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Patients' perspectives on key aspects influencing needling for haemodialysis: A qualitative study

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Abstract

Background: For many patients, cannulation ('needling') is essential for haemodialysis. It is associated with anxiety and fear and contributes to the overall burden of treatment. Limited research exists on patient experience of needling and how this might vary by individual and clinical characteristics.

Objectives: To explore and identify key aspects of needling impacting patients' experiences.

Design: Qualitative, multicentre, cross-sectional, co-produced.

Participants: Adults on haemodialysis with working fistulae or grafts ($n = 41$).

Approach: We used interviews to explore patients' experiences of needling and key aspects contributing to this. Interviews were conducted in two sets: unstructured ($n = 24$, broadly investigated needling experience) and semistructured ($n = 17$, refined themes and assessed cultural relevance). Thematic analysis was used to identify themes driving experience and examine variation. A Patient Steering Group comprising people with lived experience of needling was integral to the study.

Findings: A thematic framework capturing patients' view of needling was developed. It defined a core theme (The Nature of needling) and five foundational aspects of needling (Health of the fistula or graft, Steps in needling, The needler, The patient, Organisational context). We identified two further themes important to overall experience, Learning from needling experience and Reciprocity (the two-way interaction between patient and needler). Both interrelated across themes, highlighting the complexity of needling and junctures where patient experience can be influenced.

Conclusions: Needling is shaped by multiple psychological and relational influences. These findings provide healthcare professionals with a basis to improve patient experience as part of a broader drive to enhance quality in healthcare delivery.

KEYWORDS

cannulation, chronic kidney disease, co-production, haemodialysis, vascular access

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INTRODUCTION

People on haemodialysis face significant treatment burden (Karamanidou et al., 2014), with cannulation problems highlighted as a critically important outcome in vascular access research (Viecelli et al., 2020). Cannulation, commonly referred to as needling by patients, refers to the placement of needles for haemodialysis (British Renal Society Vascular Access Special Interest Group and Vascular Access Society of Britain and Ireland, 2018). Although most rely on a fistula or a graft (Ethier et al., 2008; UK Renal Registry, 2023), people consistently report their experience of needling as one of the lowest scoring areas of kidney care (UK Kidney Association and Kidney Care UK, 2024). Addressing this requires a better understanding of patients' perspectives on needling and what influences them (Fielding et al., 2021).

LITERATURE REVIEW

Existing qualitative research has provided a glimpse into patients' experience of needling, suggesting that needling is a complex procedure associated with personal meanings, from fear and anxiety to being a source of pride and offering an element of control in their care (Casey et al., 2014; Duncanson et al., 2023; Fielding et al., 2023; Mafara et al., 2016; Moore et al., 2018; Romyn et al., 2015; Wilson & Harwood, 2017). Although a growing area of inquiry, research has focused on specific groups, access types, points in treatment or single kidney units (e.g., self-cannulators on home haemodialysis, only people with fistulae, early needling experience). These studies identified the significant impact of needling on subsets of patients in a particular context, but research is lacking that captures patients' universal experience of needling that is common to all patients.

We aimed to explore, across a range of characteristics, the experiences of people on haemodialysis who are currently needled. We also sought to identify key aspects of needling that impact needling experience and assess their importance and variation.

MATERIALS AND METHODS

Design

This research formed the first phase of a multiphase, exploratory sequential mixed methods study to develop a comprehensive needling patient reported experience measure (NPREM), an instrument for assessing patients' experience of haemodialysis needling (Moore, Ellis-Caird et al., 2024). Findings from this study helped inform the concepts from which items in the NPREM were derived. Additional supporting documents are available (Supporting Information S1: 1; Moore, Busby et al., 2024).

We utilised qualitative methods to explore patients' experience of needling. In line with prior research and evidence indicating the personal nature of needling, we embedded co-production by establishing the Patient Steering Group (Ramsden et al., 2020). They were instrumental in grounding the study in patient experience and providing insight on the analysis and interpretation of findings.

The study is reported in accordance with COREQ-32 (Tong et al., 2007) (Supporting Information S1: 2) for qualitative studies and GRIPP-2 (Supporting Information S1: 3) for patient and public involvement in research (Staniszewska et al., 2017).

Setting and participants

We recruited patients from six kidney centres across England. Patients were eligible to participate if they: received haemodialysis with a working fistula/graft, were >18 years, and spoke English, Guajarati or Urdu (South Asian languages aligned with patient demographics at participating centres). Patients were excluded if deemed too unwell to be interviewed by their kidney care team. We used purposive sampling to maximise variation characteristics: access type/age, self-needling, needling technique, cultural background. Kidney care teams approached potential participants, gave them study information and received written consent.

Data collection

We conducted individual interviews via telephone or video-call from January to October 2021. One researcher (C.M.) conducted in-depth unstructured interviews, using open-ended questions and prompts to elicit patients' full range of experiences (e.g., experience over time, good and bad experiences). The topic guide was piloted with members of the Patient Steering Group prompting minor modifications. Following the unstructured interviews, three researchers conducted semistructured interviews in English (C.M.), Guajarati (J.C.) or Urdu (R.M.) using a modified topic guide (Supporting Information S1: 4). Interviews were audio-recorded and transcribed verbatim (English: professional transcription services; Non-English: forward translation [R.M./J.C.], quality assurance [S.S.]). We checked transcribed files for accuracy, removed personal identifiable data and applied pseudonyms.

