

Check for updates

## Dialysis Needle-Related Distress: Patient Perspectives on Identification, Prevention, and Management

Emily L. Duncanson<sup>1,2,3</sup>, Anna Chur-Hansen<sup>1</sup>, Richard K. Le Leu<sup>2,5</sup>, Luke Macauley<sup>1,2</sup>, Anne L. J. Burke<sup>1,4</sup>, Fiona F. Donnelly<sup>2</sup>, Kathryn L. Collins<sup>1,4</sup>, Stephen P. McDonald<sup>2,3,5</sup> and Shilpanjali Jesudason<sup>2,5</sup>

<sup>1</sup>School of Psychology, Faculty of Health and Medical Sciences, The University of Adelaide, Adelaide, South Australia, Australia; <sup>2</sup>Central Northern Adelaide Renal and Transplantation Services (CNARTS), Royal Adelaide Hospital, Adelaide, South Australia, Australia; <sup>3</sup>Australia and New Zealand Dialysis and Transplant Registry (ANZDATA), South Australian Health and Medical Research Institute, Adelaide, South Australia, Australia; <sup>4</sup>Psychology Department, Royal Adelaide Hospital, Adelaide, South Australia, South Australia, Australia, Australia; and <sup>5</sup>School of Medicine, Faculty of Health and Medical Sciences, The University of Adelaide, Adelaide, Adelaide, South Australia, Australia

**Introduction**: Needle-related distress is common among people receiving hemodialysis and affects quality of life and treatment decisions, yet little evidence exists to guide management. This study explored patients' experiences of needle-related distress to inform the development of prevention, identification, and management strategies.

**Methods**: Semistructured interviews concerning dialysis cannulation, needle-related distress, and potential solutions were conducted with people with current or recent experience of hemodialysis (N = 15) from a tertiary hospital-based service. Interviews ceased at thematic saturation. Transcripts were analyzed thematically.

**Results:** There were 4 themes and 11 subthemes generated: (i) uncovering a hidden source of distress (dismissal and minimization by others; suffering in silence to stay alive; preparation, assessment, and education); (ii) coping with cannulation pain and trauma (interaction between physical damage, pain, and distress; operator dependency—the importance of nurse skill and technique); (iii) the environment created by dialysis nurses (emotional transference; communication during cannulation; valuing empathy and person-centered care; a psychosocially supportive dialysis unit); and (iv) supporting patient self-management of distress (accessing tools to help themselves; distraction to reduce distress).

**Conclusion**: Needle-related distress is an often-hidden element of the hemodialysis experience. Patients learn to tolerate it as an inevitable part of dialysis for survival. Nurses' technical skills and the dialysis environment they create are key determinants of the patient cannulation experience. Proposed solutions include psychological screening, education for patients to self-manage distress, and training for nurses in communication and providing relevant psychological support.

*Kidney Int Rep* (2023) **8**, 2625–2634; https://doi.org/10.1016/j.ekir.2023.09.011 KEYWORDS: arteriovenous fistula; cannulation; hemodialysis; patient perspectives; qualitative research; vascular access

Crown Copyright © 2023, Published by Elsevier Inc. on behalf of the International Society of Nephrology. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

nsertion of needles into a large blood vessel is a necessary but invasive and unpleasant experience for many patients receiving hemodialysis through an arteriovenous fistula.<sup>1</sup> Most must undergo the insertion and removal of at least 6 large-bore needles per week, totaling more than 300 needling procedures per year. Needle-related distress influences kidney replacement therapy and vascular access choices, including preferences for and reluctance to remove dialysis catheters.<sup>1–</sup>

<sup>5</sup> Needle-related distress is likely underreported by patients, who accept it as the price for remaining alive with dialysis.<sup>1,6</sup> Needle fear has been reported by 25% to 47% of adults receiving dialysis.<sup>7</sup> It is not routinely assessed in care and represents a psychological burden for patients and challenge for dialysis nurses to manage.

Needle-related distress can be considered on a continuum from dislike or discomfort to needle phobia,

**Correspondence:** Shilpanjali Jesudason, Central Northern Adelaide Renal and Transplantation Service, Royal Adelaide Hospital, Adelaide, South Australia 5000, Australia. E-mail: shilpa.jesudason@sa.gov.au

Received 13 June 2023; revised 20 August 2023; accepted 4 September 2023; published online 14 September 2023

characterized by severe physiological response including vasovagal syncope and avoidance behaviors, requiring psychologist-delivered intervention such as desensitization therapy.<sup>8–10</sup> The less severe yet more common subclinical level of needle-related distress experienced by many dialysis patients currently has little evidence regarding identification and management.<sup>2,7</sup> Patients describe worry about the success of needling, bodily intrusion and disfigurement, and resigned acceptance of pain and anxiety about dialysis needles.<sup>1,11</sup> Past traumatic or unsuccessful needling experiences likely contribute to the onset and worsening of needle-related distress<sup>1,12,13</sup> and explain patients' desires for consistent nurse assignment for cannulation.<sup>11,14</sup> Vascular access function, including its impact on quality of life, is also a core outcome of critical importance to patients and clinicians.<sup>15</sup>

Alternative cannulation techniques, complementary therapies, and local anesthetic agents were found to have varying efficacy in managing pain associated with arteriovenous fistula cannulation.<sup>16</sup> Virtual reality (VR) technology has also been trialed in clinical settings to manage the pain and anxiety associated with needlerelated procedures.<sup>17–19</sup> Research in children revealed a beneficial impact of VR as a distraction in reducing needle-related pain, fear, and anxiety<sup>18</sup>; however, the effects of VR on needling experiences in adult hemodialysis patients are limited. This study explored the experiences of dialysis patients regarding cannulation, needle-related distress, and potential solutions for its prevention, identification, and management, to improve care and the dialysis experience.

