

**How does the experience of haemodialysis impact a patient's ability to cope with a fear of needles and the needling procedure?**

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## Table of Contents

<b>Abstract.....</b>	<b>5</b>
<b>Declaration.....</b>	<b>6</b>
<b>Contribution Statement.....</b>	<b>7</b>
<b>Acknowledgements .....</b>	<b>8</b>
1.1 End Stage Kidney Disease .....	9
1.2 Dialysis Choices.....	10
1.3 Needle Fear .....	12
1.4 Coping Strategies .....	14
1.5 The Current Study .....	16
<b>Chapter 2: Method.....</b>	<b>17</b>
2.1 Participants.....	17
2.2 Procedure.....	18
2.3 Analysis.....	19
<b>Chapter 3: Results.....</b>	<b>20</b>
3.1 Challenges with the physical procedure.....	22
3.2 Emotional responses to sources of pain .....	23
3.3 Regaining control through self-reliance.....	25
3.4 Improved outcomes through patient-centred care.....	27
3.5 Influence of nursing skills on psychological outcomes .....	27
3.5.1 Technical skills.....	28
3.5.2 Interpersonal skills.....	29
<b>Chapter 4: Discussion .....</b>	<b>30</b>

IMPACT OF DIALYSIS ON COPING WITH FEAR OF NEEDLES	3
4.1 Overview .....	30
4.2 Transactional Model of Stress and Coping Mechanisms .....	37
4.3 Strengths and limitations.....	39
4.4 Implications of this study .....	41
4.5 Conclusion.....	44
<b>References .....</b>	<b>45</b>
<b>Appendix A .....</b>	<b>51</b>

**List of Figures**

*Figure 1.* Map representing the themes, and how they affect coping.....21

### Abstract

Haemodialysis is the most common treatment used to prolong the life of patients living with kidney disease. This requires three treatments a week, with two large needles inserted at each treatment. There has been limited investigation into the causes of needle distress in dialysis patients, so it is difficult to implement appropriate interventions to address this issue. The aim of this study is to explore patient fear around needles and identify processes to better manage the fear of needles. I aim to answer the question, *how does the experience of haemodialysis impact a patient's ability to cope with a fear of needles and the needling procedure?*

Interview data from fifteen haemodialysis patients was provided by the Central Northern Adelaide Renal and Transplantation Service (CNARTS). The interviews went through a thematic analysis coding process and were ultimately grouped into five overarching themes. These interviews were analysed under the theoretical lens of the transactional model of stress and coping, with three coping methods, emotional-, task- and avoidance oriented, to explore the coping of haemodialysis patients.

The central themes were, *Challenges with the physical procedure, Emotional responses to sources of pain, Regaining control through self-reliance, Improved outcomes through patient-centred care and Influence of nursing skills on psychological outcomes.*

This study will provide valuable insight into the mechanisms that affect patient coping during dialysis, and the data can be used in the development of a patient-led and nurse-supported intervention to be delivered by a health psychologist to address needle fear in dialysis patients.

*Keywords:* haemodialysis, needle fear, coping

**Declaration**

This thesis contains no material which has been accepted for the award of any other degree or diploma in any University, and, to the best of my knowledge, this thesis contains no material previously published except where due reference is made. I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital thesis repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

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### **Contribution Statement**

In writing this thesis, my co-supervisors created the interview guide, conducted the interviews and provided transcripts of the interviews that made up the data corpus. My primary supervisor and I collaborated to generate a research question of interest. I conducted the literature search. My primary supervisor and I collaborated in selecting the relevant psychological theory. I was responsible for manually coding all the posts, creating the categories, and identifying the relevancy of this research. I wrote up all aspects of the thesis.

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To my secondary supervisors, Emily Duncanson, I sincerely thank you for trusting me with your research and the opportunity to build upon it. To Associate Professor Shilpa Jesudason and Dr Richard Le Leu, thank you for inviting me into the CNARTS Research Group and allowing me to learn so much over the months from the multi-disciplinary research team with such obvious dedication to improving patient and caregiver outcomes.

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### **1.1 End Stage Kidney Disease**

Chronic kidney disease is categorised in 5 stages. Stage 1 and 2 are labelled the early stages where there are typically no symptoms as the kidneys are slightly damaged but are still able to function, and stage 3 and 4 are labelled the middle stages where the level of waste in the blood rises and the person starts to feel unwell. The 5th stage of kidney disease is the final stage of chronic kidney disease, at the point where the kidneys can no longer function on their own. When an individual reaches end stage kidney disease, their body can no longer remove extra water and waste products from their blood (Kidney Health Australia, 2021). When this stage is reached there are limited options available to prolong life, other than a kidney transplant or dialysis. The Australian Bureau of Statistics estimated that in 2019 approximately 1.7 million Australian adults were demonstrating signs of chronic kidney disease, and as of the end of 2019 about 13,900 Australians were receiving dialysis due to kidney disease (ANZDATA Registry, 2019).

Rates of treated kidney disease almost doubled from 6 people per 100,000 population in 1989 to 11 people per 100,000 in 2018. The increase in numbers can be attributed to population growth and ageing (Australian Bureau of Statistics, 2018). The increase in the population with the 5<sup>th</sup> stage of kidney disease is reflected in an increase in the use of chronic kidney disease related healthcare services, with hospitalisations and regular dialyses increasing by 51% and 58% respectively (Australian Institute of Health and Welfare, 2018). In addition, the number of Australians receiving dialysis or a kidney transplant increased by 51% between 1997 and 2013 (Australian Institute of Health and Welfare, 2018; ANZDATA Registry, 2019). This increase in the number of people with kidney disease has led to a shortage in the renal nursing workforce,

affecting the workload on nurses and their ability to provide appropriate levels of care to dialysis patients. (Hill & Arnold-Chamney, 2020)

A review of the relationship between the symptoms of chronic kidney disease and the physical health-related quality of life of patients demonstrated that quality of life decreases as symptoms increase. These symptoms can come from both the disease and the treatment, and are unlikely to exist in isolation leaving the patients dealing with a high symptom burden (Almutary, Bonner & Douglas, 2013). The most common symptoms related to chronic kidney disease are feeling washed out, fatigue, drowsiness, pain and dry skin (Almutary, Bonner & Douglas, 2013; Bonner et al, 2018; Yapa, Purtell, Chambers & Bonner, 2020;). Studies have also shown that patients with kidney disease typically have a higher prevalence of depression and anxiety, which leads to a lower quality of life (Goh & Griva, 2018; Kilicoglu et al, 2016). However other studies have demonstrated that over time quality of life from a psychological perspective can remain stable, which could be explained by a gradual adaptation to lower quality of life due to changes in living standards over time (Bonner et al, 2018; Yapa et al, 2020). These increased comorbidities and reduced health-related quality of life highlights that medical care needs to be responsive to the needs of patients, and involve them in making decisions about their treatments. (Guha, Viecegli, Wong, Manera & Tong, 2021).

## **1.2 Dialysis Choices**

There are two main dialysis choices, haemodialysis and peritoneal dialysis. In haemodialysis the blood is pumped out of the body to an artificial kidney machine, then returned to the patient's body by tubes that are connected to the dialysis machine. This is predominantly achieved through an arteriovenous fistula or arteriovenous graft in the patient's arm into which needles are placed to connect the patient to the machine, with a less common access method

being through a catheter. In peritoneal dialysis the inside lining of a patient's belly acts as a natural filter. Wastes are taken out by a cleansing fluid called dialysate, which is washed in and out of the belly in cycles (Kidney Health Australia, 2021). Currently, dialysis providers such as nephrologists and program administrators commonly recommend haemodialysis via arteriovenous fistula as the preferred dialysis method, with an arteriovenous graft conducted if the veins are not suitable for a fistula. While fistulas are generally associated with better access to the vascular system for the nurses and improved health outcomes for the patients, including lower chances of infections and lower mortality, increasing the use of shared decision making in selecting a dialysis method is important to ensure the appropriate method is selected for each individual patient (Murea, Grey & Lok, 2021).

