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"My bloody leg" – The lived experience of arthrofibrosis after total knee arthroplasty

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Abstract

Purpose Arthrofibrosis following total knee arthroplasty (TKA) is a recognised complication resulting in severe stiffness with limited options for treatment. To date, little is known about the lived experiences of those affected. This study aimed to understand the perceived impact of arthrofibrosis, the experience of the treatment pathway, and perceptions of barriers to optimal care.

Methods Participants who had undergone elective TKA with postoperative arthrofibrosis, were recruited from three NHS orthopaedic units. All interviews were conducted using a semi-structured interview schedule, digitally recorded, and transcribed verbatim. Data were analysed using thematic analysis.

Results Fourteen patients were recruited. Four themes were developed from the data:

Adjusting to Loss: Erosion of Function and Identity – the impact on function was overwhelming and significantly impaired social functioning. This resulted in self-reported adverse mental health outcomes. *Seeking Clarity and Compassion: Navigating Communication with Healthcare Professionals* – many participants described inconsistency in advice given post-TKA, particularly concerning exercise. Many felt that they had unmet needs related to their rehabilitation. *Making Sense of a Stalled Recovery: The Quest for Answers, Solutions and Hope* – significant emotional labour was invested in understanding what was happening to their knee. *Commitment and Constraint: Navigating Rehabilitation in Everyday Life* – participants described a commitment to post-operative exercise regimes; all had integrated exercises into daily activities but continued to face challenges.

Conclusions The experience of arthrofibrosis after TKA is disruptive, distressing and frustrating. Future development of interventions and clinical pathways should ensure person-centred approaches that offer consistency and clarity of advice, particularly regarding exercise.

Contribution of paper

- This paper provides a rich account of the lived experience of arthrofibrosis after total knee arthroplasty, highlighting the significant disruption to biopsychosocial functioning.
- Individuals' experiences were framed by a quest for understanding, but their communication with healthcare professionals was typically perceived as inadequate and inconsistent.
- Exercise was identified as a crucial component of rehabilitation, with individuals expressing commitment to their programmes. Other treatment adjuncts were rarely discussed.
- The results support the future development of person-centred, non-reductionist interventions that meet informational needs and support active patient involvement.

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Keywords: Arthrofibrosis; Total knee arthroplasty; Physiotherapy; Exercise; Rehabilitation

Introduction

Total knee arthroplasty (TKA) is a common and cost-effective intervention for end-stage osteoarthritis of the knee [1]. Data indicate an increasing frequency of TKA internationally, with projections suggesting sustained growth in its use [1,2]. Whilst most patients report satisfaction after TKA, 20% or more experience less favourable outcomes [1,3].

A significant and debilitating complication following TKA is arthrofibrosis, a restriction in knee flexion and/or extension caused by soft tissue fibrosis that was not present before the surgery [4]. Arthrofibrosis is associated with severe stiffness, poor functional outcomes and lower rates of patient satisfaction [5,6]. The incidence of arthrofibrosis in patients undergoing TKA ranges from 1.3 % to 19.8 % [7], and it accounts for a considerable number of hospital readmissions within 90 days of discharge, and surgical revisions within five years of the original procedure [8]. These factors, along with additional imaging, follow-up appointments and intensive rehabilitation, contribute to an increased economic burden of this complication [9].

The pathological mechanisms underlying arthrofibrosis are inflammatory in nature. Several risk factors including genetic predisposition, pre-operative range of motion (ROM), complexity of surgery, and delayed postoperative rehabilitation have been identified [8]. Early recognition and prediction of arthrofibrosis after TKA are crucial, as deficits in ROM must be addressed before the fibrotic tissue matures and becomes resistant to rehabilitation efforts [4, 8]. Non-operative management involves physiotherapy aimed at addressing stiffness, pain and function [5] but there are no guidelines as to what this should include, and optimal strategies are still unknown [10]. Procedures such as manipulation under anaesthesia (MUA) are performed when more conservative management fails.