Data analysis

Thematic analysis (Braun & Clarke, 2006; Braun & Clarke, 2013) facilitated in-depth exploration of needling experience and followed an iterative process of coding and reflection. The unstructured interview transcripts were coded line by line using inductive codes (to capture nuanced needling experiences, e.g., empathy) and deductive codes (derived from the topic guide, e.g., needling process). QDA Miner (v5, Provalis Research) facilitated data management. Initial analysis identified preliminary aspects of needling pertinent to patient experience (Supporting Information S1: 5). We refined these in the semistructured interviews, additionally assessing cultural relevance in the non-English interviews. We (C.M./H.E.C.) block coded semistructured interview transcripts using theme labels as codes and new concepts coded as 'developing themes'. We then combined data across interviews to further develop and refine themes with input from the Patient Steering Group, healthcare professionals and researchers.

Rigour and reflexivity

The Patient Steering Group ensured rigour by reviewing the study's development and findings throughout (Moore, Busby et al., 2024). The group preferred the term 'patients' rather than 'participants' or 'people' in the manuscript as it distinguished the perspective presented. During data collection, they highlighted the importance of giving participants space to tell their needling story. They noted how positively participants framed their needling experience, contrasting their own experiences, which may indicate the influence of social acceptability and positioning. During analysis, we considered how this impacted interviews and overall needling experience and incorporated it into the analysis (see later in *Learning through needling experience)*. Recognising the researchers' influence, the primary researchers (C.M./H.E.C.) used reflexive practices such as bracketing interviews to identify personal and professional contexts we brought to the study (Starks & Trinidad, 2007). These were held bi-monthly during data collection and analysis led by H.E.C. who asked questions to identify latent beliefs or assumptions and ensure they did not unduly influence the findings.

RESULTS

Sixty-two patients were approached; 54 returned consent forms; and 41 were interviewed (nonparticipation: 5 = declined, 4 = change in health/circumstances, 3 = no response, 1 = received transplant). Table 1 provides an overview of participant characteristics. Additional characteristics aggregated to protect anonymity: Buttonhole needling: 10; Ethnicity: 25 White, 7 Asian, 6 Black, 3 Mixed/Other; Non-English speakers: 4; Average time on dialysis: 4 years (range 5 months to 19 years); Using pain relief: 9 (8 numbing cream, 1 lignocaine injection); receiving haemodialysis at private satellite unit: 13; Using plastic needles: 0; Needling with ultra-sound guidance: 0. Patients used a range of needle gauges. We conducted interviews in two sets, firstly unstructured ($n = 24$) and then semistructured ($n = 17$). Interviews lasted on average 61 (range 12–115) minutes.

We identified eight themes. The nature of needling theme established what needling means to patients, with five further themes depicting the foundational aspects which make up needling experience (Figure 1). The final two themes, relating to personal and relational factors, influenced patient experience of needling on any given day. Table 2 presents the themes with example quotations. As the latter two 'influencing themes' reflect more novel findings, we have described these in detail below with foundational aspects described fully in Supporting Information S1: 6. How the themes interrelate and how to consider the findings in relation to fictional cases are provided in Supporting Information S1: 7.

The nature of needling

Needling was described as necessary, the crucial step in haemodialysis, variable and painful. This theme highlighted the significance and complexity of needling; however, needling experience may vary from individual to individual and day to day.

Foundational aspects of needling

The health of the fistula/graft

Fistula/grafts were viewed as 'lifelines' and providing the foundation for needling, with patients recognising the value of a well-working access versus ones with continual complications. We identified three subthemes that impacted patients' needling experience: (1) nuances and characteristics of their fistula/graft, (2) managing problems, (3) underlying worry about their fistula/graft.

Steps in needling

Basic steps in the process affected needling experience. These related to availability and effectiveness of pain relief, how needles were placed, elements of the process specific to cannulation techniques (e.g., rotating sites in rope ladder) and the needle removal and how the site was dressed when the session ended.

The needler

A key element in needling experience was who does the needling, or who 'puts you on' and 'takes you off' or 'the needler'. Most patients were needled by members of the dialysis team, usually nurses or healthcare assistants. Patients noted the high degree of variation in needling experience between needlers and described four key characteristics affecting needling: technique, experience, skill and knowing your fistula/graft. This theme reflected self-needlers' experiences who described the importance of learning the techniques, gaining experience and skills and understanding their fistula/graft.

The patient

The next critical foundational aspect was the patient, with emphasis on 'how you are on the day'. Both physical and psychological aspects impacted needling experience. Physical health related to feeling well and not being tired or dehydrated which could prolong needling and

TABLE 1 Individual participant characteristics.