Peritoneal dialysis is currently used by about 20% of people who are on dialysis. It can be done through two methods, either automated overnight dialysis, or continuous ambulatory dialysis which typically involves three to five exchanges during a 24-hour period, lasting about 30 to 40 minutes at a time. Haemodialysis can be done at a specialist centre or at home. In a clinic, it is typically done three times a week requiring a patient to remain sitting or lying down for four to five hours at a time (Kidney Health Australia, 2021). With two needles required for each dialysis session, this is at least six needles per week, meaning a patient is likely to have at least three hundred and twelve needle insertions per year. Dialysis needles are much larger than typical blood taking needles, being approximately 3mm x 25-38mm. The needles are inserted into specially-created blood vessels (arteriovenous fistula) which are connected to the dialysis machine. Using home haemodialysis can allow for increased treatment flexibility for patients, allowing them to choose the frequency, duration and timing of their dialysis sessions, and can also be done overnight. This increased flexibility allows for increased patient independence and

quality of life (Walker et al, 2018). However, it has been reported that 47% of haemodialysis patients avoided home-based self-care treatment choices due to a fear of needles (McLaughlin, Manns, Mortis, Hons & Taub, 2003). Becoming someone who self-cannulates can be a gradual process, requiring time and training to be comfortable with dialysing at home. Moore et al (2018) described becoming comfortable with self-cannulation as a series of three steps. The first of those steps was Gaining Control, both mentally by reducing the fear of needles and physically by starting to learn how to insert the needles. The second step was Building Confidence, involving training, experience, and moral support when mistakes happen. The final step is Becoming the Norm, accepting that this is an integral part of their treatment, normalising it as part of their normal routine and that it forms part of their identity as a dialysis patient. Reducing needle fear may increase the number of patients who consider the first step, and ultimately choose to undertake self-care treatments, increasing their independence and reducing the burden on healthcare services.

### **1.3 Needle Fear**

A scoping review was completed by Duncanson et al (2021) to investigate the prevalence of needle fear in adults with chronic disease, and the effectiveness of evidence-based management strategies to assist with needle fear. They identified 32 articles related to needle discomfort, distress, anxiety, fear or phobia in chronic disease populations. This review identified the high prevalence of needle fear in adults with cancer, diabetes, and kidney failure. However, of the 32 studies identified only 8 included management strategies, and of these many did not include details such as the timing and frequency of the strategy, or any formal evaluation of the effectiveness. As they identified that needle fear is frequently stated as a reason for

treatment avoidance, it is important that evidence-based interventions are developed and tested to enhance patients' psychological well-being and ability to access lifesaving medical treatments.

Needle fear can impact on starting and continuing regular medical treatments, with long-lasting effects on the quality and length of people's lives. It is a prevalent but under-discussed and under-prioritised health issue that could potentially affect everyone since needle procedures are common across the lifespan from vaccinations to blood tests, to chronic conditions that may necessitate regular needles on a long-term basis. It is not easy to understand and treat, because each person with needle fear can develop this in their own way through a unique set of characteristics and behaviours, which interact differently with their own environment over time (McMurtry et al, 2015). Fear of needles has been identified as having both a hereditary and learned component (Hamilton, 1995). In twin studies the heritability of fear of injections, wounds, blood and pain has been estimated to be about 48%, and high heritability was found in physical fear responses such as changes in blood pressure and heart rate. From this, the release of stress hormones can reasonably be assumed to have a genetic influence. In addition, studies have shown that needle fear is also learned through early experiences, both personal negative experiences and through seeing another child having a negative reaction to needles. These learned fears can also lead to fear around items or experiences that have associations with needles, such as blood, injuries, syringes, doctors, dentists, nurses, white laboratory coats, examination rooms, hospitals, and even the antiseptic smell of offices or hospitals. (Hamilton, 1995).

Needle fear has been identified with a higher than average prevalence within the kidney disease population, with 10% of the general population identifying as having difficulties with needles (Hamilton, 1995) and 22% of people who attend the GP identifying as having difficulties

with needles (Wright, Yelland, Heathcote, Ng & Wright, 2009), compared to the 25-47% of haemodialysis patients expressing a fear of needles (Duncanson et al, 2021) leading to avoidance of home-based self-care treatment choices due to a fear of needles (McLaughlin et al, 2003). For a population that is potentially exposed to hundreds of needles in a year, negative needling experiences may be having more of an impact on perspectives about needles than acclimatisation over time.

Development of needle fear in dialysis can come from a range of sources, starting with being in an uncomfortable environment, the pain from the local anaesthetic injection, the pain from the dialysis needle insertions, and from traumatic injuries such as multiple needling because of missing the veins, or blown veins when a needle irritates or injures a vein which causes blood to leak into the surrounding area.

#### **1.4 Coping Strategies**

In the literature, coping is typically described as a conscious response or reaction to external stressful or negative events (Parker & Endler, 1992). In stressful situations, people need to employ coping strategies to deal with the adverse effects. Coping styles have been long discussed and a range of different theories have been proposed, as evidence suggests that coping strategies can play a major part in the physical and psychological well-being of an individual when they are confronted with stressful life events (McCrae & Costa, 1986; Miller, Brody & Summerton, 1988).

The transactional model of stress and coping describes coping as a phenomenon that involves both cognitive and behavioural responses that individuals use to manage both internal and external stressors perceived to exceed their personal resources (Lazarus & Folkman, 1984). It begins with primary appraisal of the situation, in which an individual interprets the current

stressor as positive, dangerous or irrelevant, followed by a secondary appraisal of the dangerous stressors in which if an individual does not possess the resources to mitigate the source of stress, they are likely to suffer negative effects. Coping strategies are then utilised to overcome the stress response, and to develop and learn new resources to bolster their ability to reduce the stress response in the future. In Lazarus and Folkman's model, they suggested that coping mechanisms can be described through two broad categories, problem-focused strategies, and emotion-focused strategies. In coping research completed since this initial development of the model Endler and Parker (1990) extended Lazarus and Folkman's research to develop the Coping Inventory for Stressful Situations, which breaks coping into three main categories. The first category is task-oriented coping which is similar to Lazarus and Folkman's problem-focused coping and includes strategies like finding ways to solve a problem, cognitively reconceptualising it, or minimising its effects. The second category is emotion-oriented coping which is similar to Lazarus and Folkman's emotion-focused coping, and includes strategies such as emotional responses, self-preoccupation, and fantasising reactions. The third category is avoidance-oriented coping and includes strategies such as distraction and social diversion.

Prior research into coping with needle fear and pain has predominantly focused on groups of children and adolescents. Previous studies have found that a range of psychological strategies can help to reduce the pain and distress of children during needling experiences, such as distraction, hypnosis, Cognitive Behavioural Therapy (CBT) and breathing exercises. Effective distraction techniques can include reading, watching a movie, listening to music, playing video games or virtual reality experiences (Birnie, Noel, Chambers, Uman & Parker, 2018; Gerceker et al, 2021). Hypnosis involves deep relaxation and imagery, typically taught to a child by a trained professional. The most positive support for effective treatment was for a combination of

strategies (Birnie et al, 2018; Uman, Chambers, McGrath & Kisely, 2008) with a combination of CBT, distraction and hypnosis as the most effective combination, and some preliminary support demonstrated for the efficacy of providing information on the process and preparing the individual for what is to come (Uman et al, 2008).

### **1.5 The Current Study**

As the current literature focuses on needle fear and mitigation strategies in children, more in-depth investigation into the reduction of needle fear for adults is required. In particular, the research that does reference needle fear in adults primarily focuses on vaccination needles which are administered infrequently and are typically much smaller than the needles used in haemodialysis. Developing a deeper understanding of what increases fear and concerns around needles and the cannulation experience can be utilised to find ways to increase comfort in a clinic setting or know what a patient requires to be comfortable with dialysing at home. Developing knowledge on what aspects of the cannulation process have negative and positive impacts on these experiences can be used to design interventions to improve the process for both the patients undergoing dialysis and the nurses delivering the care.