## **MATERIALS AND METHODS**

Study is reported according to the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) Guidelines.<sup>20</sup>

## Participants and Setting

This study was conducted within an Australian adult tertiary kidney service consisting of 22 sites including 12 regional and 4 metropolitan dialysis units. The service provides dialysis to more than 800 patients (including approximately 110 peritoneal dialysis and 30 home hemodialysis patients). The proportion of hemodialysis patients with an arteriovenous fistula or an arteriovenous graft was 88%, whereas 12% had a central venous catheter, compared with 82% with an arteriovenous fistula/arteriovenous graft and 18% with a central venous catheter in the national cohort.<sup>21</sup> Eligible patients were those who spoke English and were able to provide informed consent. To capture diverse perspectives across the spectrum of needle experiences, we recruited from a broad cohort with any

experience of dialysis cannulation irrespective of current kidney replacement therapy modality, including drawing from patients who had self-reported needlerelated distress from a recent cross-sectional study in our unit<sup>2</sup> or those identified by nurses as suspected to have needle-related distress. Patients diagnosed with having true needle phobia were excluded. Purposive sampling ensured diversity of participant views, characteristics, and experiences across the spectrum of needle-related distress. Potential participants were approached by phone or at dialysis clinics by clinical staff and then followed up by the first author (ED) for consenting and to arrange the interview. Recruitment ceased at thematic saturation. Ethics approval was obtained from the institutional ethics committee (HREC/19/ CALHN/72).

## **Data Collection**

ED conducted semistructured interviews between April and July 2020 through a telephone or Zoom or at dialysis clinics. ED was a female registered psychologist with no prior relationship to the participants. Potential participants were informed that ED was conducting interviews to understand patients' experiences of dialysis needle-related distress, with the aim of developing management strategies. Interview questions were informed by existing literature and study investigators, including psychologists, nurses, and patients (Supplementary Material 1). A pilot interview with a person with experience of kidney failure was conducted to refine the interview guide. Interviews were audiorecorded and transcribed. Written informed consent was obtained from all the participants.

## Data Analysis

Transcripts were coded by ED using NVivo software and inductive and deductive thematic analysis (data familiarization, initial code generation, generation of themes and subthemes, reviewing themes, defining themes, and reporting themes).<sup>22</sup> High-level categories of prevention, identification, and management provided the analysis framework based on relevant literature,<sup>7</sup> and smaller codes relevant to each of these were generated inductively from the data. Grouped codes were collapsed into themes and subthemes with triangulation by authors ACH and SJ. Final themes and their relationships were agreed on by authors ED, ACH, and SJ. Participants were provided a summary of the findings and reported that the results reflected their views accurately and offered a basis for much-needed strategies to address dialysis-related needle distress. ED maintained an audit trail documenting identified concepts after interviews and analytic decisions.

## RESULTS

There were 23 patients invited to participate. Seven declined or were unable to be contacted at follow-up and one withdrew due to poor health. Of the 15 participants, 13 (87%) were receiving hemodialysis and 10 (67%) reported current or past experience of dialysis needle-related distress. Interviews lasted between 21 and 86 minutes (average duration = 50 minutes) (Table 1).

There were 4 themes and 11 subthemes generated representing participants' experiences of needle-related distress and views on its identification, prevention, and management (Figure 1). Illustrative quotes are displayed in Table 2.

## Uncovering a Hidden Source of Distress *Dismissal and Minimization by Others*

Participants reported withholding disclosures of needle-related distress due to these being dismissed by health professionals and family members previously. Some reported receiving invalidating comments about their distress, including being told to "suck it up" (participant 3). Although often intended with humor or to diffuse tension, such comments perpetuated beliefs that needle-related distress should not be disclosed.

## Suffering in Silence to Stay Alive

Needles were described as a lifeline, the literal connection to life-sustaining dialysis. Participants accepted distress, having to "grin and bear it" (participant 5) or mentioned the need to relax, but uncertainty about how to achieve this. They suspected needle-related distress was common but rarely

Table 1. Participant characteristics ( $N = 15$ )		
Variable	Value	
Men ( <i>n,</i> %)	8 (53%)	
Age (average, range)	59 (36–83 yr)	
Current KRT (n, %)		
In-center hemodialysis	13 (86.67%)	
Peritoneal dialysis	1 (7%)	
Transplantation	1 (7%)	
Duration of current KRT (average, range)	(1 mo-5 yr)	
Current hemodialysis access type		
AV fistula	10	
Permacath	3	
Current or past experience of dialysis needle-related distress (yes) (n, %)	10 (67%)	
Experience of professional support for needle-related distress		
Yes, psychologist:	2 (13%)	
No, but would have like to:	4 (27%)	
No, not needed:	9 (60%)	
Interviews		
Face-to-face (n, %)	3 (20%)	
Telephone/Zoom (n, %)	12 (80%)	
Duration (average, range)	50 (21–86 min)	

AV, arteriovenous; KRT, kidney replacement therapy.

disclosed due to beliefs that it was untreatable, unavoidable or from a reluctance to bother clinicians. One reported confiding in their nephrologist, but many stated their nephrologist would be unaware of concerns as reviews focused primarily on reviewing clinical results.

