Understanding Patients' Experiences of Cannulation for Haemodialysis, by Healthcare Staff

Catherine Fielding (RN, BNurs (Hons), MSc)

Academic Unit for Translational Medical Sciences,
School of Medicine

Submitted to the University of Nottingham for Doctor of Philosophy

September 2023

1 Abstract

Haemodialysis is a life-sustaining treatment for people with end stage kidney disease. Approximately 70% of patients on haemodialysis use arteriovenous access to provide access to the circulation, which requires cannulation (insertion of two needles) thrice weekly before each haemodialysis treatment. Patients struggle to cope with regular cannulation, for some throughout their time on haemodialysis, but studies exploring patients' experiences of this cannulation are sparse. Therefore, this thesis aims to understand patients' experiences of cannulation for haemodialysis as performed by healthcare professionals. This is completed through three studies described below.

The first study is a qualitative systematic review exploring what is currently known about patients' experiences of cannulation for haemodialysis. A comprehensive literature search identified twenty-six studies with findings related to patients' experiences of cannulation, including both studies on cannulation performed by healthcare professionals and carer or self-cannulation. These studies underwent critical appraisal, identifying that the quality of studies varied. A meta-aggregation of findings from studies identified that cannulation is an unpleasant procedure associated with pain, abnormal appearance, vulnerability and dependency. The necessity of the procedure to receive a life-sustaining treatment caused worry about its success. People survived this necessary, repetitive and unpleasant procedure, with feeling safe and in control making this easier. However, some patients still tried to avoid cannulation for haemodialysis.

The second study developed the 'Patient’s Perspective of Needling Questionnaire' (PPN), designed to capture the consequence of cannulation from the patients’ perspective, for use in research evaluating interventions to improve cannulation for haemodialysis. This was designed with six patient representatives, using the results from the systematic review. Face validity tests led to the removal of some questions. The final PPN had 17 questions around pain, worry and problems related to cannulation. Further reliability and validity tests were completed with 99 participants from two renal centres. The results of these tests are: 1) Internal consistency = 0.937 (95% CI 0.917-0.954, p<0.001); 2) Convergent validity using the Short Form Vascular Access Questionnaire = -0.347 (-0.146-0.521, p<0.001). The negative correlation was predicted; 3) Test-retest reliability = 0.856 (0.788-0.904, p<0.001); 4) Group smallest detectable change (95% CI) = 0.135.

The third study was a qualitative study exploring what influences patients' experiences of cannulation. Semi-structured interviews were completed with thirty participants from two renal centres. Constant comparison analysis, intensive interviewing and theoretical sampling were used to add depth to findings. The analysis created three categories: 1) Trying to make cannulation more comfortable, through familiarity, avoiding or minimising pain, increasing predictability and reducing anxiety; 2) Preserving humanity and individuality during cannulation through empathy and trust in the cannulator; 3) The necessity of cannulation forces coping, with acceptance, stoicism and contributing to cannulation facilitating coping. These categories were formed into a model describing a person coping with cannulation.

These studies have developed understanding of cannulation for haemodialysis by healthcare professionals. This has created recommendations for both clinical practice and research.

2 Acknowledgements

I would like to start by acknowledging the contribution from the patients on haemodialysis who took part in my research. I have always been in awe of what patients on haemodialysis must go through and how they cope with this. However, to then provide their time and support to research activities above and beyond their treatment is exceptional. I am truly grateful for the time they took completing my research, but also the enthusiasm and integrity with which they did this. I also then must acknowledge the contribution of the six patient representatives throughout this thesis. They approached this research with enthusiasm, integrity and commitment. They always strived to improve the quality of the research.

This thesis was completed during an exceptionally difficult period in healthcare in the UK. Both the COVID 19 global pandemic and unprecedented strikes by the workforce in the NHS affected the conduct of this research and my workload throughout this thesis. Therefore, I could not have completed this thesis without the support and encouragement of those around me, keeping me motivated.

I especially want to thank my two supervisors, Dr. Heather Buchanan and Professor Nicholas Selby. They helped me navigate the challenges posed throughout this thesis and always encouraged me to optimise the quality of this research. However, there have also been numerous collaborators who have also shared their wisdom and support in difficult times. These are too many to name but include Dr. Sarah Brand, Dr. Louise Bramley, Professor Maarten Taal, Professor Paula Ormandy, Professor Fergus Caskey, Dr. Charlotte Bebb, Dr. Carol Stalker, Suzanne Toft, Dr. Apostolos Fakis, Rachelle Sharman, Caitlin Sorrell and the research teams at Nottingham and Derby Hospitals. There have also been numerous clinical and academic colleagues who have supported me through this journey including Professor Adam Gordon, Karen Swift, Jennifer Riley, Clare Sutherland, Sevim Hodge, Dr. Ben Smith, the team of advanced clinical practitioners at Derby Hospitals and Professor Kathryn Radford and the team at the Centre for Research into Rehabilitation and Aging at the University of Nottingham. The team at the Department of Medicine for the Elderly at Derby hospitals have embraced my research, and I am truly grateful for their support.

Finally, I would also like to acknowledge the support from my family and friends. I could not have done this without their support and encouragement. My husband, Andy, often picked up the slack when I needed to focus on this thesis and provided energy when I had none left. I also cannot leave this without mentioning Cloud, my horse, who provided necessary perspective and work life balance.

2.1 Scholarly Outputs from Thesis

2.1.1 Publications

Fielding C.A., Bramley L., Stalker C., Brand S., Toft S. and Buchanan H. (2022) ‘Patients’ Experiences of Cannulation of Arteriovenous Access for Haemodialysis: A Qualitative Systematic Review’ Journal of Vascular Access IN PRESS doi: 10.1177/11297298211067630

2.1.2 Invited Presentations

‘Gold Standard Fistula Cannulation’, Annual Dialysis Conference 2021, hybrid conference presented virtually on 22/09/2021

‘Understanding Patients’ Experiences of Vascular Access for Haemodialysis, UK Kidney Week, Birmingham, presented on 08/06/2022 and European Dialysis and Transplant Nurses Association Conference, Rotterdam, The Netherlands, presented on 11/09/2022

The Ali Bakran Lecture at Vascular Access Society of Britain and Ireland Conference, Glasgow presented on 29/09/2022, entitled ‘Improving Vascular Access for Haemodialysis’

2.1.3 Conference Presentations

‘What are Patients’ Experiences of Cannulation for Haemodialysis? A Qualitative Systematic Review’, Vascular Access Society of Britain and Ireland Virtual Conference 2021, presented virtually on 17/09/2021

‘What are Patients’ Experiences of Cannulation for Haemodialysis? Developing and Piloting the Patients’ Perspectives of Needling Questionnaire’, Vascular Access Society of Britain and Ireland Virtual Conference 2021, presented virtually on 17/09/2021

2.1.4 Conference Posters

‘What are Patients’ Experiences of Cannulation for Haemodialysis? A Qualitative Systematic Review’, UK Kidney Week Virtual Conference 2020

‘Development of a Questionnaire to Capture Patients’ Experiences of Cannulation for Haemodialysis’, UK Kidney Week Virtual Conference 2020

‘What are Patients’ Experiences of Cannulation for Haemodialysis? Developing and Piloting the Patients’ Perspectives of Needling Questionnaire’, UK Kidney Week Virtual Conference 2021 with moderated session on 07/10/2021

2.1.5 Awards

Second place in Sue Watson Oral Presentation Event, University of Nottingham

Gold Award by Vascular Society of Great Britain and Ireland

3 Abbreviations

AKI – Acute Kidney Injury

AV - Arteriovenous

CCA – Constant Comparison Analysis

CI – Confidence Interval

CINAHL - Cumulative Index of Nursing and Allied Health Literature

CKD – Chronic Kidney Disease

CVC – Central Venous Catheter

D-FIQ - Dialysis Fear of Injection Questionnaire

ESKD – End Stage Kidney Disease

GT – Grounded Theory

HRA – Health Research Authority

HDF - Haemodiafiltration

ICE-HD – Investigating Cannulation Experience in Haemodialysis

ID - Identification

IQR – Interquartile range

JBI – Joanna Briggs Institute

JBI-QARI – Joanna Briggs Institute’s Checklist for Qualitative Research

MAGIC – Managing Access by Generating Improvements in Cannulation

NHS – National Health Service

POCUS – Point of Care Ultrasound

PPN – Patient’s Perspective of Needling Questionnaire

PPN v1 - Patient’s Perspective of Needling Questionnaire Version 1

PPN v2 - Patient’s Perspective of Needling Questionnaire Version 2

PREM – Patient Reported Experience Measure

PROM – Patient Reported Outcome Measure

RCT – Randomised Controlled Trial

RRT – Renal Replacement Therapy

SF-VAQ – Short Form Vascular Access Questionnaire

SD – Standard Deviation

T1 – Time 1

T2 – Time 2

UK – United Kingdom

UK GDPR – UK General Data Protection Regulation

VAQ – Vascular Access Questionnaire

VAS – Visual Analogue Scale

VASQoL – Vascular Access Quality of Life Questionnaire

4 Glossary

Area Puncture – A cannulation technique where cannulation sites are ad hoc, rather than systematic and planned. Patients are cannulated in a similar place over a small area each time, but not in exactly the same place.

Anastamosis – the name for the anatomical joining of two structures, normally initiated through surgery. In the context of this thesis, the artery and vein are joined together to create arteriovenous access.

Arteriovenous access – the combined name including both arteriovenous fistulas and grafts.

Arteriovenous fistula – a blood vessel used for haemodialysis, created by joining an artery and vein together through an anastomosis.

Arteriovenous graft – an artificial tube inserted between an artery and vein that is normally used to provide blood supply for haemodialysis.

Brachiocephalic fistula – an arteriovenous fistula where the brachial artery and cephalic vein are joined together at the elbow

Brachiobasilic fistula – an arteriovenous fistula where the brachial artery and basilic vein are joined together in the elbow or upper arm

Buttonhole – a cannulation technique where the needle is inserted into exactly the same place each time. Therefore, the scab from the previous cannulation has to be removed before the next cannulation.

Cannulation – the insertion of needles into a blood vessel.

Cannulator – the person performing the cannulation

Central Venous Catheter - a catheter is inserted into a central vein for use for haemodialysis. For haemodialysis, these are normally tunnelled, sitting in a subcutaneous tunnel underneath the skin before entering the circulation.

Haemodialysis – an extracorporeal therapy used to replace the functions of the kidneys during end stage kidney disease.

Infiltration – where the needles punctures the wall of the blood vessel but then continues through the back wall of the blood vessel, leaving the tip of the needle sitting in the tissues not the vein. When this happens with AV access, this can often be called a *'blow'.*

Radiocephalic fistula – an arteriovenous venous fistula where the radial artery is joined to the cephalic vein, normally at the wrist or lower arm

Rope ladder – a cannulation technique where the needles sites progress up the vessel systematically, moving up 0.5-1cm each time.

Vascular Access – access to the circulation created for the purposes of haemodialysis.

5 Table of Contents

6 Table of Figures

7 Table of Tables

1 Chapter 1: Introduction

This thesis describes and discusses research exploring patients' experiences of cannulation for haemodialysis. As a registered nurse, with specialist knowledge and practice of haemodialysis, I have cannulated many patients. I have recognised the distress cannulation for haemodialysis creates, often providing reassurance and comfort through this procedure. This created a desire to improve cannulation for patients on haemodialysis, initially developing national recommendations and completing a national quality improvement to improve nurses' technical cannulation skills (Fielding, Oliver, Swain, Gagen, Kattenhorn, Waters, Graham et al., 2021; Fielding, Stronach, Roberts, Lahart and Brogan 2018a; Fielding, Glover and Kumwenda, 2016a). Throughout this and my day-to-day practice, I increasingly recognised that patients' experiences of cannulation were not optimised by solely developing nurses' technical skills, recognising a further need to also focus on improving other aspects of cannulation. However, whilst I could make assumptions about patients' experiences of cannulation for haemodialysis and what may improve this, I recognised I did not fully understand this. The research evidence detailing patients' experiences of cannulation for haemodialysis was also limited, with little recognition that this procedure is of concern for patients on haemodialysis. This PhD has provided me with an opportunity to scrutinise this element of practice, aiming to understand what patients' experiences of cannulation for haemodialysis are.