This study utilised semi-structured, open-ended interviews with current and former haemodialysis patients to focus on their experiences during haemodialysis, and what of these experiences impact on their ability to cope with needle fear. Thematic analysis was used to identify key themes in the data, developed out of patterns both within and across the data (Braun & Clarke, 2017). The key aims are to explore their patients' experiences, perceptions, and opinions around needle fear, to identify what processes are involved in managing needle fear and what strategies and supports can prevent needle fear. Topics of interest in the interviews included the patients' experiences throughout haemodialysis and their experiences with needles and the



nurse-patient interaction during dialysis sessions. Potential new intervention strategies being developed by the Central and Northern Adelaide Renal and Transplantation Service (CNARTS) were discussed to obtain feedback on the feasibility of different support methods. Qualitative research assisted in obtaining information that keeps patient-centred care, patient opinions and shared decision making as key factors in the analysis as it is the patients' perspectives and goals that underpin these aspects of quality healthcare (Guha et al, 2021). Ultimately, this study aims to contribute to the literature through the research question: *How does the experience of haemodialysis impact a patient's ability to cope with a fear of needles and the needling procedure?*

## **Chapter 2: Method**

### **2.1 Participants**

Participants were recruited from an existing pool of current or former dialysis patients who participated in a 2018 audit conducted by the Central and Northern Adelaide Renal and Transplantation Service (CNARTS) to identify the prevalence of needle fear in haemodialysis and peritoneal dialysis patients (Shanahan et al, 2019). Participants included in this study expressed interest in receiving further information on managing needle fear and were subsequently approached by external researchers from the CNARTS group.

A total of 15 participants took part in the study. Of these, 13 were currently undergoing haemodialysis, 1 had previously undergone haemodialysis but was currently undergoing peritoneal dialysis and 1 had previously undertaken haemodialysis and had since received a transplant so was no longer undergoing dialysis treatment. Participants were aged between 48 and 83.

The inclusion criteria for participation in this research project was any individual who had received dialysis. The exclusion criteria included non-English speaking patients, or those unable to provide informed consent.

## **2.2 Procedure**

The Central Adelaide Local Health Network Human Research Ethics Committee (CALHN HREC) approved this study (HREC/19/CALHN/72).

An interview guide was developed (Appendix 1) by researchers from the CNARTS Clinical Research Group to assist in the course of the interview, however it was left open-ended to allow participants to guide the interview. The guide consisted of prompts relating to experiences with needles during dialysis, sources of distress from needling and psychological and behavioural strategies employed to reduce or combat that distress.

Participation in the study was voluntary, with participants provided with an information sheet and consent form prior to commencement. They were also advised of their right to withdraw from the study at any time. Psychologists were available if participants expressed any discomfort or distress from the topics discussed in the interview. Interviews were conducted by researchers from the CNARTS Clinical Research Group over a three-month period from April 2020 to July 2020. The length of the interviews ranged from 21 minutes to 86 minutes, with an average time of 50 minutes. Interviews were conducted via Zoom, phone or in-person at a time convenient for the participant. Interviews were transcribed by Temi (<https://www.temi.com/>), an audio to text automatic transcription service. Temi utilises an automated speech-to-text algorithm to convert the audio and video files into text, which are then encrypted and stored securely. All data collected from the interviews was recorded and stored as per the standards contained in the

Australian Code for Responsible Conduct of Research (ARCaU, 2018) and the National Standard on Ethical Conduct in Human Research (tARaUA, 2018).

Transcripts were de-identified to protect confidentiality, then the de-identified data was provided to the researcher for analysis. Transcripts were formatted to include line numbers for ease of reference of quotes. Participants were asked if they would like a copy of their transcript, and an update on the study findings when available. Three participants requested a copy of their transcript, and nine participants requested a copy of the study results.

### **2.3 Analysis**

An audit trail was maintained throughout analysis to demonstrate transparency and self-reflexivity, two factors that are key in qualitative analysis to achieve sincerity in reporting and commenting upon results (Tracy, 2010). The analysis was completed by an individual that has limited knowledge of what it is like to experience a prolonged serious medical condition, and also does not have lived experience with dialysis needles. However, the researcher does have existing relationships with other individuals that have lived through the experience of kidney failure and dialysis.

Qualitative analysis was used as it is an iterative and interpretive process that aims to produce a description or explanation of a phenomenon capturing the depth and breadth of participants' perspectives (Baumgart, Crain & Tong, 2021). Qualitative research is effective in this research area because the focus on participants' perspectives in this style of research aligns with the focus on patient-centred care and shared decision making that underpins quality healthcare (Guha et al, 2021). Specifically, thematic analysis was utilised to analyse the data as it can be used to identify patterns within and across data in relation to participants' lived experiences, views and perspectives (Braun & Clarke, 2017). Data were collected through the form of semi-structured,

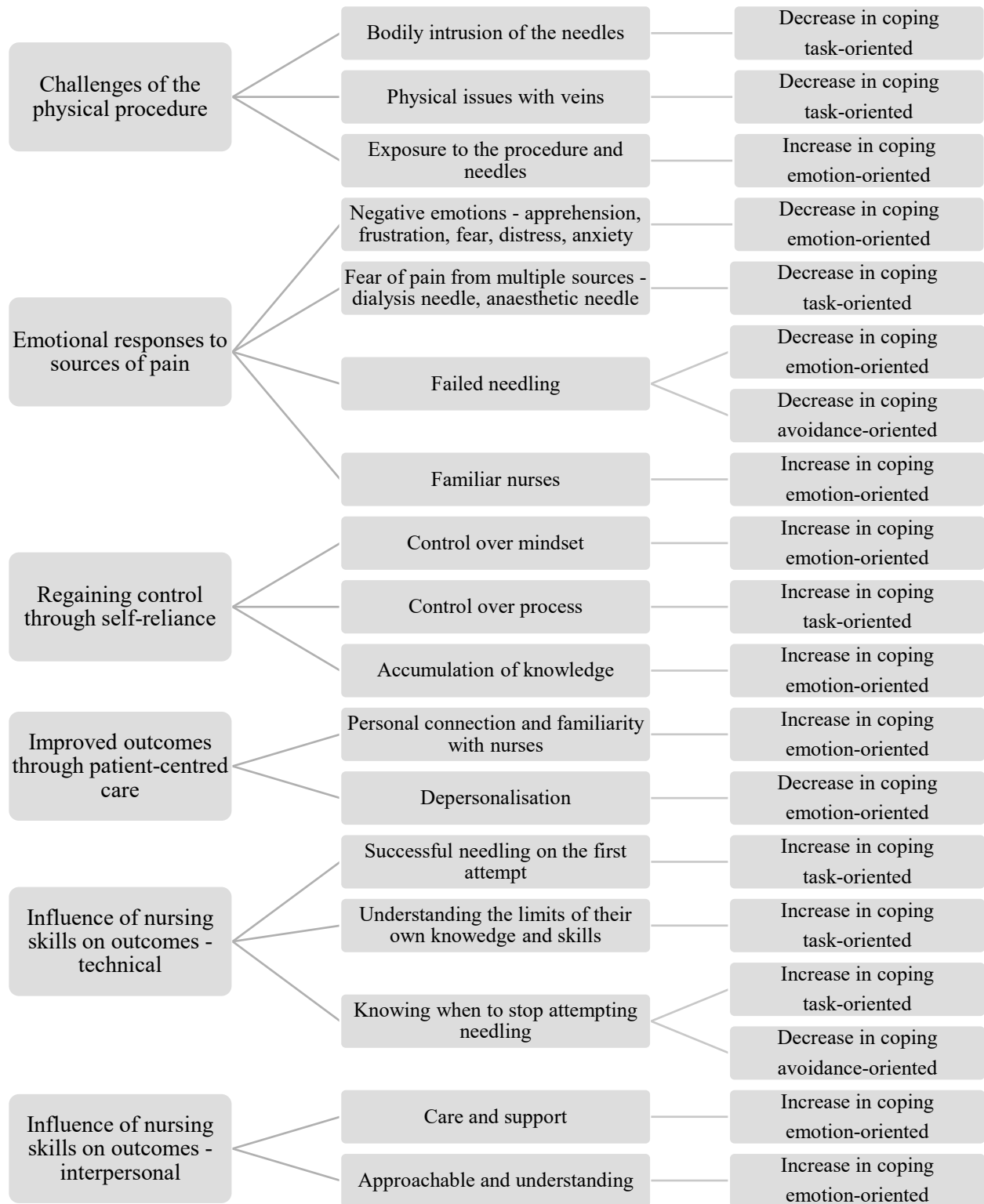
open-ended interviews, which continued until saturation was reached, when no new themes appeared in the data. Analysis was completed in six stages, data familiarisation, initial code generation, generating themes, reviewing themes, defining themes, and reporting themes (Braun & Clarke, 2013). A theme in the data is a word or phrase that captures something significant about the data and the research question, and represents a pattern of response throughout the data set. While these stages follow on from one another this analysis was performed in a cyclical process, moving backwards and forwards through the phases to refine the results, and to uncover both semantic and latent themes contained within the data. This flexible process results in a rich, detailed and complex account of the interview data.