Pseudonym	Gender	Age range	Dialysis location	Access type	Access age (months)	Needler
Abigail	Female	60–69	ICHD—Main RDU	Graft	>87	Nurse
Aiden	Male	30–39	HHD	Fistula	13–24	Self
Amara	Female	60–69	ICHD—Satellite	Graft	13–24	Nurse
Ben	Male	60–69	ICHD—Main RDU	Fistula	25–36	Nurse
Carlton	Male	60–69	ICHD—Main RDU	Fistula	>88	Self
Daniel	Male	70–79	ICHD—Satellite	Fistula	13–24	Nurse
Edward	Male	50–59	ICHD—Satellite	Fistula	13–24	Nurse
Eric	Male	50–59	ICHD—Main RDU	Fistula	73–84	Nurse
Ethan	Male	40–49	ICHD—Main RDU	Fistula	25–36	Nurse
Fatima	Female	30–39	ICHD—Satellite	Fistula	13–24	Nurse
Grace	Female	70–79	ICHD—Main RDU	Fistula	25–36	Nurse
Henry	Male	60–69	ICHD—Main RDU	Graft	25–36	Nurse
James	Male	60–69	ICHD—Main RDU	Fistula	13–24	Nurse
Janet	Female	70–79	ICHD—Satellite	Fistula	49–60	Nurse
Jason	Male	50–59	ICHD—Satellite	Graft	37–48	Self
Jeremy	Male	60–69	ICHD—Main RDU	Fistula	25–36	Nurse
Julia	Female	70–79	ICHD—Satellite	Fistula	37–48	Nurse
Katarina	Female	20–29	ICHD—Main RDU	Fistula	25–36	Nurse
Kenneth	Male	>80	ICHD—Main RDU	Fistula	25–36	Nurse
Leila	Female	20–29	ICHD—Satellite	Fistula	13–24	Self
Liam	Male	50–59	ICHD—Satellite	Fistula	>85	Nurse
Lucas	Male	20–29	ICHD—Main RDU	Graft	13–24	Nurse
Martha	Female	60–69	ICHD—Main RDU	Fistula	61–72	Nurse
Martin	Male	60–69	ICHD—Main RDU	Fistula	25–36	Nurse
Maurice	Male	60–69	ICHD—Satellite	Fistula	61–72	Nurse
Mia	Female	<20	ICHD—Main RDU	Fistula	25–36	Nurse
Michael	Male	60–69	ICHD—Main RDU	Fistula	73–84	Nurse
Neel	Male	40–49	HHD	Graft	>86	Self
Noah	Male	70–79	HHD	Fistula	25–36	Self
Noura	Female	70–79	ICHD—Satellite	Fistula	13–24	Nurse
Olivia	Female	60–69	ICHD—Satellite	Fistula	37–48	Nurse
Patrice	Female	40–49	ICHD—Main RDU	Graft	6–12	Nurse
Rahul	Male	60–69	ICHD—Satellite	Fistula	25–36	Nurse
Rajesh	Male	60–69	ICHD—Satellite	Fistula	13–24	Nurse
Ruth	Female	60–69	ICHD—Main RDU	Graft	49–60	Nurse
Simone	Female	70–79	ICHD—Main RDU	Fistula	73–84	Nurse
Stella	Female	70–79	ICHD—Satellite	Fistula	61–72	Nurse
Stewart	Male	20–29	ICHD—Main RDU	Fistula	6–12	Nurse
Tariq	Male	>80	ICHD—Satellite	Fistula	6–12	Nurse

(Continues)

TABLE 1 (Continued)

Pseudonym	Gender	Age range	Dialysis location	Access type	Access age (months)	Needler
William	Male	70–79	ICHD—Satellite	Fistula	37–48	Nurse
Yusuf	Male	70–79	ICHD—Satellite	Fistula	13–24	Nurse

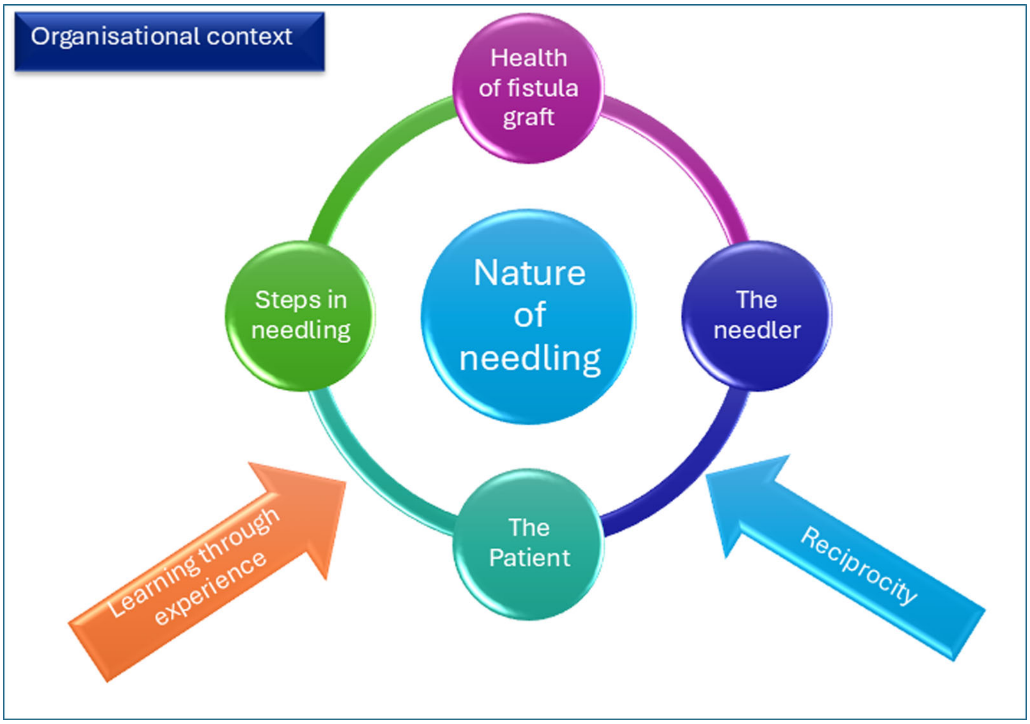

FIGURE 1 Visual representation of the thematic framework of patients' experience of needling. This figure represents our understanding of patients' experience of needling. At the heart of needling was the awareness that it is necessary and a key step in dialysis. It can be painful and varies depending on the day. The health of the fistula/graft, steps in needling, the needler, the patient and the organisational context form the foundations, or key aspects, that make up needling. Any of these may vary on a given day and affect how needling goes. However, how these aspects play out may be significantly influenced (helping or hindering) by what has been learned through needling experience and the reciprocity (mutual exchange of confidence and empathy and ultimately trust) between the patient–the needler.

increase discomfort. Both self-needlers and those needled by others stated that their psychological mindset on the day impacted needling experience. For a minority, frame of mind did not affect needling experience (Maurice, Edward). Needling became associated with a range of negative emotional responses, from tension to dread to constant worry. Seeing the staff rota often sparked patients' thoughts and dread. Even long-established self-needlers described a lingering sense of worry. However, negative emotional responses did not affect everyone.