This introductory chapter initially further defines the aims and objectives of the thesis and research included within this. The second section describes the clinical context for the thesis, explaining the need for haemodialysis, what it is and how treatments are performed and the role of cannulation. The third section summarises what we currently know about patients’ experiences of cannulation for haemodialysis from existing studies, exploring my rationale for conducting the research within this thesis and exposing the gap in understanding patients’ experiences of cannulation for haemodialysis. The fourth and final section includes descriptions of relevant research methodology that span all three projects included in the thesis. Of note, the research within this thesis was conducted between April 2019 and July 2022. This period included the COVID-19 global pandemic, which impacted the conduct of this research and where appropriate this is discussed.

1.1 Aims of the Thesis

To define the thesis and research within it further, the following research aim, question, and objectives were developed:

- *Research Aim*: To understand patients’ experiences of cannulation for haemodialysis undertaken by healthcare professionals, from the patient’s perspective
- *Research Question*: What are patients’ experiences of cannulation for haemodialysis undertaken by healthcare professionals and how do we improve this?
- *Research Objectives*:

1) To systematically review current evidence to understand what we know already about patients' experiences of cannulation, form the patient's perspective
2) To develop and evaluate a robust patient reported outcome to measure patients' experiences of cannulation for haemodialysis undertaken by healthcare professionals, based on current understanding from research
3) To develop a deeper understanding of patients' experiences of cannulation for haemodialysis undertaken by healthcare professionals, including an exploration of factors that patients perceive influence their experiences of cannulation to understand how to optimise this, using a qualitative approach
4) To employ the new knowledge generated by this research to provide recommendations for both clinical practice and further research to help improve patients' experiences of cannulation for haemodialysis

Of note, this thesis focusses solely on cannulation for haemodialysis. Therefore, when the word cannulation is used, this means cannulation for haemodialysis unless clarified otherwise.

Using the word 'Understanding' in the aim of this thesis is a purposeful choice, taking the study beyond just describing patients' experiences of cannulation. Understanding in this context means 'you know how it works or what it means' (Collins, 2023) or it is 'knowledge about a subject, situation etc. or about how something works' (Cambridge University Press and Assessment, 2023). This implies understanding goes beyond description, understanding the intricate workings of a phenomenon. The aim of this thesis is to achieve this deeper understanding, not just describing cannulation experience, but understanding how different elements of the patient experience interact and affect each other, 'understanding' the whole experience. Of note, 'understanding' also focuses on what patients are experiencing in their own reality and understanding this from the inside, rather than observing and describing this from the outside. Therefore, this thesis focusses on patients' views of their experiences of cannulation, not what others' experiences are (e.g. healthcare staff) or what others believe are patients' experiences.

1.1.1 Three Research Studies to Understand Patients' Experiences of Cannulation for Haemodialysis

The aim of the thesis was achieved through three complimentary studies:

1) A qualitative systematic review exploring patients' experiences of cannulation for haemodialysis (Chapter 2)
2) Development and evaluation of a questionnaire to capture patients' experiences of cannulation (Chapter 3)
3) A qualitative semi-structured interview study to understand in-depth what factors that patients perceive influence their experiences of cannulation for haemodialysis (Chapters 4 and 5)

These three studies occurred sequentially (Figure 1), with each study building on findings from the previous study. However, later changes were made to Study 2, following completion of Study 3.

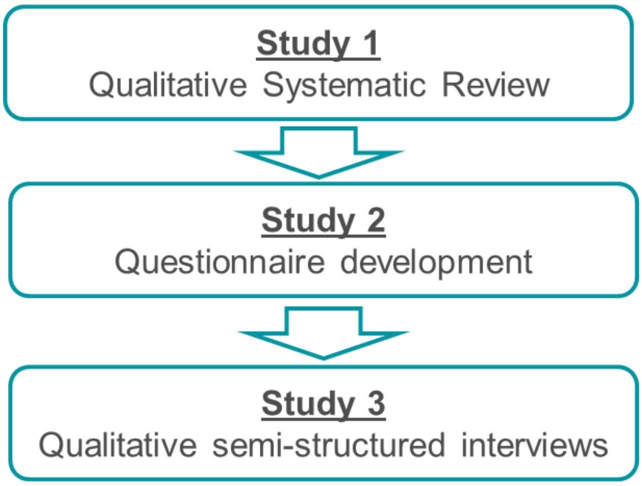


Figure 1: Sequence of studies within this thesis

The first study, the qualitative systematic review of patients' experiences of cannulation for haemodialysis, determines current understanding of this phenomenon from the patient's perspective, meeting Objective 1 of this thesis. This also identifies where gaps are in current understanding to provide a focus for future research. The second study, development and evaluation of a questionnaire to capture patients' experiences of cannulation for haemodialysis, achieves Objective 2. This aims to create a patient reported tool to be used in research designed to improve cannulation for haemodialysis, enabling this to be included as a valid outcome. This is based on the findings from the first study, but also provides further insights into patients' experiences of cannulation for haemodialysis from the patient's perspective. The third study explores what influences patients' experiences of cannulation for haemodialysis from the patient's perspective, considering that this is variable, but how this is variable is unknown. This aims to create deeper understanding of patients’ experiences of cannulation for haemodialysis, but also provide insights into what influences patients’ experience and thus how this can be improved, achieving Objective 3. Whilst Objective 4 is the most important objective, this does not have an individual study, but provides focus for the three studies already outlined. Each study generates recommendations for both clinical practice and research, ensuring that the findings are applicable to and influence future practice, meeting Objective 4. In combination, these studies will extend our understanding of patients’ experiences of cannulation for haemodialysis, providing insight into how we can improve this for the future.

Whilst each study is an individual research study, for the purposes of this thesis a mixed methods approach has been taken, where the results for each study are enhanced by the presence of the other studies. Mixed methods provide a more complex understanding of a phenomenon than qualitative or quantitative alone can provide (Shannon-Baker, 2016). Thus, this was considered the best way to explore and understand patients’ experiences of cannulation, adding depth to what appears to be a complex phenomenon. The first two studies utilise an exploratory sequential mixed methods design, where an initial qualitative study provides data that then contributes to the later quantitative study (Creswell, 2014). In this case the qualitative systematic review provides data for designing the questionnaire in the second study. The third study provides a further exploratory phase, where what is then known about cannulation is explored further to add greater understanding, making this a multi-phase mixed methods research

(Creswell, 2014). As well as building understanding through each subsequent study, the results of the three studies are examined together in the final chapter. Studies are explored for complementary and contradictory findings, strengthening the confidence in findings and generating recommendations for cannulation practice. The combination of these studies adds to our understanding of patients' experiences of cannulation. Therefore, this thesis is a collection of three research studies which aim to understand patients' experiences of cannulation for haemodialysis, using a mixed methods approach to build and extend our understanding of this.

1.1.2 Summary of Thesis Chapters

To achieve its aim and describe the three research studies that are part of this thesis, the thesis is divided into six chapters. The first chapter is an introductory chapter providing context to the research. As described earlier, it provides an explanation of the clinical context, a literature review of what is currently known in research about patients' experiences of haemodialysis, vascular access and cannulation and an explanation of the thesis, describing its content but also explaining methodological considerations relevant to the whole thesis. The second chapter describes the qualitative systematic review exploring patients' experiences of cannulation. This chapter provides a meta-aggregation from qualitative and mixed methods studies that have findings related to this phenomenon, with a diagram of how the themes generated interact to describe patients' experiences of cannulation. Chapter three outlines the development and evaluation of the 'Patient's Perspectives of

Needling' (PPN) questionnaire. This includes a description of the initial design of the questionnaire, and then testing its measurement properties. Chapters 2 and 3 follow a traditional research format, including the aim, rationale, methods, results sections with a discussion of the results. Both chapters conclude with recommendations for clinical practice and highlight gaps in knowledge for future research.

The next chapters describe the final research study, the qualitative semi-structured interview study to explore what influences patients' experiences of cannulation. This study uses elements of grounded theory to develop a deeper understanding of this phenomenon. These chapters are structured differently to chapters 2 and 3, due to the size of the study. Therefore, rather than describing the study in one chapter, the description is spread over the two chapters. Chapter 4 defines the aims of the study, providing an introduction, rationale and in-depth description of the methods used. There are many ways the results of semi-structured interviews could be interpreted and formed, and thus the methods used are important to describe in detail as they form the analysis produced. Chapter 5 describes the results from the semi-structured interview study, describing participant characteristics, the analysis of semi-structured interviews including a model of the components that create a patient that is coping with cannulation, with a discussion section which explores the results and strengths and limitations of the study. Chapter 6 summarises the results of all three studies, bringing the thesis to a conclusion. This chapter also explores the strengths and limitations of the thesis and identifies specific recommendations for future clinical practice and research in this area generated by all three research studies.

1.2 End Stage Kidney Disease, Haemodialysis, Vascular Access and Cannulation

Before starting to explore patients' experiences of cannulation for haemodialysis, it is important to understand the clinical context around this procedure. Therefore, this next section explores this. Haemodialysis is a life-sustaining treatment for people with end-stage kidney disease (ESKD). To be able to perform haemodialysis requires special access to the circulation, known as 'vascular access'. Some forms of vascular access require needles to be inserted before each treatment, known as cannulation. Therefore, the initial part of this chapter will explore what ESKD is, what dialysis is and why it is required, including haemodialysis, and the different forms of vascular access and cannulation.

1.2.1 End Stage Kidney Disease (ESKD)

Kidney disease is where the kidneys do not work as well as they normally would do. Different types of kidney disease include acute kidney injury (AKI), chronic kidney disease (CKD) and ESKD. These different types vary as to their severity and how long they last. AKI is considered a temporary loss of kidney function, where there is the potential to recover function with the correct treatment. However, if AKI lasts longer than three months, it is then classified as CKD (Kidney Disease Improving Global Outcomes Acute

Kidney Injury Working Group, 2012). Once CKD is diagnosed, whether it is caused by AKI or another cause, this means the damage to the kidneys is irreversible and will not recover.

The extent of kidney failure and how much function is lost, either temporarily in AKI or permanently in CKD, can vary. AKI has three stages, numbered 1-3, where kidneys function often moves between the stages as AKI progresses or resolves. Stage 3 is considered the worst stage of AKI and most likely to progress to CKD (Kidney Disease Improving Global Outcomes Acute Kidney Injury Working Group, 2012). CKD has five stages of classification, numbered 1-5, according to the level of kidney damage, again with a higher number indicating more damage to the kidneys. In CKD 5, the kidneys have less than 15% of normal kidney function remaining (Kidney Disease Improving Global Outcomes Chronic Kidney Disease Working Group, 2013). CKD 5 can progress to ESKD where the kidney function is negligible and must now be replaced to sustain life. This replacement of kidney function is known as renal replacement therapy (RRT), which includes a kidney transplant and different forms of dialysis.

In 2020, in the United Kingdom (UK) approximately 68,000 people were receiving RRT, with 35.4% (approximately 24,000 people) receiving in-centre haemodialysis and 2.0% (approximately 1,365 people) receiving haemodialysis at home (UK Renal Registry, 2022). Whilst this seems a small proportion of the UK population, it remains a significant number of people requiring RRT to replace their kidney function due to almost complete and irreversible kidney failure. This thesis focusses on patients on permanent haemodialysis, which automatically means it focusses on people with ESKD.

ESKD can be caused by numerous different diseases. These can include: diseases that put extra pressure on the kidneys (e.g. cardio-renal syndrome, hepato-renal syndrome); diseases that damage the kidneys directly (e.g. diabetes, hypertension, auto-immune conditions); cancers; infections of the kidneys (known as pyelonephritis); genetic conditions that often causes structural abnormalities to the kidneys or urinary tract from birth (e.g. Down’s syndrome, ureter structural abnormalities); and damage caused to the kidneys by things like medication, dehydration and obstruction of the urinary tract, which often start as AKI but can progress to CKD and ESKD. Within the UK in 2020, common causes of ESKD included glomerulonephritis (a group term for auto-immune disorders causing damage to the nephron) (19.6% of patients), diabetes (18.4%), polycystic kidney disease (an inherited genetic abnormality) (10.5%), pyelonephritis (9.6%) and hypertension (6.3%) (UK Renal Registry, 2022). However, in 14.4% of people, the cause of ESKD is still unknown (UK Renal Registry, 2022). Often the exact pathology of how diseases cause ESKD and why some people progress to ESKD whilst others do not, remains unclear.