## Preparation, Assessment, and Education

Learning the size of dialysis needles was shocking and added to the challenge of commencing dialysis. Many participants reported not being asked about their tolerance of needles when making treatment decisions or during predialysis education. Participants suggested this topic be raised by health professionals in treatment and vascular access planning and formally assessed before dialysis start. Treatments for diabetes and arthritis, blood tests, or observing family members self-cannulate for home hemodialysis were perceived as tolerable compared with hemodialysis cannulation for some participants, but for others, exacerbated dialysis needle-related distress. Psychoeducation for clinicians regarding needle-related distress was expected to improve understandings of the patient experience.

Some participants reported seeing needles for the first time at their initial dialysis session, whereas others recalled opportunities to handle cannulation equipment and needles as part of predialysis education. Cannulation education through a video, hemodialysis unit tours, and spending time with existing patients for peer explanations of cannulation were suggested as opportunities to reduce fear. Peer support and explanations were expected to be particularly effective for information retention. Conversely, some participants worried that receiving too much information about cannulation before commencing dialysis may deter people from hemodialysis. Ongoing education about cannulation in the initial weeks of hemodialysis was also considered important.

Use of a needle-related distress screening tool during the predialysis phase was suggested to identify distress and aid treatment decision-making; however, participants emphasized that it should be brief. A lengthy or in-depth assessment was expected to induce fear and overburden patients with information. Ongoing monitoring at 6 weeks or 8 weeks postdialysis start and/or after traumatic cannulation was considered as important as initial screening.

## Coping With Cannulation Pain and Trauma Interaction Between Physical Damage, Pain, and Distress

Participants described cannulation experiences that were physically and psychologically traumatic, using phrases such as "bullet holes" (participant 14), "stabbing"



Figure 1. Schema revealing relationship between themes and opportunities for improved identification, prevention, and management of needlerelated distress in dialysis care.

(participant 8), and "ramming" (participant 3). Such experiences contributed to the onset and worsening of needle-related distress and resulted in worry about infection, damaged veins, and access complications. For some, mental preoccupation about miscannulation resulted in disrupted sleep on the night before or missed dialysis sessions. Increased blood pressure and muscle tension due to anxiety hindered the success of needling, leading to repeated attempts, damaging veins, and increased distress. Traumatic cannulation experiences had also influenced some participants to choose peritoneal dialysis or hemodialysis by self-cannulation or permcath, despite known infection risks.

Local anesthetic was reported as effective for pain and distress management. Many participants were reliant on this early in their dialysis experience, expecting it to make cannulation more comfortable, but realized they experienced greater pain from anesthetic needle insertion than dialysis needles. One participant reported benefit from anesthetic cream and believed this should be routinely offered to patients.

## *Operator Dependency—the Importance of Nurse Skill and Technique*

Difficult needling experiences could result in a stress response associated with specific nurses. Failed and

persistent needling attempts, including when some participants believed it inappropriate for the nurse to continue, resulted in fear and anger. This created preferences for nurses who had performed cannulation successfully in the past. Uncertainty about nurse assignment at dialysis sessions could evoke anxiety. Participants described successful needling as the correct insertion of the needle on first attempt with minimal physical sensation. Nurses' use of ultrasound to correctly locate the patient's fistula provided reassurance and was perceived to minimize unsuccessful needling.

## The Environment Created by Dialysis Nurses *Emotional Transference*

The patients' perceived nursing confidence (or lack of) with cannulation was reported to influence patients' emotional state. When multiple needling attempts were required, increased pressure on staff was perceived, exacerbating tension between patient and nurse. Concerns about being viewed as a difficult [to needle] patient resulted in added anxiety. Participants expressed empathy for nurses during difficult cannulation, suspecting this to take a toll on staff also.

### Table 2. Illustrative guotations

#### 1. Uncovering a hidden source of distress

#### Dismissal and minimization by others

"I think lots of medical staff really need to listen to the patient and what the patient is saying. Especially, with needle fear. One of the comments that the surgeon said to me was, 'Well you've just got to suck it up and you've got to deal with it.' Well that's not really a very helpful comment. I said to him, 'You sit in the chair and let me needle you ten times!" (Participant 2) \*My daughter says 'Oh come on Dad, you big baby' when it comes to needles, and I say 'Well I just don't like them, I can't help the way I feel, that's it, I'm frightened of them.' But as I said before, you've got to do it." (Participant 7)

#### Suffering in silence to stay alive

1 don't like them [needles]. They make me nervous and make me tense up and get sweaty and shake a bit. Sometimes they make me feel sick. You just grin and bear it I guess. And I didn't want to bother them. It was just something that had to happen, so I thought I had to cope with it basically." (Participant 5)

"I tense up. I can't relax. And it's not good for anyone when you're tensed up. But how do I relax? I don't know." (Participant 9)

#### Preparation, assessment, and education

"I think in the beginning people need to be asked a lot more, 'Do you have a needle phobia?', 'Are you scared of needles?', 'Do you understand what's going to happen to you?'. I think we need to be asked a lot more questions and a lot more regular in the beginning. It's all to do with the beginning, the very beginning process of going on dialysis. I think that's the key for people coping, is in that first month of going on dialysis." (Participant 8)