To date, little is known about the lived experiences of individuals affected by knee arthrofibrosis. This gap is significant because understanding patients' perspectives is essential for developing and testing future rehabilitation interventions. This study aimed to explore the experiences of patients with knee arthrofibrosis, specifically focusing on the impact of arthrofibrosis, their experience of the treatment pathway, and their perceptions of barriers to recovery.

Materials and methods

This study adopted a qualitative methodology informed by a relativist ontology and interpretivist epistemology [11]. A phenomenological approach was employed that prioritised participant experiences, utilised in-depth interviews, and developed themes to capture the essence of participants' perspectives. Data were analysed using thematic analysis, as described by Braun and Clarke, to generate patterns of meaning [12]. The research was reported using the consolidated criteria for reporting qualitative research (COREQ) [13]. Ethical approval was received from the East of England - Cambridge South Research Ethics Committee [22/EE/0205].

Participants

A purposive sampling strategy was utilised to ensure relevance to the study aim. Participants were individuals who had developed arthrofibrosis following TKA and undergone MUA in the past 12 months. They were identified and approached by clinical gatekeepers at three orthopaedic units in the East Midlands. Demographic data were collected (age, identifying gender, employment status, ethnicity). This purposive approach enabled the inclusion of diverse perspectives while maintaining specificity, supporting the generation of rich, thematically relevant data.

Data collection

Prior to participation, informed consent was obtained. Individual, semi-structured interviews took place remotely via telephone or MS Teams between February and July 2023. Single interviews were conducted by a sole, female, qualitative researcher (MN) who had no prior relationship with the participants. MN has extensive experience in health-care research but does not have a clinical role, which she disclosed at interview. Participants were asked to reflect on their experiences of knee replacement, the impact of arthrofibrosis on their lives, and their experience of care and management. Interviews were guided by a topic schedule developed and piloted by the research team and the study's Public and Patient Involvement group (see Supplementary file 1). Field notes were captured during and after the interview to support analysis. All participants completed the interviews, and the study distress management plan was not required.

Sample size adequacy was based on information power rather than reaching a point of saturation [14]. The concept of information power considers the adequacy of data relative to several factors including the study aim, sample specificity and quality of dialogue. Given the focused aim, a specific and relevant participant group, and strong interview engagement, the sample was deemed sufficient to support meaningful interpretation.

Data analysis

Interview recordings were transcribed verbatim and NVivo™ software was used to manage and analyse data [15]. Analysis was completed by MN, FM and MH. FM and MH are experienced physiotherapists and academic researchers. Data analysis proceeded inductively using the six steps described by Braun and Clark: data familiarisation through repeated reading (FM and MN); coding (FM); initial theme generation (FM); theme development and review to ensure alignment to research aims (FM, MN, MH); theme refinement, definition and naming (FM, MN, MH); and writing up (FM) [12]. A coding tree was developed (see Supplementary file 2). Member checking was not completed due to time constraints and to avoid participant burden.

Results

Fourteen participants (Table 1) were recruited with an equal mix of genders, and ages ranging from 56 to 82 years (mean 68). No participants declined to be interviewed, twelve were White British and two were White Irish. Individuals participated in a single interview ranging from 40 to 95 min (average 59 min).

Four themes were generated which are discussed in detail below.

Table 1
Demographic details of participants.

Participant number	Identifying gender	Age	Occupational status
R1	Male	62	Part-time
R2	Female	71	Retired
R3	Female	56	Part-time
R4	Male	77	Retired
R5	Female	61	Unemployed
R6	Male	68	Retired
R7	Male	82	Retired
R8	Female	66	Part-time
R9	Male	78	Retired
R10	Male	66	Retired
R11	Female	71	Retired
R12	Male	75	Part-time
R13	Female	64	Unemployed
R14	Female	60	Retired

Theme 1: adjusting to loss: erosion of function and identity

In this theme, participants described how physical limitations disrupted everyday functioning, reshaped their sense of self, and led to emotional and social consequences that felt both isolating and irreversible.