When the kidneys are working normally, they perform various regulatory functions within the body to maintain homeostasis, where the conditions in the body remain optimal to sustain life and function. It does most of this by regulating the excretion of various chemicals and fluid in the urine. However, when the kidneys are not working well these regulatory functions become increasingly deranged, as the kidney function becomes worse. These regulatory functions are numerous, but include:

1) *Maintenance of the correct fluid levels* – the kidneys remove excess fluid from the circulation to ensure fluid levels are maintained at the optimal level throughout the body. If the kidneys are not working properly, fluid can build up in the body to dangerous levels, eventually affecting the function of the heart, both acutely but also over time, causing heart failure.
2) *Maintenance of the correct electrolyte levels in the blood and cells* – the kidneys remove from the body excess electrolytes obtained from food. Electrolytes need to be maintained at the correct levels for optimal body functioning. There are two electrolytes that are particularly important:
    a. Potassium – this affects how the muscles function, particularly the heart. If the levels of potassium are too high or low, then it can affect how the heart beats causing arrhythmias, cardiac arrest and death.
    b. Phosphate – this affects bone metabolism, also affecting calcium levels and the parathyroid glands. If phosphate levels are deranged for long periods of time (years), they can cause bone disease.

3) *Maintenance of the correct blood and cell pH* - for enzymes to function effectively, the body's fluids must remain within a strict pH range between 7.35-7.45, with derangement from this pH incompatible with life. Metabolism within the body releases acid, which then needs to be neutralised and removed to maintain the optimal pH.

The kidneys also excrete other waste products of metabolism – urea and creatinine. When the kidneys are not working properly, urea and creatinine start to accumulate in the body. High levels of creatinine do not affect how the body functions, but these are often measured in biochemical bloods tests to determine how effectively the kidneys are working. However, high levels of urea can cause distressing and life-threatening symptoms including itching, pericarditis (inflammation of the heart muscle), anaemia and clotting abnormalities causing bleeding. The kidneys are also involved in other functions including: secretion of erythropoietin to stimulate the bone marrow to create new red blood cells, which if absent causes anaemia; and activation of Vitamin D, which if absent further deranges bone metabolism.

In ESKD, the damage to the kidneys has reached the stage where regulatory functions are completely lost. This means RRT is required to replace these functions.

1.2.2 Dialysis

As mentioned previously, dialysis is a form of RRT. There are different forms of dialysis, which include:

- Peritoneal dialysis, where fluid is inserted into the peritoneal cavity to remove excess fluid, electrolytes, acid, urea and creatinine from the blood supply in the peritoneum (membrane around the organs in the abdomen). This fluid also contains bicarbonate which can be absorbed into the blood to neutralise excess acid. This fluid is refreshed every 4-6 hours via tube into the peritoneal cavity, known as a Tenckoff catheter.
- Haemodialysis, where the blood is removed from the body, excess fluid, electrolytes, acid, urea and creatinine are removed and the blood is then returned to the body. Again, bicarbonate is also added to the blood during the haemodialysis process, to neutralise excess acid. Haemodialysis requires an extracorporeal circuit, consisting of plastic tubes to transport the blood to and from a ‘dialyser’, where the removal of molecules is regulated through diffusion and pressure. The extracorporeal circuit also contains various safety features, including chambers to trap air, pressure monitors to detect problems with flow through the circuit and anti-coagulation to prevent clotting. Haemodialysis can be performed in renal centres, with seventy renal centres around the UK, or in the person’s home.
- Haemodiafiltration (HDF), is a type of haemodialysis which includes an additional fluid exchange within the extracorporeal circuit, which may increase the life-span of patients on haemodialysis, although the benefits are currently debated and under investigation (Blankestijn, Vernooij, Hockham, Strippoli, Canaud, Hegbrant, Barth, et al., 2023; Caskey, Procter, MacNeill, Wade, Taylor, Rooshenas, Liu et al. 2022).

This thesis focusses on patients who are on permanent haemodialysis, which includes HDF.

As mentioned previously, dialysis is used to replace the function of the kidneys. Whilst a kidney transplant can replace ‘native’ kidney function in a similar manner, dialysis struggles to fully replicate this. Firstly, dialysis only replaces some of the functions of the kidneys, with some requiring medication (e,g. erythropoietin secretion, vitamin D activation). Secondly, dialysis must regulate fluid and electrolyte levels, ensuring the excess is removed, but ensuring what is required by the body remains. This balance of the removal of some but not all fluid and electrolytes can be complex and difficult to achieve, causing unpleasant and life-threatening symptoms if this balance is not correctly maintained. Thirdly, dialysis itself can cause complications within the body that cause unpleasant symptoms like fatigue. It can also cause ill-health, particularly affecting the heart but also other organs. Fourthly, haemodialysis replicates in four hours, what the kidneys do in 48-72 hours often. This rapidity of the correction of fluid and electrolytes excess and removal of the waste products of metabolism can also cause unpleasant and life-threatening complications. This is not so much of a problem in peritoneal dialysis. Fifthly and finally, dialysis does not make the ‘native’ kidneys better, but only replaces some of functions of the kidneys. Therefore, dialysis has to be performed regularly and is a life-long commitment, which can only be stopped after kidney transplant. If regular dialysis is stopped then fluid, electrolytes, acid and waste products of metabolism increase to life-threatening levels rapidly, in a matter of days or weeks. Therefore, whilst dialysis can replace the function of the kidneys for those with ESKD, often prolonging life for decades, it is far from ideal and can be wrought with problems.

1.2.3 Vascular Access

As outlined above, haemodialysis requires access to the circulation to be able to remove and return the blood, so that the dialysis process can happen in the extracorporeal circuit. However, normal blood vessels are unable to sustain the flows required for haemodialysis. Therefore special ‘vascular access’ is required.

There are three common types of vascular access used for haemodialysis:

1) ***Arteriovenous (AV) fistula*** is an artery is joined to a vein, diverting the high blood flow and pressure from the arterial blood supply directly into the vein. This join of the artery and vein is known as the anastomosis and is normally small, solely enabling diversion of the blood flow from the artery to the vein. This arterialised vein, with higher arterial flow, then has two needles inserted (cannulated) for each haemodialysis session, one to remove the blood and one to return the blood.
2) ***AV graft*** is similar to an AV fistula but uses an artificial plastic tube to divert blood from the artery and the vein. There are two anastomoses, one at the artery and one at the vein. The artificial plastic tube is cannulated with two needles for each haemodialysis session.

3) ***Tunnelled central venous catheter (CVC)*** where a catheter is inserted into a central vein and remains in place for long periods (i.e. years). The catheter is dual lumen, allowing separate lumens to remove and return the blood. For haemodialysis, these are normally tunnelled, sitting in a subcutaneous tunnel underneath the skin before entering the circulation.

The type of vascular access used for haemodialysis is thought to impact patients' outcomes. AV access is currently considered the optimal form of vascular access for the majority of patients, although current guidelines on the type of vascular access used are re-focussing on patient choice and considering the patient's goals, alongside clinical outcomes (Aitken, Anijeet, Ashby, Barrow, Calder, Dowds, Fielding et al. 2023; Lok, Huber, Lee, Shenoy, Yevzlin, Abreo, Allon et al., 2020; Schmidli , Widmer, Basile, De Donato, Gallieni, Gibbons, Haage et al., 2018). AS this thesis focusses on cannulation, going forwards only AV access will be explored.

In 2020, within the UK, approximately 50% of patients on dialysis used AV access (estimated from UK Renal Registry, 2022). This is estimated as approximately 70% of patients on haemodialysis using AV access (approximately 17,000 patients), although no exact figures are available. However, it appears to be a significant number of patients using AV access for haemodialysis.

Within the UK, there are different types of AV access in use for haemodialysis. The type of AV fistula is normally denoted by the names of the two blood vessels joined together. AV fistulas in the arms use the radial or brachial artery and the cephalic or basilic vein. This provides three different types of common forms of AV fistulas:

- *Radiocephalic fistula* where the radial artery is joined to the cephalic vein, normally at the wrist. Whilst needles are normally inserted (cannulated) for haemodialysis wherever the vein lies, this is normally in the lower arm for these types of fistulas, although cannulation can progress onto the upper arm.
- *Brachiocephalic fistula* where the brachial artery is joined to cephalic vein, normally at the elbow. Needles are then inserted into the upper arm, on the outer (lateral) aspect, where the cephalic vein runs.
- *Brachiobasilic fistula* where the brachial artery is joined to the basilic vein. The basilic vein is often deep in the arm, so the anastomosis occurs in the upper arm, but the vein is often superficialised (raised nearer to the surface of the skin) to enable cannulation. Needles are inserted in the upper arm on the inner (anterior) aspect, where the basilic vein runs.

Whilst other combinations of vessels can be used in the arm, leg or even the torso, these are the most common type of AV fistulas.

AV grafts are less structured, being able to use any combination of artery and vein. Thus, they are often defined by their location rather than the blood vessels used. Commonly AV grafts are inserted into the upper arm, lower arm or upper leg, but again can also be inserted in the torso. AV grafts can run in a loop, as well as in a straight line. Needles are inserted wherever the plastic tube lies. On rare occasions, an AV graft can be used in combination with an AV fistula, to support parts of the vasculature that are too poor to support the AV fistula. This is a ‘hybrid’ between an AV fistula and graft.

Current research is also focussing on developing new types of AV access, to promote longevity, minimise complications and increase the number of options available to patients. This includes:

- Endo-AV fistulas where the anastomosis if formed using magnets to link together different blood vessel, to arterialise more than one vessel for cannulation (Mallios, Malik and Jennings, 2022; Wasse, 2022).
- Haemodialysis Reliable Outflow (HeRO) Graft, where an AV graft runs from the brachial artery in the arm to the right atria of the heart (Dengu, Hunter, Vrakas and Gilbert, 2021; Al Shakarchi, Houston, Jones and Inston, 2015)

Whilst these novel forms of AV access provide hope for improving vascular access for patients on haemodialysis, they have not been included in this thesis as their use is currently not established in practice but being evaluated in research.

In summary, vascular access provision for haemodialysis is complex process, with multiple options available for patients. AV access requiring cannulation is the main focus of this thesis. Therefore, this thesis will focus on established AV access.

1.2.4 Cannulation

To be able to use AV access for haemodialysis, needles need to be inserted into the AV access vein or graft at the start of each haemodialysis treatment. Two needles are inserted, one to remove blood and one to return blood. This process of inserting needles is known as cannulation and is performed by nursing staff in renal centres (also known as cannulators), informal caregivers or the patient themselves. These needles are then removed at the end of each haemodialysis session and re-inserted at the start of the next. This means that a patient on thrice weekly haemodialysis undergoes a minimum of 312 cannulations per year, making this a frequent procedure. To obtain the flows required for haemodialysis, the needles inserted are much larger than normal needles.

However, whilst cannulation is necessary to be able to perform haemodialysis using AV access, it is also associated with complications. Two scoping reviews found that pain, anxiety, inability to cannulate, multiple cannulation attempts, infiltrations, haematomas, bleeding, access infections, aneurysm formation, thrombosis and access failure were all complications associated with cannulation of AV access (Jaensch, Hill and Qunyan, 2019;

Harwood, Wilson and Goodman, 2017). When examining specific complication rates, Parissotto et al (2017) found 367 cannulations procedures out of 10,807 were associated with an acute complication (providing a rate of 3.4%). This study only looked at acute complications of haemorrhage, haematoma, infiltration or multiple cannulation attempts. Multiple cannulation attempts was the most frequent complication, causing 33.3% of complications (Parisotto, Pelliccia, Grassmann and Marcelli, 2017). Whilst the infection rate for AV fistulas is lower than CVCs, it is not completely absent, with one study quoting a rate of 0.11 infections per 100-patient months (95% CI 0.01-0.39) (Mohamed, Ali, Browne, O'Connell, Casserly, Stack and Hussein, 2019). This brief snapshot of the rate of complications from cannulation for haemodialysis demonstrates the large number of potential complications from this procedure.