Organisational context

The setting, including both macro (e.g., NHS Trust policy on needling technique) and micro (e.g., atmosphere of the unit) level factors, impacted needling experience. The main areas related to staffing, strategies related to needling and unit management.

Aspects influencing needling experience

We identified two key themes that influenced how needling played out on any given day, namely *Learning from needling experience* and *Reciprocity*.

Learning from needling experience

Patients described several ways in which they came to understand needling and their role in it, which was most often through experience. Four subthemes demonstrated both positive and negative learning and reflected key stages in the needling learning process: individual level of knowledge and involvement, resources to support needling, change over time and their talk about themselves in relation to needling.

TABLE 2 Outline of thematic framework of patients' experience of needling.

Theme	Subthemes	Example of supporting quotations
The nature of needling. This theme establishes key concepts patients described about needling.	*The nature of needling*	
	Necessary	I remember then think[ing], well, you know, it's got to be, I mean, you can't avoid this, it's, you know, **it's going to save my life… it's necessary**, because it's going to make you better. (Noah)
	Key part	**it's [needles] definitely the**—the biggest hurdle for me, you know, **the biggest part** of it…it's the main part of it, and because it's so important, because, obviously, it's your access, you know it's got to be done right… the biggest part of, of the dialysis for me is the needling. (Aiden)
	Varies on the day	Sometimes **it just depends on the day**… on the day, that's when it matters… Sometimes even in places that are normally fine, it can sting. (Lucas)
	Painful	Er, **very sharp** and very—it's as though you want to pull away… just sharp and **painful**, erm, quite quick, but the **pain doesn't last long**. As soon as the needle settles in there, then the pain goes away. So it's not painful all the time, it's just as they put the needle in. (Amara)
Five foundational themes. Four aspects that vary day-to-day for many people and form the basis of needling. It is thus important to recognise if and how they impact needling experience on any given day. • *Health of the fistula or graft* • *Steps in needling* • *The needler* • *The patient* The fifth foundational theme is organisational context which provides the setting for needling.	*Health of the fistula or graft*	
	Characteristics of the fistula/graft	I've got what they call… Well, **I think there's a more professional term, but wobbly veins**… Yeah, so in **the last six months, and it [needling] wasn't pleasant**. (Julia)
	Problems with fistula/graft	**I've had a lot of problems with blood clots**, and every now and again, I do get like a little, hard lump. **So they try to avoid that, and you would go above it**, or sort of around it, **which is not always easy** if the needle is longer. (Jeremy)
	Future concerns	The only fear I always have, probably always will have, is **what if it fails? That is the, that is quite a big fear for me, which I keep in the back of me head**. (Ben)
	Steps in needling	
	Pain relief options	And while I was in hospital, **they gave me lignocaine, but once I moved to the unit, the satellite unit, it wasn't available there**. (Olivia)
	Issues with placement	**I repeatedly get needled because they can't find the vein**… I'd much rather a slightly slower needle experience, which can be slightly more painful than multiple attempts at finding the vessel, because that's when it deteriorates. **When I get multiple attempts and you feel that needle going in three, four times, that's when it can affect my blood pressure, make me nauseous and so forth**. (Edward)
	Issues related to needling technique	**I always feel a bit anxious when it comes to needling in a fresh site**. (Leila) When they're **taking the scabs off, it hurts more than putting needles in**. (Ethan)
	End of session and needles	**I've got quite sensitive skin, so I was blistering**, and that was on all my fistula… **[do] not to apply too much tape, or anything onto my skin**. (Lucas)
	The needler	
	Technique	It's not that the nurse is a bad nurse, **it's just certain nurses they use certain techniques that are not for everyone**. (Mia)

(Continues)

TABLE 2 (Continued)