\*For someone to sit there and explain it to you, that's nothing compared to actually watching it being done and having another patient say to you, this is what I'm feeling. Going and seeing the other patients, watching all the others being needled, chatting to them while they were getting needled, that's how I got over my concerns, not fears, but I had concerns about it. I found that was a great way for me to get really comfortable doing it." (Participant 6)

#### 2. Coping with cannulation pain and trauma

Interaction between physical damage, pain, and distress

- "I felt like a pin cushion. I had pain. I had about seven, six or seven jabs in that one short session. It took him over an hour. And the trauma of that experience just, it shook me up. I didn't go in that Wednesday. I'd made my mind up that I wasn't. I was still bleeding two days later, the holes were still bleeding because I'd been punctured about seven times and I said to them, 'There's no way on earth he will get me in that hospital today'. I just couldn't do it. That's where my anxiety, my fear has stemmed from." (Participant 14)
- "I don't do local now. I was using it when I first started. But talking to other people they were saying that if you always do local, it gets thick and harder to needle, another patient told me that." (Participant 12)
- "It would have been handy if someone had said, well, hang on the problem with the local isn't the injection, it's pushing liquid into your body and that's and that's pushing flesh out of the way and that's, what's hurting rather than the size of the needle. Cause I was thinking 'Well if this hurts with the local, what the hell is it going to be like if I can feel the big one?!" (Participant 3)

#### Operator dependency-the importance of nurse skill and technique

"So if it's a new person doing it, it gets mucked up and then it goes on for ages and 'Oh just hurry up, get the needles in' and you get a bit scared with people that don't know me very well. That's why I like to see the locals here, the local nurses, because they get to know you and it's a better experience." (Participant 10)

\*The senior nurses [use the ultrasound], if they can't get it. If they look at it and can't actually find, they won't put a needle in, they'll actually go and get help from one of the other senior ones and say, 'Look, this is what I think, what do you think?' And then if neither of them can decide they'll go and get the scanner. I'd rather them use that [ultrasound] than stab me three time because they think they know where the vein is." (Participant 8)

#### 3. The environment created by dialysis nurses

Emotional transference

- "The last thing I'd want is a nurse to think 'Oh I've got [patient] today, he's really tricky', and then they get anxious about it. Because if they're worried, then that makes you worry, and it's just a circle." (Participant 14)
- "If we're talking about the patient's needling distress, we need to look at the whole 360 and taking into account the person that's actually doing that needling as well. Maybe just reminding the person that's being needled that the person that's doing it, maybe they're not distressed, but anxious about doing it. And that might potentially make some other people feel more nervous if they think that they're meant to be the guru that's doing it, they're anxious as well. There's a 360 degree thing here. It's not just one person. Even though, the person getting needled may be 80%, 90% of it, there's still a portion of someone else." (Participant 2)
- And it makes the nurses uncomfortable too, because the tension builds for everybody. They know you're nervous and paranoid about needles, that comes on them too, because then they're scared that they're gonna hurt you and make your fear worse. So it's going to play on the nurses mind as well, they've got to be involved in it as well. That way, if the nurses are there and they can understand from the patient's point of view, what their fear is, then it's a win for everybody." (Participant 6)

#### Communication during cannulation

- 1 do like to know what's going on, as I said I'm a bit of a control freak. I'm a firm believer as well that it's, it's my body and I know how I'm feeling. The whole, 'We're about to do this' or 'Now we're going to do that', I think is important rather than people just doing it and the patient just being zoned out on attending to something else entirely. I think that being stepped through it a little bit or knowing what's happening is helpful." (Participant 2)
- "I don't want to distract them from what they're doing!" (Participant 1)
- \*And I don't like people saying 'Okay, we're ready to do it now.' Don't tell me. Some people like to be told, others don't like to be told. Because when they say 'One, two, three' and then your whole body tenses up because you know that's what they're going to do. They shouldn't count 'Okay here we go, we're going to do it now, okay, one, two, three', because well that tells you-, your whole body is going to freeze up and get anxious because you know it's coming. Whereas if you're looking away and they don't tell you and then bam it's done, you haven't had time to think about it, that works for me." (Participant 8)

"And the doctor goes `This might hurt a little bit' and it's the worst needle I've ever had! That's very unhelpful." (Participant 9)

#### Valuing empathy and person-centered care

"You want someone that is gonna pick up, pick up on the way you're feeling about it and do what they can to make you feel comfortable about what's about to happen. And then normally the rest works." (Participant 15)

1 just want to get the needles in. I mean, if the nurses come in and have a laugh, not rushed, come in and give that little bit of extra time and attention to the patient, that makes it easier." (Participant 4)

A psychosocially supportive dialysis unit

"Having wonderful caring nurses, whether they're male or female, was brilliant for me. I found that if you could have some fun and make it a family unit, everybody kind of relaxed a bit and even those that were stressed could relaxed because it was more fun and games." (Participant 6)

\*That I think helps, if the atmosphere is there and if the nurses are playing in the atmosphere that brings out bedside manner an it's not 'the person in chair 19'. No it's, 'Oh [patient] is coming in." (Participant 3)