### **Chapter 3: Results**

This research analysed patient interviews to explore the dialysis experiences that affect needle fear, and what impact these were reported to have on a patient's ability to cope with dialysis needle distress. Five key themes were identified: Challenges with the physical procedure; Emotional responses to pain; Regaining control through self-reliance; Improved outcomes through patient-centred care and Influence of nursing skills on psychological outcomes. Within these five themes are seventeen sub-themes outlined in the concept map below (Figure 1). These themes capture aspects that both increase and decrease the patients' ability to cope and can be categorised into Endler & Parker's (1990) three broad categories of coping, task-oriented, emotion-oriented and avoidance-oriented.

**Figure 1**

*Map representing the themes, and how they affect coping*



### 3.1 Challenges with the physical procedure

When describing the physical aspect of the procedure, patients talked about the bodily intrusion of the needles, describing feeling like a pin cushion, feeling uncomfortable about thoughts of a foreign item being inserted, and described the aggression of needling.

*“It's just a negative phobia. It doesn't hurt it. That's just the thought of it.*

*Thought of a sharp piece of metal.” (Participant 9, line 187-188)*

Patients also discussed physical problems that can increase the difficulty of needling. These included physical limitations such as “bad” or deep veins that resulted in more traumatic sessions than successful ones. One participant talked about needing to make decisions based on their issues with veins, further operations to make haemodialysis possible or choosing to avoid it altogether by using a different method to dialyse.

*“They've said that my veins are pretty much crap. There's lots of other things I could do, put in fake veins and you can use your legs and things and whatnot, but it's just, as I said right now, I'm just not prepared to do it now.” (Participant 2, line 220-223)*

Patients commented on the need for exposure to the process of cannulation, being able to learn the procedure, understand it and therefore increase their emotional coping to reduce their fear of the process and outcomes.

*“Takes away the fear. You know, you can see the theatre, the unknown, you don't know what's going to happen, but if you see that...” (Participant 7, line 372-373)*

### 3.2 Emotional responses to sources of pain

Patients expressed a range of negative emotions connected to different aspects of the dialysis experience. Apprehension was discussed, centred around the beginning of the experience and talked about in the context of the needles. Frustration was talked about in different contexts, primarily at the time spent on this procedure, on losing control over an aspect of their life and also awareness of the frustration experienced by the nurses at failure to needle. Fear was discussed in a range of contexts, connected to feelings around the unknown, failures in needling, pain from the needling, infection, and additional medical complications from needling, overthinking and focus on the experience outside of the procedure, and thoughts of the size of the needles. Distress was talked about in connection to the needles, anticipation for the dialysis experience, and from repeated attempts after failure. The consistent emotional response mentioned across the data was that patients' central concern at the beginning of dialysis is anxiety about the pain from needling.

*“I just get nervous before, even the day before the night before dialysis. So it's mainly in the mind.” (Participant 7, line 69-70)*

Acceptance was mentioned as a mechanism to cope with these negative emotions, acceptance of the necessity of this procedure for their life, and acceptance of the lack of choice they now have.

*“I think it's the way you approach these things. I'm happy to have you say that this is what you've got to do and just get on and do it.” (Participant 1, line 413-417)*

Pain can be introduced into dialysis from more than just the main dialysis needle, with one patient describing the pain from the local anaesthetic injection as worse than any pain from the dialysis needle, from *“pushing all that extra stuff in”* (Participant 3, line 93-94). When asked, most patients described the definition of a successful cannulation as not just the needle being correctly inserted into the fistula, but it being inserted with little or no pain.

*“I’ve had a few nurses that I didn’t even know they’d put them in... But if it’s always like that, I don’t feel it. I’m happy with that. No worries.”* (Participant 4, line 208-210)

The most painful experiences came from times where needling wasn’t done correctly, when the vein was damaged or ‘blown’ from the needling. Not only did this cause pain, but it meant that a second needle, or possibly more, would need to be done in order to dialyse.

*“A person that was wanting to make the point that it was going to work needled me excessively. And it was just to the point where it was ridiculous. One of the nursing staff actually said to him enough is enough. You need to stop. Then I ended up going and having an ultrasound and my arm was pretty much a mess inside from the operations and the blunt force trauma of the person continuously trying to put needles in.”* (Participant 2, line 87-92)

Phrases like ‘blunt force trauma’ were used to describe these experiences, and these experiences reduced their ability to cope emotionally with the dialysis procedure.

*“I did attempt, um, again, once my arm sort of had recuperated, um, but yeah, you know, one would sort of get in all right. But they always had trouble with the second one and I would get to the point where I would just cry before I*



*would go to dialysis because I would just hate the whole thought of not working.” (Participant 2, line 95-98)*

As a consequence of this anxiety around painful needling, many patients expressed a preference for familiar nurses, someone the patient perceived as highly skilled in order to have a good cannulation experience. An unfamiliar or ‘less skilled’ nurse caused an increase in anxiety and reduced patients’ ability to cope during the process.

*“My apprehension and fear of the needles is still there, the level of fear depends on the nurse who is doing it. I actually score them myself, and if a few get me a nine out of ten but a lot get me a five or a four so therefore if I know I’ve got someone who scores a four, then I’m more tense” (Participant 3, line 105-109)*

### **3.3 Regaining control through self-reliance**

Many patients talked about the importance to accept that dialysis is necessary; the only choices are either dialysis or death. While end stage kidney disease brings this lack of control into a patient’s life, some of them explained that they found their own ways to exercise control in their own lives. Regaining some control allowed the patients to utilise problem focused coping strategies.

Under the overarching theme of regaining control through self-reliance is the sub-theme of control over one's own mindset, ultimately the idea that you need to rely on yourself to manage the feelings around needling and not seek psychological interventions. They described

using the ability to reconceptualise the problem or the fear in order to cope with the ongoing experience.

*“I don't know if I really agree with the whole [psychological] support thing, personally I just think it's just something you have to deal with” (Participant 2, line 60-61)*

Control for others was found in control over the process, through self-cannulation in home haemodialysis where they can choose their days and times to dialyse and regain control in a situation that has already taken away certain choices. In this, they minimised the extra effects that dialysis had on their lifestyle because this allowed for flexibility and choice.

*“I was pretty depressed and upset because I wanted to do it for myself. I liked to have total control of myself and as a patient we're having to give over that control to someone else sticking needles into our arm.” (Participant 6, line 119-122)*

With a higher level of fear of needles, some people struggled to exercise control over their mindset, or take control of their own needling. In these circumstances, another form of control patients found was through developing knowledge to advocate for themselves, allowing a possibility for choice in their treatment.