Theme	Subthemes	Example of supporting quotations
	Experience	I think because it's down to experience… this one nurse, and he's brilliant, you know, he can just feel and find your vein… it's like everything else, **the more you do it, the better you get**. (Henry)
	Skill	**I think some nurses have really got the touch** because they will literally run their fingers along there and they can feel where the artery is and they know exactly where they've got to put the needle. (Eric)
	Knowing you	**They get used to patients and how their veins react.** (Julia)
	The patient	
	Physical	I suppose it depends on the moisture in your body, how tired you are, **how physically well you are**, you know, if **you're a bit tired it might become a little bit more difficult or less easy than normal**. (Jason)
	Psychological—Frame of mind	I mean, I guess my—how I'm feeling on any given day as well, so **if I'm not in a particularly good frame of mind, that might make things not go as well**… I might **experience a bit more pain** if I'm not feeling great, as in mentally great, then I might think to myself, well, everything might be that little bit worse in my mind. And so, as a result, the pain will be that little bit worse as well. (Patrice)
	Psychological—Emotional response	It's [painfulness is] about a seven or eight [out 10, with 10 very painful]… **When I get to the hospital, I get a little bit worked up as to whether it's going to hurt a lot or not**… it's not fear, it's, it's just, 'Oh dear, here we go again' (Abigail)
	Organisational context	
	Staffing	Unfortunately, in our dialysis unit there's quite a **high turnover of staff**. So you've got like—you've constantly got like CSWs and nurses coming in and out all the time… And there's a lot of like new people learning how to needle. (Stewart)
	Strategies related to needling	…**[We] got allocated nurses… It means that you have a relationship with the nurse, and you can build up**, and you can discuss things… it's a good relationship and that's the way it ought to be… you get an allocated nurse who can needle you three times, on three occasions, which is what my routine is, three times a week, however they've got to do shift changes, they've got to have holidays, they've got to be sick, etc, etc, so there is a secondary, there is a backup as well, but it's invariably no more than two or three different nurses that come to you. (William)
	Management of the unit	**We did buttonhole for quite a while until the registrar said 'no, we don't want you doing that'.** So buttonhole was fine because that would just use the same access every time and that area just turned into, you know, scar tissue, it barely hurt at all, you know, so… **I don't think they ever sort of discussed it with me at all… I quite like buttonhole.** (Eric)
Two influencing themes. These affect how any of the foundational themes play out and are key in patients' experience of needling. • *Learning from needling experience*	*Learning from needling experience*	
	Individual level of knowledge and involvement	**I know where the needle should go roughly in my arm**, and **I know the people that can needle me**… I also look at the machine, because I can see the arterial and the

TABLE 2 (Continued)

Theme	Subthemes	Example of supporting quotations
• *Reciprocity*		venous, **you know, the numbers when it's correct, or it's right, or it's wrong**, when it's going to alarm, and I do a little bit of adjustment on the machine because I know how to use it to a certain degree, **so I kind of get involved in dialysis as well, which I think helps**... some of the nurses are not always needling you every time, you give them a little reminder of the angle, you know, to needle me you have to come in at sort of 12 to 1 o'clock, so I always remind them. (Michael)
	Resources to support needling	**I open my arm, and I'm closing the hand and open and closing, and open and closing, and I do it like that. So I don't feel [the needles]**... I don't move my hand, only my fingers and all that, that's all I move... Because when I—when they did the first dialysis with me, I was watching it and I could see. **The person told me, if you** can't see **[can't watch] it, you just need to have a laugh, or talk to somebody and let them do the job** in your hand, so you don't feel nothing... that's how it works for me. If you go to talk to somebody, or the person who is doing your needle, we just talk anything, about yourself or anybody else, right? How are you doing and, you know? So you end up putting needles, and you're not feeling nothing. (Rajesh)
	Change over time	**But, at the moment, I'm having a problem with my new fistula**... I don't know [it's] because it's bruised or whatever inside, **it really is painful to be needled... as you get older, your veins get weaker.** Then, obviously, it's harder to get the veins, so people suffer more. (Henry)
	Talk about self in relation to needling	**It's [fistula is] a bit tricky... I know I'm a problem...[Staff will say] ‘You are a bit of a problem** and we know other nurses can cater for you’... because I've had so many problems that you... **It's almost like you're getting a negative vibe before you even get there... I'm sort of probably mentally scarred**. (Jeremy)
	Reciprocity	
	Empathy	**I feel that sometimes there isn't the empathy there, that this is a big, old needle that you're sticking in somebody's arm**, that's going to be in there for three and a half, four hours, it's a long time... [I let the staff know if it hurts] because, I mean, at the end of the day, people have to know, **they have to realise it's not an easy thing**... people become desensitised to it, **because they've been doing it for so long, and they almost forget about the person underneath the arm**, you know?... And people have to realise that, you're not just a patient, you're actually a person who's having to experience this awful thing, so be aware of that when you're needling, yeah. (Patrice)
	Confidence	**If somebody can talk to you then that helps them, that helps their confidence**... I say to them [people new to needling her], **‘See you can do it’... and I say, ‘Look, you can do it, just have confidence in yourself that you can actually do it**,’ you know, when they've done it and I say to them, ‘High five,’ [laughs], because then that makes them, to me it makes them feel, 'Yes I have done

(Continues)

TABLE 2 (Continued)

Theme	Subthemes	Example of supporting quotations
		it and I know I can do it again,' because I'm sure that everybody is very nervous. (Martha)
	Trust	I mean when I first got there I wasn't very happy because **I've always been like a worried person anyway. So I'd always watch what they were doing, watch them needling me**. So, yeah, **having a good level of trust with your nurses is important.** And it was them that taught me how to do the needling and setting up anyway… Yeah, when they're needling you a lot of them just talk to you and then I watched how they did things as well. So, yeah, but **that's how I was able to build up trust**. (Leila)

The level of knowledge and involvement patients wanted, or needed, regarding needling varied. Some wanted to know everything and involvement in every decision. Others wanted limited knowledge and involvement, with many permutations in between. Knowledge was gained from each needling session and seemed to follow a pattern of first understanding clinical aspects (e.g., about their fistula/graft, needle gauge) then going on to personal preferences (e.g., preferred dressings). Patients learned from other patients and from their own research. Some developed a physical sense of whether the needles were correctly positioned, which reassured them and signalled a good session. Patients could not always make sense of what affected their needling experience and spoke of it being down to luck: 'all the stars have got to be aligned almost' (Jeremy). This mystery led some to believe they had no control, manifesting as a sense of hopelessness around needling ('there's nothing you can do' Kenneth). Negative experiences, even one-off, could quickly entrench as negative responses to needling, both short and long-term (e.g., short-term: apprehension, distress; long-term: persistent worry, developing routines to mitigate problems).