Participants detailed how stiffness impacted their physical functioning with commonly described difficulties including walking, driving, sitting, climbing or descending stairs, picking items up from the floor, and getting up from a chair. For many individuals, the effects were so severe that they had come to view themselves as disabled:

“You know when I had these boxes that say ‘are you disabled’? I do tend to tick them now. And… admitting that was hard actually because it feels like it shouldn't need to be this…” (R14)

For some participants the extent of disability was all encompassing, and they struggled to reconcile what they felt they should be able to do functionally with the reality of what they could actually achieve:

“This knee has ruined my life it’s actually ruined my life at the moment” (R2).

“One of the questions that I had to fill in… “Do you need any help getting around in the house?” and I said to my friend “No I don’t”. She says “Well you do. I’ve seen you when I come round for coffee. You struggle to get off the settee. You then fall forward and stop yourself on the coffee table. Then you hold onto the settee and the door handle”. And I didn’t realise I was doing all that.” (R11)

As a result, individuals had to make adjustments to address their functional limitations. These included modifications to vehicles to enable driving, acquisition of aids and appliances to assist with daily living and hobbies, and limitation of certain activities.

Participants expressed frustration over the functional limitations, including the statement from R12, *“My bloody leg,"* and their ongoing need to seek alternatives. Many had grown resigned to the situation, while others explained how reality had quietly crept up on them:

”I’ve sort of almost become, to realise that it’s probably not going to get any better or it will be a very long time before it does, if I can keep stretching it a little bit each day. But I’ve stopped worrying about it quite so much now. It’s just how I am now.” (R6)

The functional limitations experienced by participants had a significant and overwhelming effect on social functioning. Most participants described some form of ‘downturn’ in their social participation. For those of working age, many also recognised occupational limitations. Individuals mentioned having to move to separate beds or bedrooms from their partners, cancel holidays, work restricted hours, and take early retirement on ill health grounds. Many expressed a reliance on informal social support:

"The worst thing for me is the fact that it affects my wife so badly…I have to rely on her like I can't put the splint on myself, she has to help me… my leg can be quite stiff and I might need help in trying to get my socks on for example… it's a bit embarrassing really" (R7)

Two participants described the vulnerability they felt due to their functional limitations:

"Yes, it made me cry. I mean I could cry now about it… And I know that I've become a very vulnerable person you know. … because I'm just frightened that I'm going to fall over" (R11).

"I don't feel safe on my own to be honest with you and, like, if there was a fire in the home I don't know how I'd get out because I can't rush, I can't run" (R2).

Most participants (ten of fourteen) recognised the impact the functional limitations had (or could potentially have) on their mental health. For many, this was closely linked to the social isolation they experienced:

"I've had to go onto antidepressants because I'm so depressed because I can't go out. I want to go to the shops; I want to go into town to buy clothes – I can't unless somebody's with me. And I'm sitting in all day… I feel stuck, I really do feel stuck… I am very depressed, very" (R2)

In summary, this theme highlights not just the physical impact of stiffness, but the broader emotional, social, and existential burden. It reflects how individuals with arthrofibrosis wrestled with loss of independence, identity, and social connection, often with a sense of frustration, resignation or vulnerability.

Theme 2: seeking clarity and compassion: navigating communication with healthcare professionals

Participants described a shift from feeling generally well-informed before surgery to experiencing confusion, frustration, and emotional distress in their interactions with healthcare professionals following the onset of arthrofibrosis, highlighting a need for consistent, empathetic, and person-centred communication.

Prior to surgery, participants generally felt well-informed about outcomes, risks, and potential complications regarding their TKA; most believed that they would be able to mobilise without walking aids by 12 months based on their consultations with HCPs. Once arthrofibrosis developed, participants described more varied communication experiences. The information provided was often characterized as minimal, vague, and lacking a holistic, person-centred approach:

"And I do have conversations about it but they just say to me 'ice – elevate' and that's all I get from them" (R2).