*“I know all the risks that go with the McKesson (catheter), but as I've said to my nephrologist it's working for me and, I'm very anal with my McKesson, keep it clean and stuff. So I've only ever had the one, hopefully it will keep there until I get a kidney.” (Participant 2, line 107-110)*

### **3.4 Improved outcomes through patient-centred care**

Participants highlighted the importance of the interaction with nurses and the other health professionals that were a part of their care team, that they felt a personal connection and familiar support provided better needling experiences.

*"I like the local nurses here because they get to know you and it's a better experience" (Participant 10, line 142-143)*

When patient experience was not placed at the centre of the procedure, patients expressed feelings of depersonalisation and trauma that affected anxiety levels for future needling experiences.

*"When they had the procedure, if they didn't get the needle the first time, three different nurses had a go. I felt like a pin cushion. I had about six or seven jabs in that one short session. It took them over an hour. And the trauma of that experience shook me up. I'm not normally fazed by much." (Participant 14, line 83-86)*

### **3.5 Influence of nursing skills on psychological outcomes**

Nurses have a range of skills that can influence the results for their patients, both technical skills in cannulation, and interpersonal skills in knowing when patients are scared or helping patients to feel comfortable in this high stress environment.

### 3.5.1 Technical skills

Patients described the importance for the nurse to find the right location and angle for the needle and finding it the first time. Missing the vein caused pain and frustration, affecting the patient's emotional coping.

*“when they fluff around and get it in and dig around inside you because they haven't got you, haven't got your vein or your artery and they dig it around with a needle inside it and you think, Oh my Lord, just get it. And they're like, Oh, I'm sorry. I'm not in yet. Well, you're not feeling this, but anyway. And then they say they want to take it out and do another one.” (Participant 8, line 254-257)*

Another important skill was possessing the knowledge and awareness to understand what you know and don't know about the situation and knowing when you need help to succeed in needling. Patients expressed approval in finding nurses who were able to understand their own limitations and ensure the best possible outcome for the patient.

*“I think the nurses, the more experienced ones, get it. And if they don't know what they're doing, with new patients they'll go and get the machine and scan it.” (Participant 8, line 273-275)*

The last technical skill referenced frequently by the patients was knowing when to stop after a failed needling, instead of continuing and causing heightened distress for the patient. The below quote illustrates a situation where a patient had a bad cannulation experience and started to avoid dialysis in order to cope with the situation.

*“I had a really bad experience from that couple in a row that really shook me. It was in the second month. And since then, I got to the point where I didn't come for a few sessions. It got the better of me.” (Participant 14, line 46-52)*

### **3.5.2 Interpersonal skills**

The interpersonal skills of the nurses were deemed important through their care and support of the patients experiencing distress from needles. While this was seen as important throughout the whole process, support at the start to help a patient before they have had a chance to develop their own coping mechanisms was essential.

*“I think the first time I had two nurses helping me, probably one answering questions and distracting me from needles and the other one was carrying on doing what she had to do.” (Participant 1, line 297-299)*

Patients stated that a nurse being able to “read” what they need, or presenting as someone approachable enough that a patient felt comfortable to openly and easily communicate with them in a moment of distress to support them, was key in this high stress environment. Throughout the data, the nurses were commonly referred to using terminology such as “empathetic”, “caring” and “reassuring”, and were regularly mentioned as being important to a successful cannulation.

*“Just up to the relationship you have with the nurse and how easy going and calm, if you have to do it.” (Participant 5, line 451-452)*

## Chapter 4: Discussion

### 4.1 Overview

The main objective of this study was to explore the experiences of patients on dialysis, and how they cope with fears and concerns about needles and the needling procedure. Using thematic analysis patterns across and within the data were identified exploring the participants' lived experiences. The aim of this study is to understand the dialysis needling experiences of patients to develop an intervention that is patient-centred to address the prevalence of needle fear. Qualitative research has been used in this case as it has proven effective in developing interventions and policies that improve the outcomes for patients through shared decision making, collaborative approaches to care and patient-centred care (Guha et al, 2021).

The five themes identified through the analysis included: *challenges with the physical procedure, emotional responses to sources of pain, regaining control through self-reliance, improved outcomes through patient-centred care and influence of nursing skills on psychological outcomes*, divided into *technical skills* and *interpersonal skills*. This research has identified the main areas of fear and pain experienced throughout dialysis, and what parts of the experience can affect the ability to cope with those fears.

This data extended the research of Duncanson et al (2021) who completed a scoping review into the prevalence and management of needle fear in adults with chronic illness. The scoping review highlighted that although there is evidence that a high level of needle fear is common amongst people with chronic illnesses such as cancer, kidney failure and diabetes, there is limited information as to how to identify needle fear in adults, and what interventions can support these populations when needle fear is identified. Consistent with Duncanson et al (2021), patients in this study expressed that insufficient communication was had prior to and during

dialysis about their concerns regarding needle fear and the dialysis procedure, and improved standards and interventions are needed to identify and manage their concerns regarding needles.

In the first theme *challenges with the physical procedure*, patients described the fear connected to thinking about the bodily intrusion of the needles and feeling like a pin cushion. This fear is consistent in findings from previous research, highlighted in a thematic synthesis of 46 studies done by Casey et al (2014) where patients described the insertion of needles as an agonising invasion of their body. It was described as an assault and was compared to being stabbed or ripped. This fear of bodily intrusion also extended to surgeries associated with cannulation. This aligns with the next sub-theme in this study that physical limitations like ‘difficult’ veins caused both physical and psychological trauma over and above the fear from the needles, with this increase in fear leading to a reduced ability to cope and a feeling of being vulnerable. Patients discussed the need for exposure to the procedure, wanting to be able to understand what happens so they can prepare themselves for the experience.

Patients expressed a range of negative emotions connected to the needles and needling process throughout the interviews, which reduced their ability to assess this as a manageable or controllable situation. In the theme of *emotional responses to sources of pain*, the range of emotions often evolved over time starting with apprehension from the unknown, to frustration over the time ‘wasted’ sitting still to distress from failures and repeated attempts at cannulation to the regular anxiety from knowing what had happened in the past, and not being able to know exactly how everything will happen in the future. Consistent with this study, in previous research patients have expressed a range of emotional responses to the pain and that finding methods to cope with this is essential for them to continue receiving treatment, however when pressed on possible methods they were unable to express how to manage this (Wilson & Harwood, 2017).

This study found that patients commonly described accepting the necessity of dialysis as an important way to cope with needing to continue the procedure, but this didn't change the pain and anxiety felt from the needling. The need for acceptance was echoed in other studies (Casey et al, 2014), explaining they didn't need to agonize about the future but rather accept that "whatever will be, will be".

Pain during dialysis came from a range of sources. In this study the most common experiences of pain were from the dialysis needles, both from times when the cannulation was successful and from when it wasn't, but it could also come from the anaesthetic needles which were intended to reduce the overall pain, and back pain from the length of time sitting still during dialysis. Successful needling was described by patients across this study and others (Wilson & Harwood, 2017) as a cannulation that involved little to no noticeable pain. Pain is experienced differently by each individual, and the methods needed to avoid it or reduce it to manageable levels weren't always consistent. While some patients manage to develop a tolerance for the pain over time, others appeared resigned to the regularity and persistence of the pain and were powerless to fight or manage it. The levels of pain increased anxiety of the needles and the dialysis procedure because patients would worry about potential issues during cannulation and could only hope that their haemodialysis treatment would have a positive outcome. (Wilson & Harwood, 2017).