One method of minimising or preventing complications from cannulation for haemodialysis, is to examine how the cannulation is performed. Parts of the procedure that can affect complication rates include: cleaning of the AV access prior to cannulation; selection of the correct cannulation sites through thorough assessment; a gentle and specific needle insertion to minimise infiltration and miscannulation; and use of needling techniques to minimise development of stenosis (Fielding, Spooner and Aitken, 2018b). Performing cannulation to minimise complications is complex, requiring investment in nursing staff who perform this procedure to develop this skill (Fielding et al, 2018b). A current national quality improvement project, ‘Managing Access by

Generating Improvements in Cannulation' (MAGIC) is looking to improve this within the UK (Fielding et al., 2021).

In summary, the importance of preventing complications from cannulation is clear. Whilst this thesis focuses on patients' experiences of cannulation for haemodialysis, this is not a separate phenomenon from complications or clinical outcomes. Clinical outcomes and complications remain important as they are likely to impact patients' experiences of cannulation, being part of this concept rather than separate from it.

1.3 What are Patients' Experiences of Cannulation for Haemodialysis?

So far, this chapter has briefly covered ESKD, haemodialysis, vascular access and cannulation, including the benefits and challenges of ESKD and its treatment. The next section will focus on patients' experiences of cannulation. Initially I will explore my own motivations for researching this subject and then progress to exploring the existing research in this area, providing a rationale for the subject of this thesis.

1.3.1 Reflection on my Experiences of Cannulation for Haemodialysis

My clinical experience initially highlighted that cannulation for haemodialysis is problematic for patients. Prior to my PhD, I was a haemodialysis nurse for 19 years and during this period I cannulated patients as part of my day-to-day practice. I observed that some patients seemed to tolerate cannulation with no concerns, whilst for others this was a procedure they struggled with. Some struggled with this initially and then found the procedure easier, whilst others continued to struggle with this throughout their time on haemodialysis, which can last years. The variability in cannulation experience both between individuals and within individuals over time was evident. When discussing research ideas with patients on haemodialysis, both through patient representative groups and individual patients, cannulation for haemodialysis was consistently raised as an issue of concern. Patients were very keen to encourage research that improved cannulation.

At the time, I initially focussed on how to improve the technical skill of nurses performing cannulation. This led to leadership of various national projects, including developing a set of recommendations on cannulation (Fielding et al, 2018a) and the Managing Access by Generating Improvements in Cannulation (MAGIC) project (Fielding et al, 2021) that implemented the recommendations. Whilst MAGIC led to improvements in cannulation skills in nurses, it was unclear whether this affected patients' experiences of cannulation. MAGIC included the Kidney Patient Reported Experience Measure (PREM) question on cannulation experience (Hawkins et al, 2022), to assess this. However, patients' did not relate to this question, often refusing to answer it and stating it did not consider their experience. This was later replaced with an unvalidated patient satisfaction question, which patients felt was more appropriate. This began to demonstrate the complexity of patients' experiences. For example one patient, discussed with me how cannulation was not purely about technical skill, but also her relationship with the person inserting her needles, the cannulator. This challenge throughout MAGIC reiterated the complexity of patients' cannulation experience that was not well known, also indicating measuring this was not necessarily straightforward.

I recognised further research was required into patients' experiences of cannulation for haemodialysis to fully understand the complexity of it and how to measure it. Understanding patients' experiences also provided a voice to patients who did not feel they were listened to. For example, patient representatives regularly expressed the noxious nature of cannulation, yet they felt this was not recognised within the healthcare system or by healthcare professionals. This reiterated the importance of viewing this from the patient's perspective.

It became evident cannulation could be considered a complex intervention. The Medical Research Council's (MRC) framework for evaluating complex interventions defines what are complex interventions (Skivington, Matthews, Simpson, Craig, Baird, Blazeby, Boyd et al., 2021a; Skivington, Matthews, Simpson, Craig, Baird, Blazeby, Boyd et al., 2021b). Cannulation meets these criteria in the following ways: complexity in the number of components involved; expertise and skill required to deliver the intervention; the interaction between cannulation experience and the context it occurs in. Key to the MRC's framework is understanding the intervention itself, to understand factors that may influence its application into day-to-day practice, thus creating meaningful research that has real world impact (Skivington et al, 2021a, Skivington et al, 2021b, O'Cathian, Croot, Duncan, Rousseau, Sworn, Turner, Yardley and Hoddincott, 2019). The research in this thesis aims specifically to understand a complex intervention from the patients' perspective, not evaluate it or develop a new intervention. At this initial stage of purely understanding an intervention from the patients' perspective, it is important the MRC's framework does not distract from investigating this subject in a manner that is meaningful for patients or introduce inappropriate assumptions or bias. Therefore, the understanding of cannulation which this thesis generates could help guide the focus and conduct of future research that aims to improve cannulation as a complex intervention. Thus, whilst this framework is recognised as relevant to designing and evaluating complex interventions, it is not used to structure this research.

These reflections led me to conduct research into patients' experiences of cannulation. Research on this topic is important for two key reasons. Firstly, it provides a voice to patients' who do not believe their experiences of cannulation are understood or recognised. Secondly, understanding patients' experiences of cannulation can lead to ways to improve this procedure. It is important to consider not just what patients' experiences are, but how we capture and measure this within research, so this can be included as an outcome in future research. Whilst the MRC's framework for developing and evaluating complex intervention has merit, it has not been used to structure the research in this thesis but is an important consideration for future research.

1.3.2 Research Findings

Studies specifically examining patients’ experiences of cannulation are sparse, with four small qualitative studies directly exploring this. Mafara, Magarey and Rasmussen (2016) explored cannulation experience in patients new to this procedure, interviewing six patients who underwent their first cannulation in the previous 3 to 12 months. They describe nine themes to explain patients’ experiences of cannulation of new AV access: Fear, Surrender, Bracing for the worst pain, Lifeline, Loss of control, You are just a number, Body invasion, Altered body image and Sense of hope. Whilst this study is illuminating about cannulation of new AV access, it is unclear whether some of the themes are truly related to cannulation or about the wider haemodialysis treatment. It can be seen there are commonalities between this description of patients’ experiences of cannulation and experiences of vascular access and haemodialysis. However, this study shows how cannulation is painful and alters body image, involves an interaction with the cannulator where the patient feels dependent, and creates a sense of hope by enabling a life-sustaining treatment.

Wilson and Harwood (2017) completed a qualitative study exploring what successful cannulation means, including seventeen patients on in-centre haemodialysis. This study explored what patients perceive as successful cannulation through semi-structured interviews. They developed four themes describing: an ‘Emotional response – pain and anxiety’, ‘A Friendly Nurse-Patient Relationship’, ‘Nursing Interventions / Technical Skills’ and ‘Impact of the Environment’. Whilst the focus of this is successful cannulation, pain and anxiety as problems were again highlighted, as were the interaction with the cannulator and the environment.

Da Silva, Gurgel, Escudeiro and Ferreira (2015) explored patients experiences of buttonhole cannulation, with interviews with fifteen patients on in-centre haemodialysis. Patients experienced less pain, felt safer and felt the appearance of their AV access was better with buttonhole cannulation in comparison to their normal cannulation (not defined whether rope ladder or area puncture). This engendered a feeling of well-being as they felt like their cannulation experience had improved (Da Silva et al., 2015). This study indicates that patients preferred buttonhole cannulation, as it appeared to improve cannulation from their perspective. However, whilst this study indicates the benefits of buttonhole cannulation for patients, due to its design it is difficult to truly determine whether buttonhole leads to better experience than other cannulation techniques.

Moore, Majeed-Ariss, Jayanti, Mitra, Skevington and Weardon (2018) explored patients’ experiences of self-cannulation in the home setting, interviewing eight male patients. Male patients were chosen as the home haemodialysis population is pre-dominantly male. They describe a central theme exploring ‘becoming a person who self-cannulates is a process’, with three super-ordinate themes of ‘gaining control’, ‘building confidence’ and ‘becoming the norm’. This study examines a more subtle part of patients’ experiences, exploring how patients learn to cope with self-cannulation as a difficult procedure to experience and perform.

Studies that have explored patients’ experiences of both haemodialysis and vascular access also reinforce some of these findings. The Kidney Patent Reported Experience Measure (PREM) (Hawkins, Wellsted, Corps, Fluck, Gair, Hall, Bushby et al., 2022) survey in the UK, found that cannulation was an issue of concern for patients on dialysis (Kidney Care UK and UK Kidney Association, 2022, 2021, 2020; Kidney Care UK and Renal Association, 2019, 2018). Cannulation problems and clotting of the vascular access were two problems patients identified as causing a ‘bad’ haemodialysis treatment (Kuo, Saran, Argentina, Heung, Bragg-Gresham, Krein, Gillespie et al., 2020). Specific problems related to cannulation found in studies include:

- Pain (Richarz, Greenwood, Kingsmore, Thomson, Dunlop, Bouamrane, Meiklem et al., 2021, Kuo et al, 2020; Kosa, Bhola and Lok, 2016; Taylor, Hanson, Casey, Craig, Harris and Tong, 2016; Axley and Rosenblum, 2012; Xi, Harwood, Diamant, Brown, Gallo, Sontrop, MacNab et al., 2011)
- Problems getting the needles in to be able to have haemodialysis (Kuo et al, 2020)
- Anxiety related to and fear of cannulation, especially related to who would cannulate them (Taylor et al., 2016; Casey, Hanson, Winkelmayer, Craig, Palmer, Strippoli and Tong, 2014).

Caey et al.’s systematic review concluded that cannulation for haemodialysis needed to improve (Casey et al, 2014).

These studies provide insight into patients’ experiences of cannulation for haemodialysis, indicating this procedure is problematic for patients. Patients experience pain, anxiety, altered body image and feelings of dependency related to their cannulation. The interaction with the cannulator and environment affects patients’ experiences but also adds complexity to understanding these experiences. However, these study findings do not provide a full or comprehensive description of this phenomenon, rather indicating that it is an issue of interest requiring further investigation.

1.3.3 Rationale for this Thesis

Cannulation is an important and significant procedure essential for haemodialysis with AV access. However, patients’ struggle with it and find it difficult to cope with. Patients feel their experience is not acknowledged and they express a strong desire to improve cannulation for haemodialysis. This appears not just about the technical skill of cannulation, but also about other elements of the whole cannulation procedure. Studies on patients’ experiences are sparse, with only four studies focusing directly on this. These studies indicate cannulation is associated with negative experiences and findings resonate with wider studies examining haemodialysis and vascular access experience. However, all the studies focussing specifically on cannulation are single centre studies, with small sample sizes even for qualitative studies. In addition, they do not explore the complete patient experience of cannulation, but only explore experiences of cannulation in sub-populations or one facet of the cannulation procedure. Therefore, further in-depth research is needed to fully understand patients' experiences of cannulation specifically from their perspective, which will hopefully lead to understanding of how this can be improved and made less problematic for patients.

1.4 Methodological Aspects relevant throughout the Thesis

Having explored the clinical context and rationale for the thesis, this next section describes the research methodology used in all the studies that from this thesis. Whilst these methodological elements are relevant and conducted in each research study, they are utilised in the same manner in the conduct of all three studies. Therefore, to prevent repetition they are described here rather than in the chapters relevant to each individual study. This section will explore the epistemological stance of the research within the thesis, the use of reflexivity to minimise bias from my own assumptions and patient and public involvement the research.

1.4.1 Epistemological Stance of the Thesis

Epistemology affects how an individual adopts and creates knowledge (Collins and Stockton, 2018; Carter and Little, 2007). Differing epistemological stances underpin different approaches to viewing the world and different research methodologies. Defining the epistemological stance defines how the research is approached and adds transparency to the position of the researcher within the research (Shannon-Baker, 2016). It is an essential part of designing and implementing qualitative research (Wener and Woodgate, 2013; DeForge and Shaw, 2012). However, as all research is about creating knowledge, mixed methods studies have recently moved to discussing and defining the epistemological stance (Shannon-Baker, 2016), with some believing it is an integral part of all research (Creswell, 2014). Therefore, this section describes the epistemological stance of the whole thesis, which is pragmatism.

