the study focused primarily on the perspective of people with arthritis, without incorporating the views of healthcare professionals, policymakers, or informal carers, leaving the processes of multi-stakeholder collaboration to be further explored.

Future research

Future research may advance in several directions. First, the applicability of the circular framework and its six people-centred elements should be tested in other chronic conditions to assess their generalisability and scalability. Second, there is a need to deepen research involving multiple stakeholders, integrating the perspectives of people with arthritis, healthcare professionals, and policymakers to explore how different actors collectively shape and implement the circular framework. Finally, the elements proposed in this study should be translated into practical tools for service evaluation, care improvement, and policy indicator development, and piloted across different levels of the healthcare system to assess their effectiveness in practice.

Conclusion

Drawing on the lived experiences of people with arthritis, this study developed a circular framework comprising four interrelated stages and identified six people-centred elements: personalised health management, information acquisition and self-education, community support, communication and resources, financial factors, and continuity and timely support. The findings demonstrate that the care trajectories of people with arthritis are not linear but cyclical, characterised by recurrent movements shaped by symptom fluctuations and life contexts. Within this process, people with arthritis are not merely passive recipients but active agents, continually identifying needs, seeking information, mobilising resources, and pursuing long-term support.

By proposing the circular framework and its key elements, the study contributes to the theoretical understanding of people-centred care and offers practical insights for the improvement of services in arthritis and other chronic conditions. The results suggest that future models of care should be more flexible, continuous, and responsive to individual differences, while also emphasising informational equity and multi-stakeholder collaboration. Although the study is limited by the scope of its sample and the exploratory nature of its theoretical construction, its findings provide an important foundation for driving service innovation centred on people’s care experiences and set the direction for further testing and application in policy, practice, and across disease contexts.

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

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Author contributions

Y.X. (Yaohan Xing) conceptualized and conducted the study, collected and analysed the data, and drafted the manuscript. M.A. (Mersha Aftab) and J.B. (Joanne Brooke) supervised the research, provided methodological and theoretical guidance, and contributed to the critical revision of the manuscript. All authors read and approved the final manuscript.

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Data availability

The datasets generated and/or analysed during the current study include interview transcripts and related qualitative materials. Due to the sensitive nature of the data and to protect participant confidentiality, the full datasets are not publicly available. Anonymised excerpts are included within this published article, and additional anonymised materials may be available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This study was approved by the Art, Design and Media Faculty Academic Ethics Committee at Birmingham City University, UK (Reference No. xing/#10876/sub2/R(B)/2022/Nov/ADM FAEC). The study was conducted in accordance with the principles of the Declaration of Helsinki. All participants were provided with information about the study and gave informed consent prior to participation.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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