Participants indicated a desire for discussions that allowed them time to express their concern, reflect on the future and articulate their lived experience, and a more empathetic response to avoid feeling *"dismissed"* (R14) or invalidated:

"I felt very upset. I think they could have been a bit more supportive, you know, saying that – because I felt as though they didn't believe me" (R5)

"I don't think he believes how I'm saying it" (R13)

A key concern for many participants was the perceived inconsistency in the advice regarding the intensity and type of exercise. Several participants mentioned seeing multiple physiotherapists and assistants, with one stating, *"they both seemed to have… different ideas on what I should be doing, you know, types of exercises, shall we say"* (R4). Others voiced frustration at finding the right balance between doing too much and too little:

"The conflicting advice was really about how far to push it. Some people would say "Don't push into the pain too much …and then others are saying "You've got to really push through the pain" … I don't think I really know now to be honest what the correct answer to that is" (R6).

Several participants discussed the value of having ongoing support where individuals could check in, assess their progress, and have their questions answered:

"It's almost like going to Weightwatchers. You know, they're kind of checking in with you…" (R5)

"even if it was online classes… so that six months down the line you can get in touch and say… can I log in because I'm really struggling" (R8)

This theme captures the contrast between participants' initial expectations and later experiences, particularly the emotional impact of feeling dismissed, invalidated or unsupported, and the desire for continuity and clarity in care. It reflects both the content and relational aspects of communication that shaped participants' experiences.

Theme 3: making sense of a stalled recovery: the quest for answers, solutions and hope

Participants described an often-confusing realisation that their recovery was not progressing as expected, prompting a personal and emotional search for explanations and solutions. This quest frequently culminated in a various mix of pragmatism, frustration, and disillusionment.

Participants shared their diverse experiences of realising that their recovery had stalled. For some, this happened in the early post-operative period with one participant noting that soon after surgery their knee *"just didn't feel right"* (R12). For others, it occurred more gradually as they noticed their rehabilitation was not progressing in line with their expectations.

Individuals invested significant time and, in some cases, emotional labour, to understand what was happening to them. Most understood that their knee stiffness was due to scar tissue, but participants questioned other causes, including whether the correct implant size had been used, and whether muscular weakness or shortening was affecting their range of motion.

"I still can't get the back of my knee to lie flat… I said: Are you sure you've put the right size in?" (R13)

Some even considered the impact of psychological barriers to movement:

"On a static bike I can't do a full revolution. I probably can but there's something in my head that's saying no and stopping me" (R9).

In an effort to make sense of their experiences, participants sought advice and information from the internet and other individuals who had undergone TKA. For those who sought the experiences of others, a diverse range of accounts was often described. There was evidence of some acceptance that knee replacements were more *"troublesome"* (R13) compared to other arthroplasties, with one participant noting, *"they do say you sail through hips, you struggle through knees"* (R7).

The frequently fruitless search for explanations and understanding led to frustration:

"I'd like them to listen to me more and not just keep sending me for x-rays… tell me what happens if this doesn't go away… what does my future hold with this knee…" (R2).

Once realisation occurred, participants were largely pragmatic about the decision to proceed with MUA. The procedure was seen as a *"last hope"* solution (R13) to resolve problems, with R2 explaining, *"I'll do anything, anything at all to… get it loosened up a bit."* Some participants remained hesitant about the likelihood of success but acknowledged that they were *"prepared to take the gamble, I mean I can't think it can be any worse… even if it releases it slightly, it'll be a big plus"* (R9). For the majority of participants, MUA had not provided the relief they had hoped for, resulting in disillusionment:

"…then I realised actually I was absolutely no better off than I'd been over a year, eighteen months before" (R3)

This theme captures the emergent awareness of something being wrong, the active sense-making process, and the emotional burden of unmet expectations and uncertain outcomes. It reflects how participants moved from questioning to taking a gamble, and eventually to a reluctant acceptance or disappointment.

Theme 4: commitment and constraint: navigating rehabilitation in everyday life

Participants demonstrated strong personal investment in their rehabilitation, often adapting exercises to fit daily routines and seeking alternative approaches, yet faced practical barriers and limited access to supportive resources that constrained their efforts.

Most participants expressed their awareness of the need for an intensive exercise rehabilitation regimen during the post-operative period. They valued exercises that were practical and could easily fit into their daily routines, especially considering how often they needed to be performed. Individuals elaborated extensively on the exercises they did at home, with many showing their commitment to this regime:

"I did it exactly by the book" (R1).