#### 4. Supporting patient self-management of distress

#### Accessing tools to help themselves

\*Definitely not electronic websites or resources, they bamboozle me. I'm not that technically minded. I know what I can do on my computer and that's very limited. I'd rather speak to somebody, to probably get a different insight, a different point of view." (Participant 1)

(Continued on following page)

#### Table 2. (Continued) Illustrative quotations

"I dunno if they're man enough to ask for it [professional help for needle-related distress]. Some people probably aren't. I mean, it'd be nice if we had the help, like I wouldn't have minded having someone to talk to and say 'Hey, I'm scared of needles' and all that. It would've been interesting to see what they could've done to help resolve it." (Participant 4) Distraction to reduce distress

"No [wouldn't want to use VR], because I like to at least be aware of what's happening even though I don't want to look. To me, the answer is more empathy from the nurse and the nurse isn't going to be overcoming with empathy for me if I'm putting on a set of goggles and I'm somewhere else." (Participant 3)

"Personally I've just kind of gone off into my own little head space and have a happy moment. Something that was joyful for me, like horse riding, which is a passion for me, so you know being out along the river, horse riding in the paddocks." (Participant 6)

"Oh I dunno, you wouldn't want to be claustrophobic wearing one of them [VR headset]. You might think, I need some air. But you do need something to take your mind off it. I think it's a bit too late. You need something to help earlier, before you come in, otherwise you're here and it's done. The build up of getting here, walking through the doors, because it gets more and more intense as you get closer." (Participant 9)

VR, virtual reality.

## Communication During Cannulation

Participants described the importance of finding the "patient's currency" (participant 14) for communication with cannulating nurses. Some appreciated being advised of the cannulation process through nurses' explanations, including warnings of needles approaching the skin, when being inserted, and once secured. Others preferred silence, as this suggested the nurse was focused on achieving successful cannulation. Conversation with nurses about anything except the needling taking place was appreciated by some. Warnings of physical sensations and suggestions of discomfort (e.g. "this might hurt a bit") instilled a sense of control for some participants but increased anxiety and muscle tension for others. Humor provided distraction, diffused tension, and built rapport.

## Valuing Empathy and Person-Centered Care

Participants valued nurses' efforts to understand their emotional state during cannulation by noting facial expressions and body language or asking how they were feeling. Nurses' ability to recognize when to stop attempting cannulation after a failed attempt(s) was greatly valued, as this prevented additional pain and distress. In these instances, nurses seeking assistance from a second or senior nurse, or using ultrasound, was appreciated. A caring, empathetic, and friendly nursing approach from the start of dialysis sessions also increased patient comfort.

## A Psychosocially Supportive Dialysis Unit

Some participants identified the arrangement of hemodialysis units and chairs as enhancing patient comfort with cannulation. Being within talking distance of other patients facilitated social conversation, sharing of cannulation experiences, and allowed nurses to "play in the atmosphere" (participant 3). Participants valued camaraderie among nurses and patients and feeling like they were part of a relaxed unit. However, time pressures perceived by nurses often forced nurses to prioritize clinical duties over rapport building. Trials of animal visiting programs, permitting patients' pets to attend, and consistent volunteers visiting dialysis sessions were also suggested to reduce anxiety.

# Supporting Patient Self-Management of Distress

## Accessing Tools to Help Themselves

Some participants reported a desire to know about available psychology services to address needle-related distress. Nurses could facilitate such referrals and communicate with mental health professionals (with consent), in addition to providing support and encouragement during cannulation. Access to patient psychoeducation resources was supported. One described benefit from cognitive restructuring skills taught by a psychologist. Participants emphasized the need for paper-based and electronic versions of support materials early in patients' experience with kidney failure.

### Distraction to Reduce Distress

Various methods of self- and nurse-directed distraction helped patients cope during cannulation, including looking away or closing eyes, watching TV, listening to music, counting, wriggling toes, using a stress ball in the opposite hand, engaging in social conversation with nurses, and using imagery to visualize a pleasant experience. Four participants indicated being willing to trial VR; however, the remainder did not, expecting the headset to be uncomfortable or revealing to others in the unit of the patient's difficulties, or they thought it would be better suited to newer or younger patients. VR to simulate the cannulation experience for predialysis education was expected to be fear inducing and no more helpful than a video or observing cannulation at dialysis units.

## DISCUSSION

This study reveals that needle-related distress is a burdensome yet often-hidden part of the hemodialysis experience. Difficult needling and psychological distress may be experienced for many years, with patients suffering in silence to remain alive with dialysis therapy. Needle-related distress is perpetuated by dismissal from others and a lack of timely preparation, assessment, and education about cannulation from a technical and psychological perspective. Our findings

Table 3. Recommendations to improve the identification, prevention, and management of needle-related distress for patients with kidney failure