Pragmatism assumes that the world view is created by actions, situations and consequences (Creswell, 2014). It creates a preference to focus on experiences and consequences rather than an existential reality or truth (Creswell, 2014; DeForge and Shaw, 2012). Thus, pragmatic research becomes outcome orientated and focussed on the nature of experiences, exploring consequences, rather than aiming to describe reality (Kelly and Cordeiro, 2020; Shannon-Baker, 2016; Cherryholmes, 1992). This focus on experiences is congruent with the research aim, exploring the consequences of cannulation (i.e. what patients' experience because of cannulation). The importance of this focus becomes clear in section 3.1.4, where the purpose of the PPN questionnaire is defined. Pragmatism also accepts that there may be multiple perspectives to a problem or concept and research should focus on perspectives relevant to the community they wish to promote, rather than aiming to describe all perspectives (Cherryholmes, 1992). This allows the research to focus on patients' experiences of cannulation, rather than aiming to describe reality and explore others’ views that may diverge away from or dilute the impact of understanding patients’ experiences. Whilst pragmatism is often criticised for its simplicity, diversity and flexibility (Shannon-Baker, 2016; DeForge and Shaw, 2012), for this thesis it is an ideal approach that is congruent with the aim of the thesis.

Pragmatism also has other benefits for this thesis, in addition to being congruent with the aim. Firstly, pragmatism’s focus on practical experiences is congruent with my approach to work. I am often keen to ensure that the findings of research do not just extend knowledge but also impact clinical practice, an ethos of pragmatism which is not uncommon in the ‘doing’ nursing profession (DeForge and Shaw, 2012). Secondly, pragmatism is congruent with mixed methods research, focussing on using the best aspects of quantitative and qualitative methods to answer the research question (Shannon-Baker, 2016). This approach means the research question is answered in the best way possible rather using the methodology to frame how the question is answered, which may potentially diverge away from a meaningful and pragmatic answer. This further emphasises that pragmatism is ideal for this thesis.

1.4.2 Reflexivity

This research has a significant qualitative element, which requires the researcher to interpret the words of participants, being part of the research process, influencing the data collected and the analysis of this data

(Holloway and Galvin, 2017). Thus, whilst the researcher is part of the process, they may also inappropriately influence this process. Reflexivity is one technique used to promote trustworthiness and regulate the researcher's role within the research, ensuring findings reflect participants experiences and views. This locates the researcher within the research and promotes self-awareness and self-monitoring, using critical reflection to ensure their influence on the research is not driven by their own biases and assumptions (Holloway and Galvin, 2017). The researcher uses reflexivity to balance subjectivity and objectivity, ensuring they are a constructive part of research (Shannon-Baker, 2016). Therefore, two techniques have been used throughout this thesis to promote reflexivity. Firstly, an exploration of the researcher's current background, so that her position and influence on the research is transparent. Secondly, to promote self-awareness and critical reflection, a reflexive diary was used throughout the thesis.

1.4.2.1 Researcher's Background

As mentioned previously, I have been a haemodialysis nurse for 19 years before the commencement of this PhD. I worked in various roles on the haemodialysis unit, including that of registered nurse, senior sister and clinical educator. All of these roles involved cannulating patients, with the clinical educator role including teaching new cannulators how to cannulate. Throughout my clinical practice, I observed that cannulation is a difficult procedure for both patients and nursing staff, with both often anxious about the procedure. I developed great empathy for what patients went through with cannulation to be able to have haemodialysis. Therefore, I’ve become keen to promote good cannulation practice.

Whilst my own clinical practice partially forms my view of cannulation, my involvement and leadership of national projects to improve cannulation practice within the UK have also formed this. I created the first nurse-led national vascular access special interest group, which created, through consensus, a number of resources to improve cannulation practice (Gagen, Aitken, Glover, Kumwenda and Fielding, 2018; Fielding et al., 2016a). This work led a national quality improvement project called ‘Managing Access by Generating Improvements in Cannulation’ (MAGIC), which I led (Fielding et al., 2021). Through these projects, I had the opportunity to hear views of others on cannulation, both healthcare practitioners and patient representatives around the country. It was a humbling experience to recognise that my knowledge was not all encompassing or comprehensive, but that there were multiple ways to cannulate well and multiple beliefs from both patients and staff about what made good cannulation. This balanced my own view away from the local to a national perspective, facilitating recognition of the assumptions I bring.

As I had worked on the haemodialysis unit at one research site for a number of years, I also recognise that I had previously cared for and cannulated some of the research participants. I acknowledge this may influence what participants reflect on and disclose about their experiences of cannulation to me, as the researcher. To minimise this, participants were always reassured of the anonymity of findings and encouraged to be honest, being reassured I would not be upset by any of their responses. I avoided cannulating patients who were research participants. Whilst initially I tried to avoid any clinical contact with research participants, due to the COVID-19 global pandemic I was redeployed to work on the haemodialysis unit for two periods during completion of this thesis and also worked over-time for other periods. This meant my clinical contact with participants was more current than originally planned.

I also suffer with a chronic illness, that means I have received healthcare since I was a child, with multiple hospital admissions. Due to my experiences, I have always been keen to improve healthcare for those with chronic healthcare conditions and understand the challenges of leading a ‘normal’ life. I believe that due to my own ‘ill-health’ experiences I have developed some empathy with patients with chronic health conditions, understanding their frustrations. However, I am also aware that I cannot assume everyone feels this way but acknowledge everyone’s experiences will be individual.

My experiences are both a strength and weakness within this thesis. It has driven the subject of the thesis and eased the creation of relationships with both research participants and patient representatives. My background knowledge provides a context of understanding around the analysis and interpretation of data. However, it’s also important to recognise that this context means I bring assumptions about what patients’ experiences are and how to make them better. I do not believe it is possible or correct to bracket these assumptions, thus I endeavour to recognise these throughout this thesis, in my reflexive diary. I believe this helped to ensure findings reflected participants’ experiences rather than my own.

1.4.2.2 Reflexive Journal

Keeping a reflexive diary is the second strategy used throughout this thesis to promote reflexivity. The initial research design only included the use of reflexive diary to support qualitative interviews. Whilst reflexivity is traditionally performed during data collection and analysis, in reality the researcher’s assumptions and biases can influence the research process throughout, even in development of the research question (Chan, Fung and Chien, 2013). During this thesis, as the literature screening for the systematic review in Chapter 2 commenced, it became evident that my unrecognised assumptions had the potential to affect the process. Therefore, once I recognised this, a reflexive diary was maintained throughout this thesis, completed every one to two months. This diary followed the ethos outlined by Fischer (2009), recognising that full bracketing was not possible but also not always appropriate. It catalogued identification of my own biases and assumptions, the development of my views of cannulation and facilitated understanding of the phenomenon as it developed. On occasions, I discussed the content of my reflexive diary with supervisors, collaborators and patient representatives, to help identify solutions. These people sometimes identified that a solution was not needed, but that my own values and ideas added strength and quality to the research process, rather than being detrimental. On other occasions, the reflexive process within the diary enabled me to identify solutions on my own. This process helped to ensure findings were grounded in participants' views, not my own biases and assumptions.

1.4.3 Patient Involvement in this Research

Patient and public involvement in research is now considered an essential part of the research process. This is defined as working 'with' patients to develop research ideas and design, rather than implementing planned research to research participants (National Institute for Health Research, 2018). Within the UK, patient and public involvement is now considered essential to produce high quality research. They bring a different perspective of living with the specific illness or condition, which ensures the research remains embedded in what is important to patients, is conducted in a manner that is acceptable to patients and produces results that are meaningful to patients (Jackson, Pinnock, Liew, Horne, Ehrlich, Fulton, Worth et al., 2020; National Institute for Health Research, 2018; Staniszewska, Brett, Simera, Seers, Mockford, Goodlad, Altman et al., 2017). However, involving patient representatives in research can be problematic. It can be viewed as tokenistic, often because researchers do not understand how to facilitate patients' involvement in their research (Jackson et al., 2020). Researchers can also become confused between use of patients and qualitative research, using patient representatives' verbal quotes as data or research findings (Jackson et al., 2020; Pandya-Wood, Barron and Elliot, 2017). Therefore, the practical implementation of patient representation requires careful thought and consideration to be ethical and of value to the research.

To counter-act these problems, the involvement of patient representatives has been actioned in a careful manner, considering guidance from Pandya-Wood et al. (2017) and the GRIPP 2 checklist (Staniszewska et al., 2017). Some of the practical application of these frameworks has led to the following actions when working with patient representatives on this research study:

- Providing clarity on their role to patient representatives
- Taking a flexible approach, enabling patient representatives to express how meetings would work for them
- Involving patient representatives in discussions about how they are involved in the research, using their experiences to guide this
- Communicating to patient representatives the specific intent of the meetings beforehand, but then also being flexible within the meeting to explore what they felt was appropriate
- Starting each meeting with an update on current progress with the research, so patient representatives felt included and up-to-date
- Using language patient representatives are comfortable with
- Explicitly clarifying that research findings may have come from patients who they may (or may not) dialyse with, whilst maintaining

anonymity of research participants, and discussing how to be sensitive to this

- Sharing anonymous opinions and thoughts of other patient representatives, with their permission
- Transparency of the contribution of patient representatives in the reporting of this research

Whilst all patient representatives provided permission for their identity to be disclosed, their anonymity was maintained throughout, except to provide recognition of their contribution. Patient representatives were also excluded from being research participants and their views and opinions were taken as that, rather than research data.

During completion of the study, patient representatives provided:

- Assistance in development of the research aim, identifying what was important
- Feedback on the study design, particularly identifying:
    - Acceptable ways to conduct the study
    - What was important outputs of the research for patients
- Feedback on documents for use with study participants, with an element of co-writing these documents e.g. participant information sheets and consent forms
- Assisting in development of the questionnaire, including discussing changes and feedback from study participants (Chapter 3)

- Assisting in the development of the interview guide for the interview study (Chapters 5 and 6)
- Feedback on the analysis and codes for the interview study (Chapters 5 and 6)

Patient representatives had no direct involvement in the systematic review (Chapter 2).

Identification of individual patient representatives was done on a voluntary basis, approaching patients who had expressed a desire to support research to improve cannulation for haemodialysis, through clinicians or groups. Six patient representatives from two renal centres agreed to support the research within this thesis, who represented a mix of clinical backgrounds, gender, age and ethnicity. Involvement in the study was flexible with some patient representatives having periods where they could not contribute due to ill health. Unfortunately, three patient representatives passed away during completion of this research. However, these patient representatives were not replaced as adequate support was available from the remaining patient representatives. On occasions discussions were also hosted with the UK renal registry patient council, Kidney Care UK and local patient groups on the research question and design.

The majority of meetings with the six patient representatives were conducted on a one-to-one basis, as haemodialysis schedules made group meetings difficult. One-to-one meetings happened at a time and location of the patient’s choice, often either when they were on haemodialysis or at their home. However, following the start of the COVID-19 global pandemic in March 2020, all meetings were changed to remote meetings, either via telephone or video call depending on each patient’s preference. One-to-one meetings were staggered between individual patient representatives throughout the study to promote consistent patient involvement, whilst reducing burden for individuals. The frequency of meetings varied according to need, where at critical points in the study the frequency of meetings would increase and then decrease at other points. One group meeting was arranged on a Sunday, when no-one was on haemodialysis. In total 40 patient representative meetings happened throughout this research. All patient representatives were reimbursed for their time and travel expenses, with refreshment provided when appropriate, as advised in the UK (National Institute for Health Research, 2018).

1.5 Summary

This chapter states the aims of the thesis. It also provides an explanation of the clinical context of the thesis, demonstrating how cannulation is part of the wider procedure of having vascular access for haemodialysis. A brief review of current understanding of patients’ experiences of cannulation demonstrates the need for research in this area and a gap in current research. It also describes methodology relevant to all of the research studies included in this thesis. The next chapter will describe the first research study, the qualitative systematic review, exploring what is currently known about patients’ experiences of cannulation for haemodialysis.

2 Chapter 2: What are Patients' Experiences of Cannulation: A Qualitative Systematic Review

2.1 Introduction

In the previous chapter, the aim of the thesis was clarified and the research required to achieve this was outlined. The first step to achieve this is to fully explore what knowledge other research studies have generated previously about patients' experiences of cannulation. A systematic review that combines the results of research studies that explore this will enable synthesis of these findings into a description of this phenomenon. This chapter will describe what is already known in current research, identify gaps in knowledge and enable development of recommendations for future cannulation practice and research.