The ability of the patients to remain calm and cope with the experience was supported by familiar, trusted nurses when a patient would be expecting a successful result from the dialysis needling. This is consistent with the findings from other research, with Casey et al (2014) finding a theme of being wary of unfamiliar providers. Patients tended to doubt the expertise of nurses who were not familiar to them and felt relaxed and secure with trusted providers. A 'friendly'



nurse-patient relationship, involving listening, talking, joking and laughing was key to building a therapeutic relationship based on trust which in turn increased patient comfort (Wilson & Harwood, 2017).

With kidney disease, the lack of control comes into focus. The choices become dialysis or acceptance of managing a rapid decrease in their health and eventually death. In the theme *regaining control through self-reliance* patients expressed that being able to find a sense of control over part or all of the cannulation process increased their comfort and feelings of having choice in their own lives. Control over the task can increase their sense of personal security and responsibility, finding some consistency in the care because they are able to keep the process in their own hands. This is also reflected in the results from Casey et al (2014) who found task-focused control led to self-satisfaction and pride in keeping their vascular access working. Patients undergoing dialysis demonstrated increased depression and anxiety symptoms which have been noted to increase the likelihood of adverse outcomes (Goh & Griva, 2018). An increase in self-satisfaction and a decrease in anxiety may contribute to better dialysis outcomes.

In this study, patients expressed a desire to understand the process of cannulation, know what was happening to their body to assist them to develop appropriate emotional coping techniques and skills. This finding is similar to Casey et al (2014) who found a theme of unpreparedness in their thematic synthesis where some patients did not know about the need for vascular access to dialyse and others who did not understand there may be complications from the process, which then increased their insecurity. They believed knowing about the possible complications they may experience would have been better, as they could have prepared themselves to cope under unexpected circumstances. Developing knowledge could give patients the ability to advocate for themselves throughout the process, either by knowing the alternatives

to haemodialysis such as peritoneal dialysis allowing them to avoid the haemodialysis needles altogether or being able to advocate for circumstances to increase their own comfort. This mirrors the synthesis from Casey et al (2014) where patients expressed feeling comfortable enough to reject treatment if they didn't trust the provider, thereby defending their own access and maintaining control over their own situation. Finding a way to feel prepared for vascular access helped patients to approach dialysis with more confidence (Casey et al, 2014).

This study found that exercising control over their mindset was important to decrease their anxiety and to assist in accepting the necessity of the situation. This included accepting the pain of needling and the risks associated with their vascular access and needling procedure (Casey et al, 2014).

The theme *improved outcomes through patient-centred care* demonstrated that providing consistency in care and support was important to develop a personal connection, leading to increased comfort with the nurse and the ability to have open and frank communication about concerns and preferences. This was also expressed in the study from Wilson & Harwood (2017), who found that consistency in the nurse-patient assignment contributed to their perception of comfort. They expressed that feeling like a nurse knows you as a person, not just a patient, and understands individual needs in the dialysis process just makes life easier on both the nurse and the patient. Patient centred care is about treating a patient with respect and dignity and allowing them to be involved in decisions about their health and treatment. It is an approach that is linked to their rights and aims to help a patient feel responsible and connected to their own treatment and management of their health. As demonstrated through the biopsychosocial model, health management is related to all aspects of a person, including their biology, psychology, and socio-

environmental factors. Because of this, patient centred care is important to support positive outcomes for dialysis patients.

Conversely to that, feeling disregarded and depersonalised throughout the process can increase the anxiety of patients, potentially leading to lower engagement in their own health management and therefore end with negative outcomes. Shared decision making, where a patient is provided with the pros and cons of all available treatments and are an active part of selecting the most appropriate treatment, can increase a patient's connection to their own health management and therefore encourage better outcomes (Murea, Grey & Lok, 2021).

The direct involvement of nurses in the dialysis procedure means that their skills and knowledge are directly connected to the experience and coping of their patients, and from this came the theme *influence of technical nursing skills on psychological outcomes*. In this study, the technical skills of the nurses were consistently discussed including their ability to correctly place the needle first time, understand their own limitations, knowing when they need more information before proceeding, and knowing when the patient needs them to stop when problems are occurring. As in our data, Wilson and Harwood (2017) found generally nurses were quick to intervene when problems arose and were comfortable asking for help from their peers when cannulation was difficult. They were also comfortable in taking the time to use the ultrasound to assist in a positive result for the patient. However, the current increase in numbers of people with chronic kidney disease due to population increase and ageing is causing a shortage in renal nurses. This understaffing has an impact on their ability to provide appropriate care to the dialysis patients (Hill & Arnold-Chamney, 2020), which if this same trend continues over time will remove a key coping factor from many patients. Previous research into nephrology nursing has led to the development of the term 'perpetual novice', to acknowledge the difficulty some

nurses who work in haemodialysis clinics have in transitioning from novice to expert in cannulation of the fistula (Wilson, Harwood & Oudshoorn, 2013). One of the environmental factors that contributed to this difficulty in developing expertise included the patients protecting their fistulas, directing the nurses rather than trusting them to find the vein themselves. Another problem factor relates to the time pressures in the unit, ensuring patients were dialysing as quickly as possible to try to reduce a possible source of distress for a patient, but potentially in trying to be quick not acknowledging that some patients require extra time to be comfortable. Also, continuity of care was mentioned as a factor in nurses not developing expertise in cannulation quickly, as each patient had different needs both physically and in terms of education on the procedure, and the reality of nursing shift work meant that patient assignment was inconsistent (Wilson, Harwood & Oudshoorn, 2013). These three barriers to nurses developing expertise were also issues mentioned in this study by the patients that impacted their ability to cope, suggesting that similar pressure points might exist for both groups involved in the haemodialysis process.

The theme *influence of interpersonal nursing skills on psychological outcomes* demonstrated that nurses supported patients through more than just their technical skills, by providing emotional support through the start of dialysis, when apprehension about this process is highest and patients have not had an opportunity to develop their own coping mechanisms within the procedure. Consistent with prior research, patients appreciated distraction techniques provided by nurses during needle insertions and found friendly interactions with the nurses that involved listening, talking, joking and laughing to be helpful in achieving an overall positive experience. (Wilson & Harwood, 2017). These strategies seem to assist in developing a

therapeutic relationship built out of trust, which then increases patient comfort and helps them to be more relaxed and at ease during dialysis sessions.

#### **4.2 Transactional Model of Stress and Coping Mechanisms**

Prior research has shown that individuals with chronic kidney disease are already dealing with a high daily symptom burden including fatigue, lack of energy, feeling drowsy and pain (Almutary, Bonner & Douglas, 2013), and those with kidney disease are living with significant comorbidities and poorer quality of life (Kilicoglu et al, 2016). This increased level of daily stress reduces the resources they have available to cope, resulting in a reduced ability to manage any additional negative experiences. For each patient these additional negative experiences can be very different, for some it may be when problems occur during dialysis, such as blown veins or repeated needling due to misaligned cannulation and for others it may just be the need to attend dialysis. The transactional model of stress and coping (Lazarus & Folkman, 1984) provides a framework to conceptualise how patients experience stress from the haemodialysis process, and how they gradually implement coping procedures even if they are never fully comfortable with the needles and the procedure. Endler and Parker's three coping styles can help us to categorise and understand the full spectrum of coping methods. This spectrum falls under emotion-focused coping utilising emotional responses, self-preoccupation and fantasising reactions, task-focused coping utilising problem solving, cognitively reconceptualising problems and developing methods to minimise effects, and avoidance-focused coping utilising distraction and social diversion. This research has identified a number of aspects of the dialysis procedure that both positively and negatively affect a patient's ability to cope.

In primary appraisal, the patient assessed the situation for potential threats, with the high levels of needle fear found in the scoping review by Duncanson et al (2021) and the theme of

apprehension and fear prior to haemodialysis demonstrating that this is a common assessment of the dialysis process.

In secondary appraisal, the patients analyse their resources available for coping with the current threat. From this research, anxiety about the needles and possible needling issues were mentioned frequently as aspects that can lower their resources, while acceptance of the necessity of the procedure and familiar and skilled nurses can increase their available resources to avoid stress.