Domain	Suggested Action	Responsible Group
Identification through timely patient assessment and psychological screening	<ul> <li>Ask about and conduct initial screening for needle-related distress during kidney replacement therapy and vascular access decision-making and predialysis commencement. Screening instrument(s) should be brief and questions simple.</li> <li>Conduct follow-up screening 6–8 wk after dialysis commencement and consider additional ongoing screening for patients who are experiencing distress and/or who experience a traumatic cannulation event.</li> <li>Observe patient's nonverbal behavior at dialysis sessions and during cannulation—facial expressions, eye contact, muscle tension, avoidance of or shortened dialysis sessions.</li> </ul>	Renal service, nephrolo- gists, and dialysis nurses Dialysis unit Dialysis nurses
Prevention of cannulation trauma, pain, and distress through technical skill and tailored cannulation education	<ul> <li>Pause or discontinue cannulation if needling is proving difficult, avoid repeated attempts, and consult with second or senior nurse during difficult cannulation.</li> <li>Check-in with patient's emotional state during difficult cannulation using open-ended questions.</li> <li>Nurse training in and routine use of ultrasound for correct locating of patient's fistula.</li> <li>Avoid dismissive comments or jokes about patient distress and response to needles.</li> <li>Tailor cannulation education—identify patient's desire for level of detail about cannulation and needles, consider role of peer support/explanations of cannulation in predialysis education, visiting or spending time in dialysis unit.</li> </ul>	Dialysis nurses Dialysis nurses Renal service All health professionals Renal service
Management through patient-centered and psychologically supportive dialysis care	<ul> <li>Inclusion of psychology services in kidney services.</li> <li>Primary cannulating nurse or nephrologist to inform patient of available psychology services and resources, and facilitate referral if desired.</li> <li>Facilitate consistent nurse-patient assignment at dialysis sessions where possible and preferred by patient.</li> <li>Determine patient preferences for type and amount of communication during cannulation (e.g., silence, distraction [humor, social conversation], warnings of needle insertion, physical sensations, and cannulation process).</li> <li>Respond empathically to patients exhibiting distress—acknowledge and validate emotion, normalize discomfort/unpleasant experience, acknowledge patient effort and past coping.</li> <li>Identify and remind patient of helpful distraction methods to use during cannulation.</li> <li>Provide psychoeducation for nurses and nephrologists regarding needle-related distress, including "signs" of distress.</li> </ul>	Renal service Nephrologists and dialysis nurses Dialysis unit Dialysis nurses All health professionals Dialysis nurses Renal service

offer novel insights into priorities of patients regarding the identification, prevention, and management of needle-related distress to inform much-needed strategies to address this problem in dialysis care (Table 3).

Our study reiterates the painful but essential nature of cannulation and patient concerns about needling success and bodily trauma.<sup>1,14</sup> Our findings extend this knowledge by uncovering the patient experience of needlerelated distress and offering suggestions for addressing this within routine dialysis care. Patients emphasized treatment and vascular accessing decision-making and dialysis preparation as critical timepoints for psychological screening, offering of psychological support services and tailored cannulation education. Patients supported the use of a formal brief screening tool and assessment of patients' past experiences with needling procedures or treatments. To our knowledge, the only available instrument to assess fear of cannulation in dialysis patients is Dialysis Fear of Injection Questionnaire.<sup>6</sup> This could be a useful screening tool in patients receiving cannulation; however, it is not designed to assess needle-related distress in patients before the start of hemodialysis. This would be the ideal time to intervene so patients can approach dialysis fully prepared to

self-manage their fear of needles. A validated screening tool for needle-related distress in predialysis patients is desired and is currently being developed by our group. Finally, it cannot be assumed that distress will decrease over time as a result of frequent exposure to hemodialysis cannulation. Our findings suggest that psychological difficulties may persist despite throughout dialysis treatment or worsen after traumatic cannulation, and therefore, regular screening is required.

Peer support and unit visits before dialysis commencement represent opportunities to prepare patients and improve coping with hemodialysis cannulation. Some participants described a desire to learn about cannulation and managing distress from existing patients and through observations of hemodialysis sessions. Peer support programs were found to improve goal-setting, decision-making, and self-management and self-efficacy in dialysis cohorts.<sup>23,24</sup> Further research is needed to design similar programs in providing education and support for patients regarding hemodialysis cannulation and evaluate their impact on related psychological and vascular access outcomes.

Our findings highlight that patients have different views of what helps to prevent or alleviate distress.

This may be driven by past exposures, varied responses to pain, access to social and emotional supports, overall health literacy, familiarity with psychological concepts, inherent coping mechanisms, and other psychological traits. Therefore, individual patient preferences should be assessed by kidney health professionals and solutions tailored accordingly. This includes adjusting methods of cannulation education, nurse communication during cannulation, distraction techniques, and access to other psychological supports. Our findings suggest that the patientprioritized outcomes for vascular access function could be extended to also capture cannulation experience and psychological domains.<sup>15</sup> Existing clinical guidelines for vascular access recommend use of local anesthetics for pain reduction<sup>25</sup> but require updating to include psychological strategies such as psychoeducation about the physical, mental, emotional, and behavioral signs of distress and techniques to reduce this, including distraction, imagery, or relaxation.

Although greatly needed, there is a lack of highquality evidence for interventions to empower patients to manage needle-related distress and for the nurses who support them.<sup>7</sup> VR as an intervention was found to have beneficial effects in children as a distraction in reducing needle-related pain, fear, and anxiety18; however, the effectiveness in adult populations is inconclusive.<sup>19</sup> Nevertheless, although VR technology presents itself as a potential technological solution, interestingly most participants in our study stated that they would be reluctant to try VR as a distraction method during dialysis. The development of useful interventions for people with subclinical levels of distress and frequent exposure to needles as part of medical treatments should be a research priority. Our group is currently exploring the utility of a nurse-supported, patient selfmanagement program<sup>26</sup> based on cognitive-behavioral therapy principles,<sup>27,28</sup> to minimize needle-related distress among dialysis patients.