Included in this chapter is a description of the rationale for the systematic review, the methods used to conduct the review, the findings from the systematic review including a meta-aggregation of findings, and a discussion of findings, putting this into the context of the wider literature and discussing the application and limitations of these findings. This chapter concludes with a summary and recommendations generated by the review. Due to the methodology to complete a systematic review, this was not a study that could be conducted by a single person. Therefore, five collaborators were included in this study, who were later co-authors on the publication (Fielding, Bramley, Stalker, Brand, Toft and Buchanan, 2022b). However, I led the conduct of the systematic review which included: leading collaborator meetings; guiding collaborator involvement; developing the protocol; conducting the literature search; acting as first reviewer for screening, critical appraisal and data extraction on all articles; synthesising the results; and completing the CERQual assessment. Collaborators then acted as second reviewers during screening, critical appraisal and data extraction and reviewed and contributed to the content of the protocol, analysis and CERQual assessment.

2.2 Research Aim, Question and Objectives

To provide further focus for this systematic review, the following aims and objectives are outlined below. These link with the rationale for the study described in section 2.3.

Research Aim (also Objective 1 of the thesis): To systematically review current evidence to understand what we know already about patients' experiences of cannulation, from the patient's perspective

Research Question: What is current understanding of patients' experiences of cannulation of AV access for haemodialysis, from their perspective?

Research Objectives:

1) To comprehensively and systematically identify current research findings on patients' experiences of cannulation for haemodialysis from their perspective

2) To synthesise current research findings into a model and broad description of current understanding of patients' experiences of cannulation for haemodialysis, from the patient's perspective
3) To provide understanding of patients' experiences of cannulation for haemodialysis from the patient's perspective, indicating where cannulation practice could improve (linking with Objective 4 of the thesis)
4) To identify gaps in current understanding of patients' experiences of cannulation from their perspective, to guide further research
5) To identify potential topics to be included in the development of the patient reported tool to measure their experience from their perspective, as described in Chapter 3

2.3 Rationale

Prior to completion of this review, two previous reviews were identified that provided insight into patients' experience of cannulation for haemodialysis:

- A previous systematic review highlights a number of issues related to patients' experiences of vascular access (Casey et al., 2014). 'Fear of cannulation' is a sub-theme within the 'Heightened vulnerability' theme in this review, with patients' experiencing anxiety and dread about pain from cannulation, the size of the needles and potential complications affecting their haemodialysis. This causes patients to be 'Wary of unfamiliar providers'. However, as this review focusses on broader vascular access experience, it does not explore cannulation in-depth, solely recognising it as a problem.

- A scoping review of qualitative and quantitative studies identifies common problems with cannulation including pain, inability to cannulate, clinical complications and fear (Harwood et al., 2017). However, this does not provide a detailed description or synthesis of findings, solely providing a list of problems associated with cannulation.

To add to this, individual studies described in section 1.3.2**Error! Reference source not found.** explore experiences of cannulation in sub-populations or parts of the procedure. However, they provide no full description of this phenomenon.

Therefore, a systematic review will identify findings related to patients' experiences of cannulation for haemodialysis and synthesise these findings into a broad and full description of this. Focussing on qualitative studies, enables the review to use findings directly related to patients' own descriptions of their experiences. A synthesis of a breadth of qualitative studies that explore experiences of cannulation, VA and haemodialysis enables findings from different studies to be drawn together, providing a fuller, in-depth description. This will increase understanding, focusing guidance on how to improve cannulation, but also identifying gaps in our current understanding that could guide future research.

2.4 Methods

2.4.1 Systematic Review Question

The question was developed using the PICo criteria of Population (P), phenomenon of Interest (I) and Context (Co), an accepted adaptation for qualitative reviews of the traditional quantitative PICO (Aromataris and Munn, 2020; Butler, Hall and Copnell, 2016). Therefore, the systematic review question is:

‘What are adults (18 years or older) with ESKD undergoing haemodialysis (P), experiences of cannulation of AV access (I), when undergoing haemodialysis in both in-centre and home settings (Co)?'

Beyond this question, further detail was provided for inclusion criteria to frame the screening and selection of studies, ensuring this remained focussed on patient’s experiences of ‘normal’ cannulation for maintenance haemodialysis.

The population was further clarified to include:

- Patients with typical AV fistulae and grafts used for haemodialysis placed in the arm or the leg, including early cannulation AV grafts
- Patients on regular HDF, as well as haemodialysis

Studies that focussed solely on the following populations were excluded:

- Patients under 18 years old

- Patients who required haemodialysis for acute kidney injury
- Healthcare staff perspectives

The phenomenon of interest was further clarified as experiences of cannulation as performed by registered and unregistered nursing staff, carers or self-cannulation. Studies exploring solely the following types of cannulation were excluded to maintain the focus on ‘normal’ cannulation for haemodialysis:

- Cannulation of other novel types of vascular access for haemodialysis that are not classified as AV access or are non-typical AV access e.g. HeRO grafts; endo AV fistulae; CVC insertion / cannulation; AV grafts not inserted into the leg or arm
- Use of ultrasound imaging to assist with cannulation of AV access
- Cannulation not for haemodialysis
- Studies evaluating a novel intervention to improve cannulation experience
- Cannulation performed by other healthcare professionals, other than registered or unregistered nursing staff

For the purposes of this review, patient experience was considered a broad concept that is not limited to any specific definition or assumption. This included any study that produced findings on patients’ experiences, views, perspectives or opinions of cannulation of AV access for haemodialysis.

The context of the study was further clarified as including in-centre haemodialysis patients at both main and satellite units, as well as patients on home haemodialysis.

Studies that used qualitative methodology were included. This included qualitative studies, the qualitative element of mixed methods studies, PhD theses and grey literature (as well as published studies). To meet this criterion, the study report had to include a description of the qualitative methods and analysis used, and findings with direct participant quotes to illustrate findings. However, the level of detail to describe this was not restricted, with included studies required to state a minimum of the name of methods and analysis technique used. If this detail was completely absent, the study was excluded.

Studies which met both inclusion and exclusion criteria (e.g. included both adult and paediatric populations) were included. Where possible, data were only extracted on the inclusion criteria, however for the majority of these studies there was no definition between included and excluded findings. There were no restrictions placed on the date or language of study publication. Non-English language texts were translated.

2.4.2 Protocol Development

A protocol was developed using PRISMA (Page, McKenzie, Bossuyt, Boutron, Hoffmann, Mulrow, Shamseer et al., 2021; Moher, Liberati, Tetzlaff and Altman, 2009), PRISMA-P (Shamseer, Moher, Clarke, Ghersi, Liberati, Petticrew, Shekelle et al., 2015) and ENTREQ (Tong, Flemming, McInnes, Oliver and Craig, 2012) as guidance to content. The Equator Network recommends PRISMA for reporting of systematic reviews (Page et al., 2021), PRISMA-P for reporting of systematic review protocols (Shamseer et al., 2015). ENTREQ is classified as an extension to PRISMA, providing guidance relevant for reporting of the synthesis of qualitative research (Tong et al., 2012). Whilst these guidelines provide a list of essential items that should be reported in systematic reviews when publishing results, PRISMA does recommend they are consulted during development of the systematic review protocol to ensure all essential elements are captured (Page et al., 2021). Whilst the 2009 version of PRISMA was used to develop this systematic review protocol (Moher et al., 2009), this has since been updated (Page et al., 2021). The content of the updated version remains relevant and congruent with how this review was conducted, therefore the updated version has been referred to. Once finalised, the protocol was registered on PROSPERO (PROSPERO ID Number: CRD42019134583) prior to commencing the systematic review.

2.4.3 Synthesis Methodology

The synthesis methodology used for this qualitative systematic review is meta-aggregation, as described by the Joanna Briggs Institute (JBI)

(Aromataris and Munn, 2020). Meta-aggregation is a methodology that encompasses the traditions of qualitative research whilst adhering to a structured process to conduct the systematic review. It uses an *a priori* protocol, a complete search of the literature, use of independent quality assessment of studies, standardised data extraction, an aggregation of findings from studies (rather than re-interpreting findings) and generates practical recommendations. This approach ensures the systematic review applies the rigour often associated with quantitative systematic reviews whilst embracing the differences of performing a qualitative synthesis. Meta-aggregation can include studies regardless of their individual epistemology, including both interpretative and critical studies. This inclusive approach meets the aims of the systematic review, enabling exploration of all studies, and is congruent with the epistemology for this review – pragmatism (as described in section 1.4.1).

Meta-aggregation also provides further benefits for this review, beyond its suitability for qualitative synthesis. Firstly, the complete literature search strategy ensures all relevant articles are identified and included, capturing a complete perspective of the current literature. Other qualitative synthesis methodologies do not use this complete approach, but use theoretical sampling, stopping the literature search when they believe they have fully explored the phenomenon (Tong et al., 2012). In a poorly understood area, as this review covers, this ensures a complete literature search rather than imposing assumptions about the limits of patients' experiences of cannulation. Secondly, there are many different studies that illuminate patients' experiences of cannulation. Studies exploring experiences of other aspects of haemodialysis provide qualitative evidence of experiences of cannulation, as this emerges as an issue for patients. Meta-aggregation encourages a broad and complete inclusion of studies rather than limiting inclusion solely by the subject of the study, which is of benefit to this poorly understood phenomenon. Finally, the aggregation of the original findings from studies, rather than re-interpretation of findings used by other synthesis methodologies (Tong et al., 2012) is of benefit. In this poorly understood phenomenon, it is important to focus on understanding what is currently known about patients' experiences of cannulation rather than re-interpreting current findings into something new. The review needed to uncover current understanding and synthesise this into one body of evidence.

Meta-aggregation's inclusive approach provides a sound base for this systematic review. As the subject of the review is currently not well understood, this approach enables a complete presentation of current understanding of patients' experiences of cannulation, without imposing limits.

2.4.4 Literature Search and Screening

A search strategy was developed prior to initiation of the search. Qualitative research can be harder to identify through database searches, as it is often indexed less clearly (Aromataris and Munn, 2020; Butler et al., 2016; Tong et al., 2012). Therefore, the search strategy was developed and completed in three stages, to enable a thorough search to be completed (Aromataris and Munn, 2020).

Firstly, a logic grid of keywords was developed to form the search strategy for databases (Aromataris and Munn, 2020; Butler et al., 2016). This was completed through awareness of common terms, but also used keywords from 15 known articles on cannulation for haemodialysis. Table 1 shows the logic grid developed. The terms from this logic grid were inserted into the thesaurus of Cumulative Index of Nursing and Allied Health Literature (CINAHL) database to create a more expansive search strategy (Table 2) (Aromataris and Munn, 2020). As the subject of the systematic review is a nursing procedure with a psycho-social consequence, CINAHL as a comprehensive nursing and allied health professionals database provided a good basis for development of search terms. The search strategy was piloted in CINAHL before finalising it, to ensure appropriate articles were identified.