"… anything that I've been asked to do I've done it… I've put my whole heart into it… my aim was to get this knee bent…" (R8).

Some participants independently sought alternative approaches to exercise rehabilitation, including swimming and aquatic exercise (R9, 11, 13) as well as attending the gym (R2, 9). However, access to appropriate facilities was problematic for them some:

"I did have hydrotherapy after… I didn't think [the course of treatment] was long enough… I did ask about hydrotherapy pools but there was none round here. The only one round here is for dogs" (R13).

Rehabilitation adjuncts, especially bracing, were seldom mentioned. Participants with experience in bracing reported low tolerance. Continuous passive motion (CPM) devices were usually described as an intervention for preserving knee movement after MUA, although some participants had undergone brief sessions (30 min) of CPM as part of outpatient physiotherapy.

This theme reflects both the agency and motivation participants showed in their recovery journey, and the structural and contextual limitations that complicated their ability to fully engage with rehabilitation. It illustrates the tension between determination and constraint.

Discussion

The biopsychosocial impact of arthrofibrosis was clearly evident in this study. While several studies have quantitatively explored stiffness and pain, functional limitations, and psychological distress in individuals with arthrofibrosis post-TKA [6,16], to our knowledge, this is the first study to describe the lived experience of these individuals. A rich and detailed understanding of such experiences is crucial to support HCPs in the development and use of non-reductionist approaches to treatment [17,18]. This study aimed to understand the impact of arthrofibrosis, experience of the treatment pathway, and perceptions of barriers to recovery.

Impact of arthrofibrosis

This study has highlighted the significant impact that arthrofibrosis has on individuals' lives. For many the extent of disability was significant with implications for physical, psychological and social functioning. The findings of this study align with the theory of biographical disruption described by Bury [19] which proposes that chronic conditions can significantly interrupt an individual's life-trajectory, thereby challenging established identities, routines and expectations. In keeping with Bury's theory, the findings of this study demonstrate that arthrofibrosis compelled a re-evaluation of self and social relationships, and a reconstruction of personal narratives and meanings. Furthermore, individuals' struggles with sense-making and navigating healthcare reflected the ongoing disruption to recovery and the wider challenges of adapting to arthrofibrosis in a system that often did not meet individuals' expectations.

A recent study explored the differences in perspectives on 'poor outcome' after TKA between patients versus knee specialists [20]. Findings demonstrated that patients placed greater importance on functional performance and the ability to participate in valued activities, whilst knee specialists prioritised pain relief. Whilst not considering arthrofibrosis specifically, it points to the importance of HCPs better understanding patient expectations and concerns so that they can be addressed during consultations. Our study, similarly, allows HCPs to understand the lived experience of arthrofibrosis post-TKA.

Experience of the treatment pathway

Once arthrofibrosis was established and individuals deviated from the typical TKA recovery trajectory, a number reported feeling dismissed by healthcare services. This is echoed by a recent systematic review of patients' experiences following TKA where several studies reported patients feeling that they were 'on their own' and had to advocate strongly for themselves to receive follow-up care [21]. Feelings of abandonment and dismissal are linked to hopelessness and vulnerability, which healthcare providers should address by giving patients a voice regarding their treatment and care [22]. Person-centred approaches, such as shared decision-making, are recommended for facilitating patient autonomy and empowerment [23].

Exercise is a cornerstone of rehabilitation in the management of arthrofibrosis, despite limited evidence. All participants in this study reported commitment to their exercise regimen. Many described adjusting their daily routines to incorporate their exercises, while others sought opportunities outside the home to continue their rehabilitation. The commitment to exercise might be considered a strategy to regain control in line with Bury's suggestion that chronic conditions result in a search for new approaches with which to manage biographical disruption and uncertainty [19].

Interestingly, poor adherence to exercise is frequently cited as a potential factor in the development of arthrofibrosis [8]. Although participants in this study were adamant that they were following their regimen, it is possible that their responses may have been influenced by social desirability bias. An alternative explanation may be that the prescribed exercise regimen did not account for the underlying inflammatory nature of arthrofibrosis, which requires a more individualised and less aggressive approach [24]. Other studies have reported misplaced expectations of recovery norms, which may be fuelled by contradicting advice, that have led patients to push hard to gain function [25]. Furthermore, due to the conflicting advice many participants reported receiving from healthcare professionals, it is possible that the exercise regimen evolved over time and became suboptimal. There was limited discussion of adjunctive treatment.