> I was a bit iffy about going on for the next session, because my arm was all black and all bruised… I know I had to go have my treatment, so I went in, but I was a bit nervous, I wasn't going to go, to be honest I wasn't going to go. (Liam)

> [After that blow] basically [there was] always that worry. So every time I was getting needled I'd tell the nurse, even though she's familiar with me, I'd be like, yeah, remember, it's shallow, okay?—… I had my little sort of set things I had to say to them before they started. (Neel)

Problems could also lead to changes in individual approaches to knowledge and needling, with some gaining a better understanding, exercising more control and greater involvement:

> … one of the nurses who put the needle in my arm six times, and she still couldn't get it right, and one of the nurses said to me, "Oh I heard what went on, come, I'll teach you how to do it," and from then on I started doing it, I done it very quickly. (Carlton)

The level of involvement varied widely, from 'leave it to the professionals' (Ben) to not allowing anyone else to do it. Reasons for limited involvement ranged from a conviction it was the dialysis team's 'job' (Maurice, Ethan), to lacking self-confidence to take on the responsibility. However, even patients uninterested in self-needling recounted how they were actively involved, including applying numbing cream before their session, preparing their needling tray, giving information to the needler on how to needle them, and being assertive about who needled them. Those active in their needling (whether self-needing or steps in the process) said involvement gave them more control, made them feel helpful, and reduced needling pain. However, there were patients with limited knowledge or involvement who also described needling positively. The important element was that patients had the level of knowledge or involvement they needed to feel confident and assured with their needling.

Resources to support needling

Patients also learned what resources they needed to support their needling. Both self-needlers and those needled by professionals identified behaviours or roles they utilised to manage needling (e.g., breathing exercises, meditation, prayer, chatting with another patient or the needler, watching videos, not rushing it, remaining calm). Patients also learned which pain relief worked best for them, and when they no longer needed it.

Change over time

Patients also described their needling experience changing over time. A patient with a fear of needles changed from 'being completely petrified… to just like now, I don't even think about it' (Stewart). Others expressed similar sentiments, reflecting that knowing what to expect and having a developed fistula facilitated adjustment to needling. Adjustment varied widely from the second needling session to many years. Change was not always positive. Ageing, returning to haemodialysis from another modality and having a new access could impact negatively.

Talk about self in relation to needling

Another subtheme was how patients talked about themselves in relation to their needling experience. In talking about themselves, or recalling specific events related to needling, the voices of dialysis staff, family and other patients featured in how they viewed themselves. These voices shaped patients' views, both positively (conferring a sense of autonomy and pride) or negatively (reinforcing negative association):

'It's [fistula is] a bit tricky… I know I'm a problem… You are a problem'. (Jeremy)

While some patients talked about themselves and their experiences of needling in a consistent manner, others' talk was marked by inconsistency. Those with consistent talk seemed to make sense of both positive and negative needling experiences. They exhibited more control, whether through involvement, knowledge or self-needling, and their talk complemented other aspects of life (e.g., attitude towards health and well-being). They were also more likely to rationalise ('it'll be done soon… two minutes of needling three times a week, that's like six minutes of needling [a week] which isn't that bad' Mia) or reframe it (a 'life saver' Grace).

Patients with inconsistent talk often downplayed negative occurrences and used generalisations ('it's fine') but then revealed needling experiences suggesting negative or even traumatic events. Their talk showed contradictions between their recounted experience, attitude and their internal reaction to needling:

> [Needling is] Fine… when I'm sitting outside waiting to go in, and then it, by the time I get into the unit my blood pressure will go high, because I know what's coming, I mean it sounds really silly doesn't it, but I try to be really, really calm when I go in there… I just sort of let them get on with it, you know, try not to make a fuss, try not to be tense…I know it's got to be done, stop being a big baby [laughs]… it really hurts. (Martha)

Similarly, others downplayed their mental and physical responses to needling and used negative self-talk to get through needling. These patients often spoke of enduring needling ('I just grit my teeth… I've got to put up with it, I haven't got any choice' Olivia) and demonstrated more resignation and negative adjustment.

Some of the false positivity and inconsistency may be driven by societal and cultural expectations (e.g., being grateful for care, not causing staff problems):

> Sometimes I feel bad, but I can't say anything to them… I was angry about that [dressings not applied in preferred way] because that is important… You have to know how to cope with the nurses, no point in challenging them… I always give them sweets, I keep lots of chocolate… I know how to deal with them… mostly they are ok, but if anyone is a little bit rude, I don't reply to them. What I mean is that I need them, they have to do everything. I just ignore it… So far so good. Haven't had any pain, problems up to now. (Tariq)

This patient's non-English background may have limited their ability to talk candidly about experience. The inconsistency between experience and personal reaction brought short-term benefits (e.g., maintaining the nurse-patient relationship, access to care). It re-enforced negative behaviours (e.g., quelling anger, buying gifts to maintain relationships) and facilitated a disconnect between lived and expressed experience, hindering authentic reflection on needling experience.

Reciprocity

At the heart of needling is the person being needled (the patient) and person inserting the needles (the needler). Patients emphasised the importance of this interaction, with reciprocity of confidence and empathy driving positive experiences ('So it's all to do with confidence, empathy' Maurice) and, if established, fostering trust.