Population	Phenomena – Cannulation of AV Access	Phenomena – Patient Experience	Study Type
Haemodialysis Hemodialysis Dialysis Renal replacement therapy Extracorporeal therapies Chronic Kidney Disease Chronic Renal Failure Kidney Disease End Stage Renal Disease	Vascular access Arteriovenous Arteriovenous access Arteriovenous fistula Arteriovenous graft Cannulation Needling Needle insertion Venepuncture	Patient(s) experience(s) Patient(s) preference(s) Patient(s) concern(s) Patient(s) satisfaction Patient(s) perspective(s) Patient(s) attitude(s) Illness experience(s) Quality of Life Pain Anxiety Fear Personal experience	Qualitative research Qualitative Qualitative study Mixed-methods research Mixed-methods Mixed-methods study Interview(s) Focus Group(s) Audio recording(s) Field notes Narration / narrative

Kidney Dialysis Renal Dialysis		Life experience(s) Lived experience(s) Coping Patient-reported outcomes Decision making	Grounded theory Phenomenol* Ethnograph* Thematic analysis Content analysis

Table 1: Logic grid of keywords to develop the search strategy

Population	Phenomena – Cannulation of AV Access	Phenomena – Patient Experience	Study Type
CINAHL Headings (explode) Dialysis Patients/ Hemodialysis/ Kidney Failure, Chronic/ Renal insufficiency/ Renal Insufficiency, Chronic/ Keywords – all fields H?emodialysis H?emodiafiltration End ADJ2 Renal Chronic ADJ2 Renal End ADJ2 Kidney Chronic ADJ2 Kidney	CINAHL Headings (explode) Vascular Access Devices/ Shunts,surgical/ Arteriovenous shunt, surgical/ Vascular Fistula/ Catheterization, Peripheral/ Venipuncture/ Insertion site selection/ Keywords – all fields “Arteriovenous fistula” “Arteriovenous graft” “Vascular Access” Arteriovenous ADJ2 fistula Arteriovenous ADJ2 graft Cannulate Cannulation Cannulated Cannulat*	CINAHL Headings (explode) Life Experiences/ Patient Attitudes/ Personal Satisfaction/ Attitude to Health/ Attitude to Illness/ Patient Preference/ Patient-Reported Outcomes/ Quality of Life/ Pain, Procedural/ Treatment Related Pain/ Pain/ Anxiety/ Fear/ Coping/ Decision Making, Patient/ Hyperalgesia/ Anticipatory anxiety/ Keywords – all fields “Patient experience” “Patient preference” “Patient satisfaction” “Patient perspective” “Patient attitude” “Quality of Life” Patient ADJ3 experience Patient ADJ3 prefer* Patient ADJ3 preference	CINAHL Headings (explode) Qualitative Studies/ Multimethod Studies/ Semi-Structured interview/ Unstructured interview/ Focus groups/ Audiorecording/ Field Notes/ Observational Methods/ Field Studies/ Narratives/ Grounded Theory/ Thematic Analysis/ Content Analysis/ Keywords – all fields Qualitative “Mixed method*” Mixed-method* Multi-method* Multimethod* Interview* “Focus Group” “Audio recording” Narration Narrative

		Patient ADJ3 satisfaction Patient ADJ3 perspective Patient ADJ3 attitude Quality ADJ3 life Pain Anxiety Fear “Personal experience” Personal ADJ2 experience “Lived experience”	“Grounded theory” Phenomenol* Ethnograph* “Thematic analysis” “Content analysis”

Table 2: Search Strategy for CINAHL

Secondly, the devised search strategy was applied to number of healthcare databases, outlined in Table 2. The following databases were searched:

- CINAHL
- EMCARE
- British Nursing Index
- PsychInfo
- Medline
- Pubmed
- EMBASE
- Latin American and Caribbean Health Sciences Literature

Duplicate articles from database searches were removed prior to screening. However, different published articles or grey literature of the same study were retained.

Thirdly, snowballing was also used to identify relevant articles (Aromataris and Munn, 2020; Butler et al., 2016; Tong et al., 2012). Reference lists were searched of any article identified during screening as having a relevant systematic literature search or any article included in the systematic review following full text screening.

Following identification of articles, two authors independently screened title and abstracts and then the full text using pre-set questions formed around the eligibility criteria. The results of each independent screener were reviewed and where differences occurred, these were discussed between the two screeners. Where they could not come to an agreement, a third person adjudicated the decision. All articles remaining after full text screening were included in the systematic review.

When completing the literature search, more non-English language articles were identified than expected. This meant not all non-English language articles could be translated at this stage. However, all these articles had an English language abstract that was screened at the title and abstract stage. Those remaining that required full text screening were reviewed by a native speaker who assisted in the screening process. The non-English language articles that were included in the systematic review were translated into English by a medical translation service for data extraction.

2.4.5 Assessment of the Quality of Studies

The JBI’s Checklist for Qualitative Research (JBI-QARI) (Joanna Briggs Institute, 2017) was used to perform an assessment of the quality of studies. There is much debate as to the role of quality assessment in qualitative systematic reviews (Aromataris and Munn, 2020; Butler et al., 2016; Tong et al., 2012). However, both ENTREQ and JBI recommend it. For this systematic review, the quality assessment of studies provided context for the data extracted from studies, identifying the quality of studies that formed the aggregation of findings. The quality assessment was also used in the assessment of accumulated findings. No studies were eliminated due to results of the quality assessment, as it was more important to gain a complete description of patients’ experiences of cannulation, rather than exclude studies based on quality.

The quality assessment was performed by two people for each study. Each assessor was blinded to the outcome of the other’s assessment until they had completed their assessment. Discrepancies between assessments were discussed and adjudicated in a group meeting. During this process, information on ethical approval was missing from some studies. Where this was missing, the study investigators were contacted for information on this process. Two study investigators could not be contacted, but this information was clarified for all other studies.

2.4.6 Data Extraction

A bespoke data collection form was developed (Appendix 1), using the JBI form as a guide (Aromataris and Munn, 2020). Data were extracted on:

- Study type and design
- Study population
- Any description of cannulation techniques used
- Findings and illustrations
- Any model / theory developed

The bespoke data collection form was piloted with two studies and then finalised, ensuring comprehensive data extraction. Data extraction was performed by two people for each study. Each data extractor was blinded to the outcome of the other's until they had completed their own data extraction. Discrepancies between data extraction were discussed and adjudicated at a group meeting.

2.4.7 Data Analysis

Data analysis followed the structure recommended for meta-aggregation, using the terms 'finding', 'illustration', 'category' and 'synthesised finding' to describe study findings. These terms are defined in JBI manual (Aromataris and Munn, 2020) as follows:

- A finding is 'a verbatim extract of the author's analytic interpretation of their results or data.'
- An illustration is 'a direct quotation of a participant's voice, fieldwork observation or other supporting data from the paper.'

- A category is ‘a brief description of a key concept arising from the aggregation of two or more similar findings in the presence of an explanatory statement that conveys the whole, inclusive meaning of a group of similar findings’
- A synthesised finding is ‘… an overarching description of a group of categorized findings.’

The three stages of data synthesis for meta-aggregation were followed (Aromataris and Munn, 2020):

1) Extraction of findings with one to three illustrations from each finding – this was part of the data extraction process and was incorporated into the data extraction form
2) Aggregation of findings into categories
3) Aggregation of categories into synthesised findings.

Aggregation of findings and categories were discussed at a group author meeting, before being finalised.

As the data analysis progressed it became evident that solely aggregating findings produced disparate categories. Findings were extracted from a broad range of studies, as explored in the results, often with themes within studies shaped by the aims and context of the study. For example, studies that explored home haemodialysis often shaped findings around barriers to self-cannulation. Solely aggregating findings appeared to produce division in categories that were enforced by the aims and context of included studies, not by patients’ actual experiences of cannulation. Whilst all included studies provided insights into experiences of cannulation, the context within which the findings were interpreted diverted our analysis away from this. Therefore, the analysis became more interpretative than is recommended by meta-aggregation, moving away from the original author's interpretation of findings. However, where they were appropriate, the authors' interpretations of findings were still used to form and assist in the analysis.

2.4.8 Assessment of Accumulated Findings

The final stage of the systematic review was to assess the strength of accumulated findings. The protocol defined ConQual as the tool to be used to assess the strength of accumulated findings. ConQual is designed to assess the outcome of a meta-aggregation, including the assessment of credibility where the original author's interpretation of findings is assessed for congruence with the supporting illustration (Munn, Porritt, Lockwood, Aromataris and Pearson, 2014). However, as our data analysis became more interpretative than expected, it became difficult to assess accumulated findings using ConQual. Therefore, the decision was made to use the 'Confidence in Evidence from Reviews of Qualitative Research' (CERQual) framework (Lewin, Booth, Glenton, Munthe-Kaas, Rashidian, Wainwright, Bohren et al., 2018).

The CERQual assessment was conducted following the guidance provided (Colvin, Garside, Wainwright , Munthe-Kaas, Glenton, Bohren, Carlsen et al. 2018; Glenton, Carlsen, Lewin, Munthe-Kaas, Colvin, Tuncalp, Bohren et al., 2018; Lewin et al., 2018; Munthe-Kaas, Bohren, Glenton, Lewin, Noyes, Tuncalp, Booth et al., 2018; Noyes, Booth, Lewin, Carlsen, Glenton, Colvin, Garside et al., 2018). This was completed by one assessor, with a second assessor reviewing the results of the assessment. The four stages were practically applied to each synthesised finding as follows:

1) Methodological limitations were assessed using the results of the quality assessment.
2) Coherence was assessed between each synthesised findings and the studies that contributed to it.
3) Adequacy of data assessed the richness and quality of data supporting each synthesised finding..
4) Relevance assessed the extent to which individual studies that contributed to each synthesised findings were applicable to the review question.

After each stage of the assessment, two authors determined the level of concern and level of confidence in each synthesised findings for each stage.

2.5 Results

2.5.1 Literature Search

The database search produced 246 records for review. Following removal of duplicates, 137 records remained. Title and abstract screening removed 66 records, leaving 71 records for full text review. Review of reference lists from those articles with systematic literature search (Harwood et al., 2017; Cowan, Smith and Chow, 2016; Casey et al., 2014; Morton, Tong, Howard, Snelling and Webster, 2010; Mendelssohn, Malmberg and Hamandi, 2009) and articles included in the systematic review (Table 3), identified a further 20 articles for full text review. This provided a total of 91 articles for full text review. Full text screening was completed on 90 articles, with exclusion of one dissertation in Portuguese. This dissertation was related to an included published article (Da Silva et al., 2015). Therefore, due to excessive costs for translation, the dissertation was not included but the published article was. Full text screening excluded a further 63 articles, leaving 27 articles to be included in the systematic review. Two included articles covered the same study. Both articles were included, but this was counted as one study, thus 26 studies were included in the systematic review. The results of the literature search and screening process are summarised in the PRISMA flow diagram (Figure 2).

2.5.2 Description of Studies

A summary of the description of studies is provided in Table 3. Only four of the included studies were directly about cannulation. The subject of other included studies were:

- Two studies about pain
- Seven studies about experiences of vascular access for haemodialysis
- Twelve studies about experiences of in-centre and home haemodialysis
- One study on research priority setting.

Whilst the breadth of studies was large, all included studies had individual findings about cannulation. Studies were set in a variety of countries covering five continents:

- Eleven studies from North America
- Three studies from South America
- Six studies from Europe
- Four studies from Australia
- Two studies from Asia

However, despite the varied locations of studies, themes around cannulation did not seem to vary with location, with the exception of Yodchai, Dunning, Savage, Hutchinson and Oumtanee (2014) who developed themes linked to religion in a Thai culture.

Of the 26 included studies, 21 were purely qualitative studies, two were a description of the qualitative element of a mixed methods study and three were a complete description of a mixed methods study. Only 13 of the studies described the type of qualitative methodology used with eight using phenomenology, two ethnography, two grounded theory and one described as mixture of ethnography and grounded theory. Interviews were the predominant data collection tool used, although two studies used focus groups to collect information.