Barriers to recovery

Significantly, the findings of this study revealed that communication between HCPs and patients with arthrofibrosis was often inadequate due to limited and inconsistent information and, at times, a perceived lack of empathy. Consequently, participants described investing significant efforts in searching for answers – quests that were largely fruitless and which reinforced the disruption in participants' sensemaking. A recent systematic review of patient experiences after TKA also described how the provision of conflicting information and absence of a holistic approach reduced their confidence in HCPs [21]. The authors emphasise the importance of effective communication and a more tailored approach to rehabilitation to improve patient experiences [21]. While the findings of Pryce et al. support and provide further insight into the results of this study, unique differences must be acknowledged. It is important to recognise that the foundational evidence and understanding of arthrofibrosis are much less developed compared to routine post-arthroplasty recovery. The relative lack of high-quality studies investigating the pathophysiology, risk stratification, and management of arthrofibrosis is likely to contribute to informational deficits and inconsistencies. Despite this, future pathways for post-TKA arthrofibrosis should consider clarity and consistency of communication.

Clinical and research implications

Whilst similar issues have been identified for patients with pain and functional problems post-TKA [25] there is a specific need for an optimal pathway of care for individuals who experience arthrofibrosis. Future research is required to develop and evaluate multi-component programmes of rehabilitation. Having explored the patient experience of arthrofibrosis, this study provides important insight into the nature of those components.

Firstly, any future rehabilitation programme requires a tailored approach that respects the underlying inflammatory nature of arthrofibrosis. Secondly, HCPs must recognise and address the significant biopsychosocial consequences of the condition and adopt holistic, non-reductionist approaches to care to fully understand patients' needs and priorities. They should also be aware of the significant potential for distress in this patient population and the concomitant impact on mental health. Thirdly, future approaches must address patients' informational needs and recognise that these may change over time. In any future intervention or pathway, consistency and clarity will be key. Developing health literacy will be a critical consideration. Addressing these factors will foster an approach that supports active patient involvement and improved rehabilitation experience by addressing participant requirements for information, choice, and an understanding of their needs [26].

Strengths and limitations

This is the first study to explore the lived experience of people with arthrofibrosis after TKA. As such, it fills an important gap in our knowledge of the impact of this significant complication. Use of a phenomenological approach, attention to reflexivity and maintenance of audit trails within the study enhance credibility, dependability and confirmability of the findings. Whilst the sample was diverse in terms of age and occupational status, we were only able to recruit participants from a white ethnic group. Future studies should employ wider sampling strategies to increase ethnic diversity and consider other characteristics such as deprivation scores. This would ensure that individuals from a range of ethnic and social backgrounds are represented, and the transferability of findings further enhanced.

Conclusion

The lived experience of arthrofibrosis may be marked by significant distress, confusion, and frustration. Bury's theory of biographical disruption highlighted the fractured sense of self, disrupted social worlds and ongoing process of adaptation experienced by participants. For many, their rehabilitation journey included inconsistencies, and there was a sense of inadequate information, which led individuals to undertake their own search for understanding. Despite this, participants showed a strong commitment to their exercise regimen, recognizing it as a vital factor in restoring function. To optimize the management of this distressing condition, future strategies should be informed by person-centred philosophies and shared decision-making.

CRediT authorship contribution statement

All: Writing – review & editing. **FM, BS, KS, CS, MH:** Conceptualization, Methodology. **FM:** Supervision, Formal analysis, Writing – original draft. **MN:** Data curation, Formal analysis. **JS:** Validation. **MH:** Project administration, Supervision, Validation, Funding acquisition.

Ethical Approval

Ethical approval was received from the East of England - Cambridge South Research Ethics Committee [22/EE/0205].

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Conflict of Interest

The authors declare no conflicts of interest.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.physio.2025.101862.

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