Patients stated that when needlers showed empathy, or tried to understand that needling could be difficult and painful, it helped them relax, leading to better experience. They also recognised that needlers needed a level of pragmatic empathy, a balance of being caring yet focused on the task:

> Because I think with some people they don't like hurting people, and they know it hurts so they're more worried about hurting you, rather than just putting the needle in. Whereas I think some people kind of put that pain to the side, knowing that it's just one of the… It's just a necessary evil. (Stewart)

Patients noted the often difficult position that needlers were in (under-staffing, many patients to put on) and described the importance of patients showing empathy to needlers (being helpful, using humour to break tension).

Confidence was important for both needlers (exhibiting confidence) and patients (having confidence in the needler). Some needlers exuded confidence through their mannerisms or approach ('conscientious… oozes confidence… warmth like a bloody radiator' Maurice; 'the air of confidence they put out' Lucas). Patients gained confidence in needlers through experience and observing how they needled others. With every fistula/graft being unique, communication was important in building confidence. For patients, this entailed being able to be honest about their experience (which could be complex), communicating with needlers about their fistula/graft or needling preferences, encouraging needlers and giving needlers a second chance if it did not go right. Likewise, it was key that needlers actively listened to patients. Confidence could be 'knocked' (Olivia) by either party if there were problems during needling or communicating; confidence then had to be rebuilt.

For some, confidence grew into trust; however, trust could be broken if they did not feel listened to and could lead to distrust and even disempowerment:

> [One needler who] one tap, one touch on your arm… Boof! Straight in… it makes you feel powerless, because, obviously, somebody is doing something to your body that you're not necessarily happy about… Because they're healthcare professionals, and especially someone like that who is a senior [nurse]… you automatically have this sort of level of respect or compliance that they know what they're doing, and they're going to do it right. And whether that is sort of justified, most of the time it is, but sometimes if they make a mistake, then obviously your, your faith or your trust wasn't justified. (Aiden)

However, when confidence and empathy were reciprocated, mutual trust emerged which facilitated engagement, each helping the other. The ideal interaction culminated in both being able to openly and honestly talk about how needling was going and it becoming 'part of the conversation' (Martin).

Reciprocity resonated with self-needlers and home patients. Confidence in the dialysis team and the team showing empathy were critical for working together to solve problems.

DISCUSSION

We identified a core theme and five key aspects of needling which patients described as foundational to their experience. We have also provided insights into how these may vary by patient. Additionally, we described two influencing themes, relating to personal learning and patient–needler interaction, which shaped both experience of needling across patient characteristics and how the foundational aspects play out.

This is the first study examining patient' experience of needling in a large sample across multiple centres, needling techniques, access types and needlers. We found that patients had shared views and meanings associated with needling, which were important to recognise before examining experience (*The nature of needling*). This theme echoed the synthesis of Fielding et al. (2023) that needling is painful, necessary and that patients develop ways to deal with it. Establishing these ascribed meanings provided a window to examine how experience of needling was shaped by foundational aspects and influencing themes. The framework of patient experience of needling offers perspectives to begin shifting *The nature of needling* so that pain and unknown variation are not features.

We delineated five foundational aspects of needling not previously reported (i.e., *Health of the fistula or graft*, *Steps in needling*, *The needler*, *The patient*, *Organisational context*). We then provided a comprehensive view of each aspect that extended findings in the literature, such as the fistula a lifeline (Casey et al., 2014; Mafara et al., 2016; Richard & Engebretson, 2010), impact of problems with fistulae (Romyn et al., 2015), skills and experience of the needler (Richard & Engebretson, 2010; Wilson & Harwood, 2017) and the effect of environment on needling (Wilson & Harwood, 2017).

Steps in needling added new knowledge about specific elements of needling and how they impact experience. Critically, it highlighted the importance of taking on board patients' preferences related to these steps. Healthcare professional engagement with these preferences could help patients gain a sense of control and enhance involvement. Although fear and anxiety related to needling have been reported (Casey et al., 2014; Mafara et al., 2016; Romyn et al., 2015; Taylor et al., 2016; Wilson & Harwood, 2017), in this study they featured across themes. In *The patient* we showed the effect of physical and psychological well-being, as well as the long- and short-term implications of distress associated with needling, and how they may manifest, captured in the influencing themes.

The two influencing themes provided new insights into the role of learning and the patient–needler interaction, which shaped how the foundational aspects were experienced on any given day. In *Learning from needling experience*, we described how patients navigated their knowledge and involvement, found ways to manage it, adapted to changes and talked about themselves in relation to needling. Although changes in needling experience over time has been alluded to in previous research (Mafara et al., 2016; Romyn et al., 2015; Wilson & Harwood, 2017), we extended this, demonstrating that changes over time may be positive or negative.

Learning from needling experience ties together elements found in other studies—deciding to take control of needling, being positive, accepting and needling becoming part of identity (Moore et al., 2018; Romyn et al., 2015). Similar to Moore et al. (2018), we found that those who self-needle spoke consistently and positively about themselves, demonstrating positive adjustment to needling. Others talked about themselves negatively in relation to needling ('a problem'). Awareness of the potential impact of self-talk and listening to patients talk about themselves may help staff identify and reshape negative adjustments. Negative self-talk was linked to inconsistent narratives, such as talking about the painfulness of needling yet being dismissive of their own internal state. Such disconnects between lived and expressed experience make it difficult for healthcare professionals to identify and address issues. Although this study found consistency in needling experience across cultural communities, the social and cultural norms associated with healthcare were evident which impacted what was said, and not said, about needling. This may be partially due to patients not being able to express their experience or organisational factors (e.g., lacking language resources such as interpreters). Giving patients space and opportunity to say things are not 'fine' could foster more authentic connection with their experience and provide more accurate information to inform care. In paediatric nephrology, guidance exists on managing anxiety and distress around needling which could be employed with adults (Stronach et al., 2019). Such strategies to improve needling may require additional resources including ensuring sufficient staff/time to create individual needling plans, allocating named-needling nurses and having the time and confidence to manage patients' distress.