If the demands of the situation outweigh the available resources, then they experience negative stress. At this stage patients need to engage in coping strategies, broadly categorised into task-oriented, emotion-oriented, and avoidance-oriented strategies.

Task-oriented strategies employed by patients include control over their own needling, either by using home haemodialysis or needling themselves in a clinic. This control over their own process increased their sense of personal security and responsibility, and connection to their own health outcomes.

Emotion-oriented strategies employed by patients come from support from nurses and others, primarily through listening and communication on both sides. Trusted nurses support the patients' ability to remain calm during the process, with an increased expectation of a successful needling outcome. Patients also talked about gaining knowledge about the experience and their options during the procedure, allowing them a chance to advocate for themselves and be a part of the decision making in their own care.

Avoidance-oriented coping strategies were demonstrated in a few ways. Distraction by the nurses was used to avoid thinking about the procedure and environment at the moment of needling. A patient also described coping through avoidance briefly after a traumatic experience

requiring repeated attempts at needling. While this is not a long-term solution for someone who wishes to undergo haemodialysis to prolong their life, some kidney disease patients may choose to avoid haemodialysis using a fistula.

The final stage of the model is the reappraisal of the situation, when the patients assess what new knowledge they have gained or new skills or coping mechanisms they have developed, so for the next dialysis session in a few days they may be able to manage the fear, anxiety, and stress more successfully. Reappraisal about coping with stress and developing coping mechanisms can result in an improved outcome in future dialysis sessions, however as this study has identified a range of different factors that can result in negative needling experiences, reappraisal can also have negative consequences on a patient's overall coping. When needling is unsuccessful, having to return another day due to a missed treatment adds to the negative emotional response, and may have a negative impact on reappraisal (Wilson & Harwood, 2017). Psychological flexibility is an approach to coping that is key in the reappraisal process. Psychological flexibility is a response pattern including openness to experience, an individual's awareness of specific behavioural options in a given situation, and persistence or ability to change activity according to an individual's personally held values and goals. Psychological flexibility has been shown to be positively correlated to patient functioning with chronic pain, acceptance of chronic pain and values-based actions (Vowles, McCracken, Sowden & Ashworth, 2014). These results suggest that psychological flexibility may assist in a patient adjusting to the dialysis process, and ultimately lead to lower levels of distress.

### **4.3 Strengths and limitations**

A major strength of this study came through the design of the interviews and style of data analysis. Through the semi-structured interviews, it was possible to discover not only the

answers to some specific questions, but also to allow the patients to discuss and highlight the information and issues that are most important for each individual. It utilised the benefits of both a structured and unstructured interview style, to allow focus on our topic at hand but also with the freer conversation style to put the patient at ease and result in more open and honest results. The use of qualitative analysis provided a deep and informative description of the patients experiences and perspectives, and specifically the thematic analysis process allowed for patterns both within and across the data to be identified and explored. Qualitative research was effective for this study because of its focus on the patients' perspectives, values, priorities, and goals, which is essential when investigating shared decision making and patient centred care (Guha et al, 2021). This style of research has been utilised effectively on a number of occasions to drive fundamental changes in both practice and policy to improve the delivery of healthcare in nephrology. The ability to interview both face to face or through video call meant there was increased availability and flexibility for when and where the interviews were conducted. Starting this research with the aim of utilising this data to develop an intervention addressing the psychological aspects of needle fear allowed the design of the interview guide to have a clear focal point. This developed a rich and cohesive data source to develop some detailed overarching themes.

The first limitation of this study is that the views and opinions of a sample of patients from limited delivery sites may not necessarily be as generalisable on a wider scale. However, transferability has been increased by providing a detailed account of the method, participants, and data collection to provide context to the themes. Also, while thematic analysis is flexible, this can lead to inconsistency in analysis, what one researcher finds in the data may not always



be a focus for another. Self-reflexivity has been utilised throughout the analysis and writing process to examine any potential bias and increase the confirmability of this study.

#### **4.4 Implications of this study**

This research can be used in cannulation practice to develop strategies to assist patients in their needling experiences. With increased communication regarding concerns about needle fear, improved strategies for managing this fear can be introduced to assist each patient in the optimal coping methods for them. Patients expressed a range of differences as to their preferences for the needling experience, so developing a process to communicate their preferred techniques would be beneficial to effectively support patient coping. These may include distraction, relaxation or breathing techniques, and knowing if they prefer regular information or involvement in the process or to avoid it altogether. The patient opinions and perspectives on needle fear can be utilised by CNARTS to develop a patient led and nurse supported intervention, which can be delivered by a psychologist to support the patients in coping with their fear. Throughout this study and in other research on related topics (Casey et al, 2014; Wilson & Harwood, 2017) calm, friendly and familiar nurses were often mentioned as important to successful needling, so involving them as well as the patient in any new intervention is important to building trusting and supportive relationships, and successful needling outcomes for all involved. Communication and shared decision making are also important in supporting patients through this experience, as there are multiple options available for treatment of kidney disease and there is not necessarily one 'right' path to take (Murea, Grey & Lok, 2021)

Implementing strategies to decrease fear of needles, and increased confidence in communication of and their knowledge of the procedure may help to increase the number of patients willing to consider home haemodialysis. This will likely assist in addressing some of the

concerns expressed through this study relating to the nursing staff, as with a lower number of patients the nurses may be able to utilise extra time to provide excellent patient centred care and have time to ensure the patient is comfortable instead of needing to rush around dialysing several patients as quickly as possible.

The research also explored an intervention utilising virtual reality as a potential method of distraction or education for dialysis patients. Utilising VR as a distraction technique has also previously been assessed in the context of port needle insertions in paediatric hematology-oncology patients. The study considered the effects of distraction on the pain, anxiety, and fear during a needle experience, and found that in a population of children and adolescents VR distraction lowered the self-report scores on all three, indicating that the intervention had helped with coping (Gerceker et al, 2021).

This study focused on haemodialysis patients, and while this dialysis modality can be done either in a dialysis clinic or as an at home procedure only one patient stated that their preference was to dialyse themselves at home. Most patients expressed that they had concerns about needles, however did not have a clinically diagnosed needle phobia. Home haemodialysis comes with greater flexibility for the patient as they can choose their own days to dialyse and can have extra control over their environment and the length of time they are connected to a machine. This also addresses the concerns expressed in the results regarding consistency of care as home haemodialysis is performed by the patient, a trusted family member or trusted friend. The increased flexibility of performing haemodialysis at home also increases patient independence and overall quality of life (Walker et al, 2018). As is represented in this study, many patients choose to avoid this method and instead select haemodialysis in a clinic. A study was done to investigate why patients avoided home haemodialysis, and it was found that patients

expressed concern over their lack of knowledge because the various techniques were not explained adequately, fear of dialysing without direct supervision, fear of failing to perform self-care dialysis correctly, and a fear of social isolation. The variables that were identified as significantly associated with the negative attitude towards self-care dialysis were fear of substandard care, needle fears and phobias, fear of change, fear of social isolation and an unwillingness to remain awake during dialysis. (McLaughlin et al, 2003). In addition, a study was conducted by Wang et al (2011) investigated why patients might choose to avoid using a fistula even though use of a fistula to manage dialysis has been consistently associated with lower rates of morbidity and mortality. Three main themes were identified that were part of this decision and two of those themes were issues also identified in this study. The first was negative personal or vicarious experiences with the fistula which included cannulation, bleeding, time commitment or appearance. The second theme centred around knowledge and informed decision making, including information not being presented clearly enough, or experiencing an information overload at the beginning of dialysis, so they were not able to make a clear, informed decision. Shafi, Saleem, Anjum, Abdullah & Shafi (2018) also investigated why 42% of the patients hospitalised with chronic kidney disease in Pakistan refused haemodialysis. The frequency and weekly time commitment, the lifelong and permanent nature of haemodialysis, advice from family and friends, perception of the decreased and poor quality of life and fear of the needles and possible complications of haemodialysis were the main reasons given for refusal despite being hospitalised from medical complications. This overlap in reasons for refusing haemodialysis and the key themes in this study suggests that although the patients in this study all agreed to haemodialysis, the issues that reduce the ability to cope in some patients may cause others to avoid dialysis altogether.