Miscannulation and difficult needling experiences result in physical damage, worry, and even dialysis avoidance. Our study suggests that needle-related distress is often driven or worsened by physical trauma that is closely linked to technical competency of nurses. Upskilling nurses in ultrasound use may help to minimize these events and improve timing and selection of cannulation sites.<sup>29</sup> This may be particularly important in the early weeks of dialysis, where miscannulation is common and may predispose individuals to psychological difficulties.<sup>12</sup> Nurse education about signs of needle-related distress, supporting affected patients, and seeking assistance during difficult cannulation may improve care. Education should also include the bidirectional relationship between physical and psychological aspects of distress and how bodily tension can affect cannulation.

Our study highlights the many facets of nursing care beyond cannulation that are crucial to patients' dialysis experience and level of needle-related distress. From the patient perspective, a warm and friendly approach is part of successful needling.<sup>11,14</sup> Our findings also emphasize the importance of nurses' and nephrologists' ability to recognize distress and validate patient concerns to avoid embarrassment and withholding of difficulties. Although some patients develop mental resilience and tolerate cannulation,<sup>30</sup> dismissal of patient concerns may lead to poorer physical and psychological outcomes. This has implications for health professional education in recognizing distress and counselling patients during difficult medical procedures.

This study has limitations. The study was set in a high-income country, non–English-speaking participants were excluded, and patients from culturally and linguistically diverse populations were not specifically recruited. Therefore, transferability of findings more broadly is uncertain. This study focused on current or recent hemodialysis recipients to understand the strategies that are used by patients to prevent or reduce needle-related distress. Future studies that specifically recruit individuals who have declined or withdrawn from hemodialysis due to needle-related concerns may provide further understanding.

Our study provides new insights into a common yet poorly understood issue among dialysis patients. Needle-related distress is often tolerated as an unavoidable part of hemodialysis, negatively affecting well-being and treatment experience. There is an interplay of factors including patients' past needling experiences, level of hemodialysis preparation and education and nursing technical skill, and interpersonal approaches. Patients require a supportive dialysis unit and psychologically oriented nursing care, coupled with individualized strategies to self-manage their distress. Priority areas for research include the development and evaluation of screening tools and interventions for patients and nurses to address needle-related distress.

## DISCLOSURE

All the authors declared no competing interests.

## ACKNOWLEDGMENTS

The authors acknowledge the nurse unit managers and nursing staff of the Central Northern Adelaide Renal and Transplantation Service who assisted with recruitment for this study, particularly Monique Borlace and Fiona Donnelly, and psychology student Bronwyn Harris for her preliminary work on the analysis. The authors also sincerely thank the people who volunteered to offer their time and share their personal experiences for this study.

Funding support for this project was provided to SJ by the Royal Adelaide Hospital Research Committee Clinical Project Grant (MyIP ref#12879, March 2020) and Royal Adelaide Hospital Research Fund (April 2020) and Health Services Charitable Gifts Board (HSCGB)—reference number: 79-05-73-06-21.

## **AUTHOR CONTRIBUTIONS**

ED, ACH, AB, FD, KC, LM, RL, SM, and SJ contributed to the research idea and study design. ED contributed to data acquisition. ED, ACH, and SJ contributed to data analysis/ interpretation. ED, ACH, and SJ contributed to manuscript preparation. ED, ACH, AB, FD, KC, LM, RL, SM, and SJ contributed to manuscript review and final approval.

## SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Supplementary Material 1. Interview guide.

## REFERENCES

- Fielding C, Bramley L, Stalker C, Brand S, Toft S, Buchanan H. Patients' experiences of cannulation of arteriovenous access for haemodialysis: a qualitative systematic review. *J Vasc Access.* 2023;24:1121–1133. https://doi.org/10.1177/1129729 8211067630
- Shanahan L, Le Leu R, Whittington T, et al. Needle fear: a point prevalence survey of dialysis patients: needle fear in dialysis. *Hemodial Int.* 2019;23:285–286. https://doi.org/10. 1111/hdi.12752
- Xi W, Harwood L, Diamant MJ, et al. Patient attitudes towards the arteriovenous fistula: a qualitative study on vascular access decision making. *Nephrol Dial Transplant*. 2011;26:3302– 3308. https://doi.org/10.1093/ndt/gfr055
- Axley B, Rosenblum A. Learning why patients with central venous catheters resist permanent access placement. *Nephrol Nurs J.* 2012;39:99–104.
- McLaughlin K, Manns B, Mortis G, Hons R, Taub K. Why patients with ESRD do not select self-care dialysis as a treatment option. *Am J Kidney Dis.* 2003;41:380–385. https://doi. org/10.1053/ajkd.2003.50047
- Mulder M, Hoog J, Buytene S, De Vries J Ot, Buytene S, De Vries J. Validation of a screening instrument for the fear of injection in dialysis patients. *J Ren Care*. 2013;39:214–221. https://doi.org/10.1111/j.1755-6686.2013.12039.x
- Duncanson E, Le Leu RK, Shanahan L, et al. The prevalence and evidence-based management of needle fear in adults with chronic disease: a scoping review. *PLoS One.* 2021;16: e0253048. https://doi.org/10.1371/journal.pone.0253048
- Jenkins K. II. Needle phobia: a psychological perspective. Br J Anaesth. 2014;113:4–6. https://doi.org/10.1093/bja/aeu013
- Sokolowski CJ, Giovannitti J, Boynes SG. Needle phobia: etiology, adverse consequences, and patient management. *Dent Clin North Am.* 2010;54:731–744. https://doi.org/10.1016/ j.cden.2010.06.012