The other main theme, *Reciprocity*, focused on the patient-needler interaction. While previous research has identified the importance of the nurse–patient relationship on needling (Wilson & Harwood, 2017), our findings also drew out how both patient and needler influence the interaction and ultimately patient experience of needling. Empathy and confidence drove the interaction, which, when reciprocated, lead to better needling experience. A significant finding was the identification and description provided by patients on the role of empathy, extending the value of nurse friendliness reported previously (Wilson & Harwood, 2017). Wilson and Harwood (2017) and Romyn et al. (2015) linked patients' lack of confidence in needlers' skills with unease. We focused on the overall impact of confidence, for patient and needler and how confidence may be developed. Our findings echoed Moore et al. (2018) and Taylor et al. (2016) who described confidence as foundational to successful self-needling, and that confidence is influenced by others and built through experience. Our patients described instances when confidence with the needlers was lost and had to be rebuilt. Self-needlers have also described the variable nature of confidence (Moore et al., 2018). This theme also provides insight into the interplay between *empathy and confidence* and *trust and vulnerability*. We found that confidence could increase patients' trust in their dialysis team, extending the findings of Romyn et al. (2015) and Wilson and Harwood (2017). However, trust could be broken fostering feelings of disempowerment and vulnerability (Fielding et al., 2023; Mafara et al., 2016; Romyn et al., 2015; Taylor et al., 2016), which require empathy to reestablish.

Strengths and limitations

A major strength of this study was the incorporation of the Patient Steering Group, from inception to dissemination. Their involvement ensured the research team understood the context and gravity of needling (e.g., importance of pain relief options, protecting the fistula/graft) and that our findings truly reflected what patients said. Their commitment allowed us to develop a comprehensive view of patients' experience of needling. Another strength was the attention to ensuring a broad view of needling experience, particularly emphasising cultural diversity among participants. This was achieved by removing language as a barrier to participation amongst Urdu speaking Pakistani and Gujarati speaking Indian patients as per the need identified at selected centres. Addressing underrepresentation in kidney research is a national priority, which this study embedded as a priority from the outset.

Participant recruitment was limited to kidney centres in England. Patients in other areas of the United Kingdom and elsewhere may have differing experiences. In partial mitigation we included patients and healthcare professionals from Scotland, Wales and Canada in wider advisory groups. Although we assessed the relevance of the emerging thematic map in interviews with non-English speakers, our findings may not fully reflect their experiences.

Future research

Future research is warranted to challenge the current status quo in needling that pain and day-to-day variation should be accepted as part of life on haemodialysis. Furthermore, needling is often a dyadic process, involving both patient and needler, and we only examined patient experience. Further research is needed to understand the experiences and needs of healthcare professionals. Our study highlighted complexities around understanding patients' experience of needling, such as the influence of social and cultural norms on the relationship between internal state and expressed experience. The patterns of those with inconsistent talk echoed an avoidant attachment style (i.e., not expressing emotions, downplaying distress). In contrast consistent talk reflected secure attachment (i.e., self-awareness, reflection). Research exploring these concepts may help to better understand these relationships.

Implications for clinical practice

The major recommendations from our findings are:

- Talk to patients about their individual preferences for needling.
- Strengthen relationships with patients by building confidence and showing empathy.
- Be aware that conversations and behaviours occurring around a patient may impact needling experience. These can be encouraging and bolster confidence or may foster anxieties.
- Due to social expectations or cultural norms, patients may find it difficult to express their actual experience. Dismissive phrases such as 'it's fine' may be a signal to follow-up with questions giving patients space to speak candidly.
- The findings from this study informed the development of the NPREM (Moore, Ellis-Caird et al. 2024), which may be helpful in addressing these recommendations.

CONCLUSION

This study provided a comprehensive overview of patients' experience of needling, first outlining what needling means to patients; mapping foundational aspects and how these may impact any given needling session; and how patients' own learning about needling and the interaction with the dialysis team are key to needling experience. Patients described the complexity of their needling experiences and often had distinct preferences about needling. Working with patients to identify these may lead to more engagement in needling and facilitate rapport, potentially reducing overall burden of care. For kidney care teams, developing confidence and empathy, and in turn trust, with patients is key to improving needling experience.

AUTHOR CONTRIBUTIONS

Currie Moore led study, contributed to study's design, conducted interviews, analysed data, drafted manuscript and approved the final manuscript. Helen Ellis‐Caird designed the study, oversaw coordination, analysed data, drafted manuscript and approved the final manuscript. Catherine Fielding, David Wellsted, Ken Farrington, Sabine N. van der Veer conceived study, designed the study, oversaw coordination, contributed to manuscript and approved the final manuscript. Faizan Awan, Kieran McCafferty, Rebecca Flanagan, Shivani Sharma and Tarsem Paul contributed to study design and coordination, reviewed analysis, contributed to manuscript and approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions. Additional supporting information may be found in the online version of this article at the publisher's web‐site.

ETHICS STATEMENT

This study received a favourable ethical opinion from the UK Heath Research Authority and NHS Research Ethics Committee (Cornwall‐Plymouth, RefNo.17/NW/0501). Participants gave verbal and written informed consent before interviews commenced.

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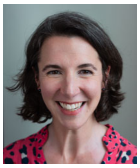

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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