#### **4.5 Conclusion**

This study contributed to a gap in the literature by investigating the causes of needle distress in haemodialysis patients, and the experiences that affect their ability to cope with that needle fear. Thematic analysis identified five overarching themes, a number of which were consistent with findings from the limited research that already exists in similar areas (Casey et al, 2014; Wilson & Harwood, 2017). Difficulty coping with the cannulation procedure can come from a range of sources, physical limitations, emotional reactions to pain and an individual's inability to manage those emotions, lack of control, depersonalisation through clinical procedures and fear stemming from the perception of nurses without the correct expertise to needle successfully. In addition to the aspects of cannulation that decrease a patient's ability to cope, some coping mechanisms that improve their experience were identified. These included acceptance of the necessity of dialysis, patient centred care from the nurses and finding a method of control through their mindset, through the procedure or through knowledge and advocating for themselves. The present findings provided insight into the perspectives of patients undergoing haemodialysis and identified the areas where patients could be better supported to manage fear and concerns around needles. These insights can be utilised to develop and improve interventions to be delivered by psychologists and nurses to improve the outcomes for haemodialysis patients. The insights from this study demonstrate that these interventions need to include shared decision making between the patients and medical professionals and find ways to increase opportunities for regular communication regarding needle fear and concerns about the needling process.

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Appendix A

**INJECT Qualitative Study – Interview Guide (Dialysis Patients)**

**Participant demographic information sheet (to collect at start of interview)**

<b>Name:</b>		<b>Age:</b>	
<b>Sex</b>		<b>Relationship status</b>	
<input type="checkbox"/> Male	<input type="checkbox"/> Female	<input type="checkbox"/> Single	<input type="checkbox"/> Divorced/separated
		<input type="checkbox"/> Married/defacto	<input type="checkbox"/> Widowed
			<input type="checkbox"/> Not reported
<b>Employment status</b>		<input type="checkbox"/> Volunteer work	
<input type="checkbox"/> Unemployed (due to kidney disease)	<input type="checkbox"/> Unemployed (other)	<input type="checkbox"/> Retired	<input type="checkbox"/> Home duties
<input type="checkbox"/> Part-time	<input type="checkbox"/> Full-time	<input type="checkbox"/> Disability pension	<input type="checkbox"/> Student
<input type="checkbox"/> Casual			
<b>Current dialysis modality</b>		<b>Time receiving current dialysis modality</b>	<b>Location of current dialysis</b>
<input type="checkbox"/> Haemodialysis	<input type="checkbox"/> Continuous ambulatory peritoneal dialysis	_____ years	<input type="checkbox"/> Home
<input type="checkbox"/> Automated peritoneal dialysis		_____ months	<input type="checkbox"/> Royal Adelaide Hospital
			<input type="checkbox"/> Queen Elizabeth Hospital
			<input type="checkbox"/> Hampstead Dialysis Centre
<b>Past dialysis modalities &amp; duration</b>			
<input type="checkbox"/> In-centre haemodialysis		_____ years	_____ months
<input type="checkbox"/> Home haemodialysis		_____ years	_____ months
<input type="checkbox"/> Continuous ambulatory peritoneal dialysis			
<input type="checkbox"/> Automated peritoneal dialysis		_____ years	_____ months
<b>Age at dialysis start</b> _____			
<b>Current access type</b>		<b>Previous access type</b>	
<input type="checkbox"/> AV Fistula	<input type="checkbox"/> Catheter	<input type="checkbox"/> AV Fistula	<input type="checkbox"/> Catheter
<input type="checkbox"/> Graft		<input type="checkbox"/> Graft	

<p><b>Past experience of difficulties/distress associated with dialysis needles?</b></p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><b>Current difficulties/distress associated with dialysis needles?</b></p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p>	<p><b>Previous professional support for anxiety/needle distress</b></p> <p><input type="checkbox"/> Yes, psychologist</p> <p><input type="checkbox"/> Yes, social worker</p> <p><input type="checkbox"/> Yes, other: _____</p> <p><input type="checkbox"/> No</p>
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## Patient interview – Question guide

### 1. Needle Distress

- Can you think back to when you were beginning/new to dialysis, how was your initial experience? *[use patient's descriptor word(s) in subsequent questions, i.e. fear, distress, anxiety, dislike of, difficulty with]*
- When were you first introduced to dialysis needles? What was that like?
- What is 'successful' needling to you?
- What do you think 'successful' needling to the nurse is?
- Can you tell me about your response to needles?
- How have your response(s) to dialysis needles changed since then?
- Have you currently or ever had *[descriptor]* of needles?
- On a scale of 1-10 how would you rate how comfortable you are with needles? With 0 being completely uncomfortable and 10 being completely comfortable? Has that changed over time?
- Tell me about how you feel about needles?
- Where do you think *[descriptor]* of needles comes from?

Prompts:

When did *[descriptor]* start for you?

How long has/did the *[descriptor]* last?

How did it impact you? Has it affected any other domains of your life?

If so, how?

How does it impact you currently?

Did it/does it influence your treatment experience or your treatment choices?

Did/do you think about needles before you started treatment?

Do you have experience of other health conditions or treatments where needles are involved? If so, can you tell me about those.

What in your experience is most *[descriptor]* about receiving needles for dialysis?

For example, some people find the length of the needle, the approach of the nursing staff, the environment of the dialysis room etc.

- How have you coped with or managed your *[descriptor]* of needles?

Prompts: What was/is helpful? Or what made it better?

What was/is unhelpful? Or what made it worse?

Consider: Things you did for yourself

Things other people did such as the nurses or other medical staff, family/friends reactions

Have you spoken to/speak to anyone about *[descriptor]*?

Have you spoken to your family or another professional (your GP a psychologist)? How did they react?

Other options such as medication or hypnosis or relaxation or psychotherapy?

Have you ever seen a psychologist or been diagnosed with needle phobia?

- How have these strategies affected your experiences with needle *[descriptor]*?
- Given your experience can you identify any other strategies or other people to talk to that might help to improve your experience with needles?

Prompts: Should professional support be offered? If so, from whom?

What form of help would be most suitable for you?

When should this be offered?

How would you like this to be offered – in a training package, electronically, one to one?

## **2. Feedback on proposed INJECT Intervention**

*Interviewer to provide overview of the entire INJECT intervention, and in greater detail: Develop case conceptualisation of needle distress/fear on paper with participant (physiological, emotional, cognitive, behavioural components) and explain how strategies in patient modules will address each. The modules will be reviewed and talked through with participant.*

- What do you think? (Question re: content, length)
- Anything you think would be important to include that we haven't?
- Is there anything in the modules you think would be unclear or unhelpful?
- How successful do you think this intervention will be in helping you to better manage difficulties with needles [*descriptor*]?
- How easy or difficult do you think it will be to use these modules in your own time and practice the strategies?

*Participants will then have opportunity to hold/wear/experience VR technology and headset in particular, and shown some example simulation videos (available on YouTube). The interviewer will explain its potential uses in addressing needle distress (i.e. as distraction whilst on dialysis, or pre-dialysis phase for education/information about dialysis and cannulation process)*

- What do you think?
- What was wearing the headset/viewing the video like?
- How successful do you think this will be in helping you improve difficulties with needles/needle distress?
- How likely would you be to use this whilst you're on dialysis in the chair/during needling?
- In hindsight, do you think you would have used this technology in the lead up to dialysis, to watch or experience a video of what the dialysis/needling process was going to be like?

### **3. Concluding questions**

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- If you were to speak to a patient about needles, who had not yet started dialysis, what would you say to them?
- Is there anything you know now that you would've liked to have known about needles and dialysis earlier?