- Kenny RA, McNicholas T. The management of vasovagal syncope. *QJM Mon J Assoc Phys.* 2016;109:767–773. https:// doi.org/10.1093/qjmed/hcw089
- Wilson B, Harwood L. Outcomes for successful cannulation of the arteriovenous fistula: perspectives from patients on hemodialysis. *Nephrol Nurs J.* 2017;44:381–388.
- Hill K, Xu Q, Jaensch A, et al. Outcomes of arteriovenous fistulae cannulation in the first 6 weeks of use: a retrospective multicenter observational study. J Vasc Access. 2021;22:726– 732. https://doi.org/10.1177/1129729820954717
- Mafara K, Magarey J, Rasmussen P. The lived experience of haemodialysis patients who have had a new arteriovenous fistula cannulated in a satellite unit. *Ren Soc Australas J*. 2016;12:88–92. https://doi.org/10.3316/informit.4504505243 92582
- Casey JR, Hanson CSB, Winkelmayer WCMDS, et al. Patients' perspectives on hemodialysis vascular access: a systematic review of qualitative studies. *Am J Kidney Dis.* 2014;64:937– 953. https://doi.org/10.1053/j.ajkd.2014.06.024
- Viecelli AK, Tong A, O'Lone E, et al. Report of the standardized outcomes in nephrology-hemodialysis (SONG-HD) consensus workshop on establishing a core outcome measure for hemodialysis vascular access. *Am J Kidney Dis.* 2018;71:690–700. https://doi.org/10.1053/j.ajkd.2017.12.003
- Alzaatreh MY, Abdalrahim MS. Management strategies for pain associated with arteriovenous fistula cannulation: an integrative literature review. *Hemodial Int.* 2020;24:3–11. https://doi.org/10.1111/hdi.12803
- Omonaiye O, Smyth W, Nagle C. Impact of virtual reality interventions on haemodialysis patients: a scoping review. *J Ren Care.* 2021;47:193–207. https://doi.org/10.1111/jorc.12362
- Czech O, Wrzeciono A, Rutkowska A, Guzik A, Kiper P, Rutkowski S. Virtual reality interventions for needle-related procedural pain, fear and anxiety—a systematic review and meta-analysis. *J Clin Med.* 2021;10:3248. https://doi.org/10. 3390/jcm10153248
- Kılıç A, Brown A, Aras I, et al. Using virtual technology for fear of medical procedures: a systematic review of the effectiveness of virtual reality-based interventions. *Ann Behav Med.* 2021;55:1062–1079. https://doi.org/10.1093/ abm/kaab016
- Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19:349–357. https://doi.org/10.1093/intqhc/mzm042
- Australia & New Zealand Dialysis & Transplant Registry. ANZDATA 45th annual report 2022 (data to 2021). Accessed June 1, 2023. https://www.anzdata.org.au/anzdata/publicat ions/reports/
- 22. Braun V, Clarke V. *Thematic Analysis: a Practical Guide*. SAGE Publications Ltd; 2022.
- Bennett PN, St Clair Russell J, Atwal J, Brown L, Schiller B. Patient-to-patient peer mentor support in dialysis: improving the patient experience. *Semin Dial.* 2018;31:455–461. https:// doi.org/10.1111/sdi.12703
- Kha-Moua K, Paulus AB. Patient peer-to-peer mentoring for patients with kidney failure: methods, facilitators, and lessons learned. *Nephrol Nurs J.* 2021;48:227–235. https://doi.org/10. 37526/1526-744x.2021.48.3.227

## **CLINICAL RESEARCH** -

- EL Duncanson et al.: Dialysis Needle-Related Distress
- Polkinghorne KR, Chin GK, MacGinley RJ, et al, [KHA-CARI Guideline]. Vascular access central venous catheters, arteriovenous fistulae and arteriovenous grafts. Nephrol. 2013;18:701–705. https://doi.org/10.1111/nep. 12132
- Radisic G, Duncanson E, Le Leu R, et al. Improving management of needle distress during the journey to dialysis through psychological education and training—the INJECT study feasibility pilot protocol. *Pilot Feasibility Stud.* 2022;8:28-28. https://doi.org/10.1186/s40814-022-00989-2
- 27. Craske MG, Stein MB. Anxiety. *Lancet*. 2016;388:3048–3059. https://doi.org/10.1016/S0140-6736(16)30381-6

- Kaczkurkin AN, Foa EB. Cognitive-behavioral therapy for anxiety disorders: an update on the empirical evidence. *Dial Clin Neurosci.* 2015;17:337–346. https://doi.org/10.31887/ DCNS.2015.17.3/akaczkurkin
- Hill K, Sharp R, Childs J, et al. Cannulation practices at haemodialysis initiation via an arteriovenous fistula or arteriovenous graft. *J Vasc Access*. 2020;21:573–581. https://doi.org/ 10.1177/1129729819869093
- Taylor MJ, Hanson CS, Casey JR, Craig JC, Harris D, Tong A. "You know your own fistula, it becomes a part of you" – patient perspectives on vascular access: a semistructured interview study. *Hemodial Int.* 2016;20:5–14. https://doi.org/ 10.1111/hdi.12340