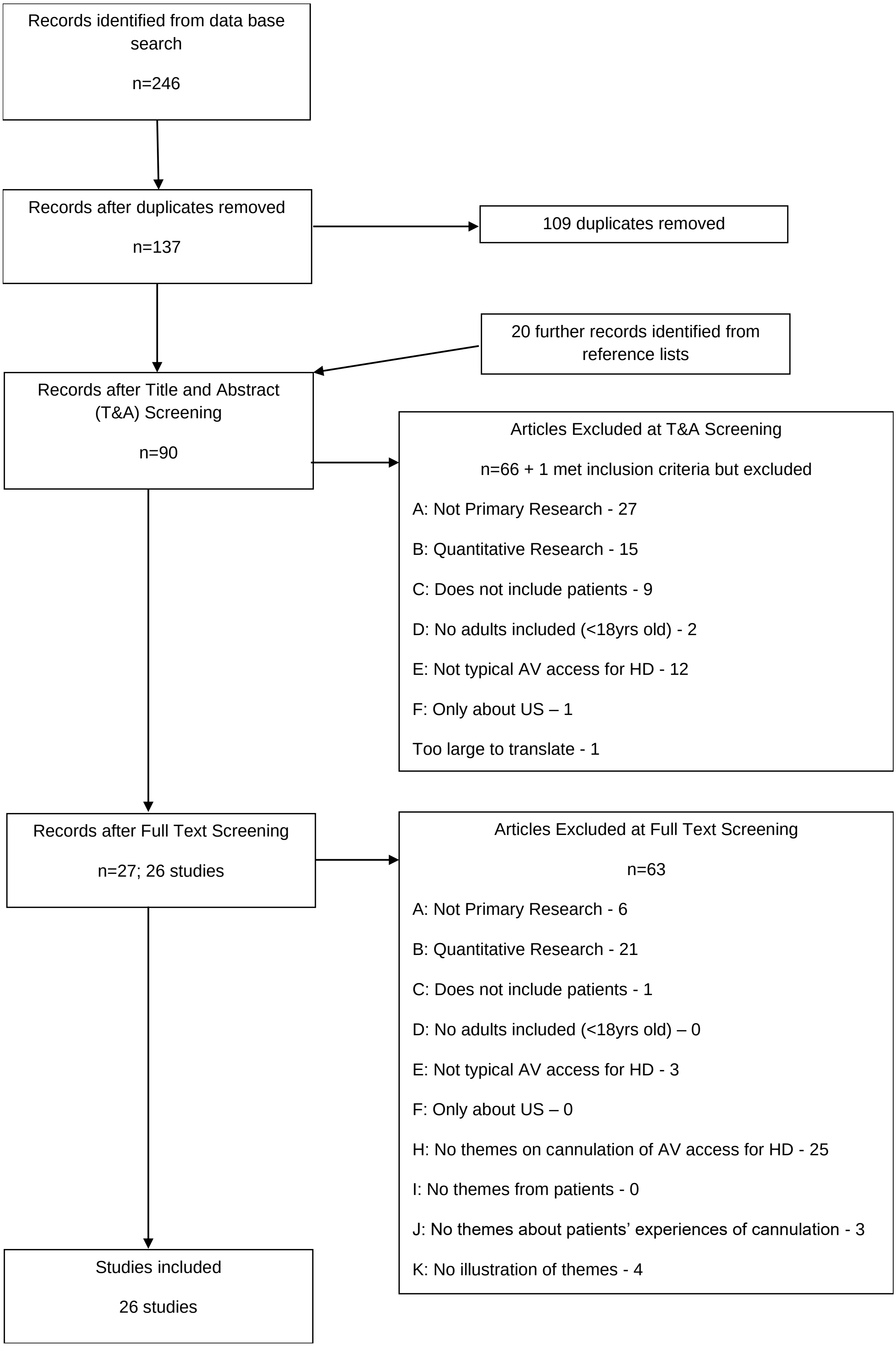


Figure 2: PRISMA Flow Diagram

Authors	County	Study Methodology	Sample Size	Population	Phenomenon of Interest	Cannulation	Data Collection Methods
Bourbonnais and Tousignant (2012)	Canada	Qualitative	25	Adult in-centre HD patient	Pain experience of patients on maintenance HD	Not specified	Interviews
Cafazzo et al. (2009, 2007)	Canada	Ethnography	13 HD (20 in all)	Adult in-centre HD and nocturnal home HD	Barriers to nocturnal HD	Not specified	Interviews
Da Silva et al. (2015)	Brazil	Qualitative	15	Adult HD patient	Buttonhole cannulation, as perceived by patients	BH, 6 converted from RL	Interviews
Da Silva et al. (2018)	Brazil	Report of qualitative part of a mixed methods study Social phenomenology	30	Adult in-centre HD patients	Experience of people using AVF for HD	RL	Unstructured interviews
Furtado and Lima (2006)	Brazil	Descriptive qualitative	21	Adult in-centre HD patients	AVF knowledge of HD patients	Not specified	Semi-structured interviews
Giles (2004)	Canada	Phenomenology	4	Adult home HD patients either dialysing at home or training in-centre	Life experiences of ESKD and having home HD machine	Not specified	Semi-structured interviews
Hagren et al. (2001)	Sweden	Interpretative qualitative design	15	Adult in-centre HD patients	Suffering from ESKD for patients on HD	Not specified	Semi-structured interviews

Hagren et al. (2005)	Sweden	Qualitative	41	Adult in-centre HD patients	How patients on maintenance HD interpret their life situation	Not specified	Semi-structured interviews
Hanson et al. (2017)	Australia	Mixed methods	20	Adult home HD patients training in-centre and then dialysing at home	Patients' perspectives of home HD training and transition period	Patient and carer cannulation	Interviews
Herlin and Wann-Hansson (2010)	Sweden	Phenomenology	9	Adult in-centre HD patients	30-45 years old experience of dependence on HD	Not specified	Interviews
Lima et al. (2016)	Brazil	Descriptive qualitative	28	Adult in-centre HD patients	Care of CKD patients towards their AV access	Not specified	Semi-structured interviews
Lin (2005)	Taiwan	Phenomenology	12	Adult in-centre HD patients	Experiences of making a decision about HD in Taiwanese patients	Not specified	Interviews
Mafara et al. (2016)	Australia	Interpretative phenomenology	6	Adult in-centre HD patients	Lived experience of cannulation of a new AVF in a satellite unit	Not specified	Interviews
Moore et al. (2018)	UK	Report of qualitative part of mixed methods study Interpretative phenomenology	8	Adult home HD patients	Experiences of self-cannulation of male HHD patients	Self cannulation	Semi-structured interviews
Piccoli et al. (2001)	Italy	Mixed methods	30	Adult home and in-centre HD patients	Advantages and disadvantages of daily HD	Not specified	Semi-structured interviews
Richard and Engebretson (2010)	US	Descriptive ethnography	14	Adult HD patients	How patients on HD negotiate living with an AVF	Not specified	Semi-structured interviews

Romyn, Rush and Hole (2015)	Canada	Interpretative descriptive qualitative	11	Adult in-centre HD patients	Experiences of patients on HD who had used a CVC and transition to AVF	Not specified	Semi-structured interviews
Sanz Turrado et al. (2017)	Spain	Phenomenology	7 1 focus group	In-centre HD patients	Factors that affect patients' satisfaction with nursing staff	Not specified	Focus group
Taylor et al. (2016)	Australia	Qualitative	26	Adult home and in-centre HD patients	Vascular access experience in both in-centre and home HD patients	Nurse, patient and carer cannulation	Interviews
Tong et al. (2008)	Australia	Qualitative	63 9 focus groups	Adult pre HD, transplant and dialysis patients	Patient priorities for health research into renal disease	Not specified	Focus groups
Wells (2009)	US	Mix of ethnography and grounded theory	12	Adult in-centre HD and PD patients, previously on HD	Lived experiences of ESKD for Mexican Americans and the effect on occupational deprivation	Not specified	Semi-structured interviews & video recording
Whittaker and Albee (1996)	US	Grounded theory	20	Adult dialysis patients	Dialysis modality decision making for patients with ESKD	Not specified	Unstructured interviews
Wilson and Harwood (2017)	Canada	Descriptive qualitative	17	Adult in-centre HD patients	What successful cannulation means to HD patients	Nursing cannulation	Semi-structured interviews and field notes
Wise et al. (2010)	US	Mixed methods - grounded theory	26 (13 dyads)	Adult home HD patients and their carer	Experiences of dyads who successfully perform short daily HD at home	Patient and carer cannulation	Semi-structured telephone interviews

Xi et al. (2011)	Canada	Phenomenology	13	In-centre HD patients	Patients decisions making in those who have refused an AVF	Not specified	Semi-structured interviews and field notes
Yodchai et al. (2014)	Thailand	Qualitative	20	Adult in-centre HD patients	How Thai HD patients perceive and manage pain and the effect of HD on pain	Not specified	Semi-structured interviews

Table 3: Description of Studies.

HD=Haemodialysis; PD=Peritoneal Dialysis; AVF = AV Fistula; BH = Buttonhole; RL = Rope Ladder

Authors	Qu 1	Qu 2	Qu 3	Qu 4	Qu 5	Qu 6	Qu 7	Qu 8	Qu 9	Qu 10	Total Yes's
Bourbonnais and Tousignant (2012)	U	Y	Y	Y	Y	N	N	Y	Y	Y	7
Cafazzo et al. (2009, 2007)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
Da Silva et al. (2015)	U	Y	Y	U	N	N	N	Y	Y	Y	5
Da Silva et al. (2018)	Y	Y	Y	N	N	N	N	Y	Y	U	5
Furtado and Lima (2006)	U	Y	Y	Y	Y	N	N	Y	Y	Y	7
Giles (2004)	Y	Y	Y	Y	Y	N	N	U	Y	U	6
Hagren et al. (2001)	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8
Hagren et al. (2005)	U	Y	Y	Y	Y	N	N	N	U	N	4
Hanson et al. (2017)	U	Y	Y	Y	Y	N	N	U	Y	Y	6
Herlin and Wann-Hansson (2010)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
Lima et al. (2016)	U	Y	Y	Y	Y	N	N	Y	Y	Y	7
Lin (2005)	U	Y	Y	Y	Y	N	U	U	Y	U	5
Mafara et al. (2016)	Y	Y	Y	Y	Y	N	U	Y	Y	U	7
Moore et al. (2018)	U	Y	Y	Y	Y	Y	Y	Y	Y	Y	9
Piccoli et al. (2001)	N	N	Y	N	N	N	N	N	U	N	1
Richard and Engebretson (2010)	Y	Y	Y	Y	Y	Y	Y	U	Y	Y	9
Romyn, Rush and Hole (2015)	U	Y	Y	U	Y	N	N	N	Y	Y	5
Sanz Turrado et al. (2017)	U	Y	N	N	N	N	N	Y	Y	Y	4
Taylor et al. (2016)	U	Y	Y	Y	Y	N	U	Y	Y	Y	7
Tong et al. (2008)	U	Y	Y	Y	Y	N	U	N	Y	Y	6
Wells (2009)	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8
Whittaker and Albee (1996)	U	Y	N	Y	Y	N	N	N	Y	U	4
Wilson and Harwood (2017)	U	Y	Y	Y	Y	N	U	Y	Y	Y	7
Wise et al. (2010)	U	Y	Y	Y	N	N	U	Y	Y	U	5
Xi et al. (2011)	Y	Y	Y	Y	Y	U	U	Y	Y	Y	8
Yodchai et al. (2014)	Y	Y	Y	U	N	N	N	N	Y	U	4

Table 4: Quality Assessment of Studies by JBI QARI checklist

Key: Y=Yes, U=Unclear, N=No
Qu 1 = Is there congruity between the stated philosophical perspective and the research methodology?
Qu 2 = Is there congruity between the research methodology and the research question or objectives?

Qu 3 = Is there congruity between the research methodology and the methods used to collect data?
Qu 4 = Is there congruity between the research methodology and the representation and analysis of data?
Qu 5 = Is there congruity between the research methodology and the interpretation of results?
Qu 6 = Is there a statement locating the researcher culturally or theoretically?
Qu 7 = Is the influence of the researcher on the research, and vice- versa, addressed?
Qu 8 = Are participants, and their voices, adequately represented?
Qu 9 = Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
Qu 10 = Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

2.5.3 Quality of Studies

The quality assessment of studies varied considerably and is summarised in Table 4. Most studies displayed congruity between the research methodology and the research question (present in 25/26 studies), methods used to collect data (24/26), data analysis (20/26) and interpretation of results (20/26). The most frequent limitations identified were a lack of: a stated philosophical perspective (absent in 16/26); statement locating the researcher (22/26); and the influence of the researcher on the research (22/26). Many of the studies were published in journals that did not traditionally publish qualitative research, so this may have been limited by the publisher rather than absent in the study. The only study that provided concern as to its quality was Piccoli, Bechis, Pozzato, Ettari, Alloatti, Vischi, Mezza et al. (2001) which did not appear to consider any rigorous application of qualitative methods despite labelling itself as mixed methods study with qualitative findings.

2.5.4 Patients' Experiences of Cannulation for Haemodialysis

Three synthesised findings and ten categories were synthesised from included studies, to describe patients' experiences of cannulation:

1) Cannulation is an unpleasant, abnormal and unique procedure described by categories of:
    a. Pain
    b. Abnormal appearance

    c. Vulnerability
    d. Dependency
2) Cannulation is necessary for haemodialysis described by categories of:
    a. What successful cannulation means
    b. Worry about success of cannulation
3) Surviving this unpleasant, necessary and repetitive cannulation described by categories of:
    a. Learning to tolerate cannulation
    b. Feeling safe
    c. Exerting control
    d. Avoiding cannulation

Each synthesised finding interacts with the others, influencing and altering the impact of each. Therefore, cannulation experience is one holistic entity, with three overlapping and influencing themes. Cannulation is part of the haemodialysis process and as such difficult to separate from this, thus happens within this wider context. The interaction of synthesised findings describing patients' experiences of cannulation is summarised in Figure 3.

The next sections shall describe each synthesised finding, with categories highlighted in bold. Quotes extracted from studies to illustrate these are shown in italics in the text.

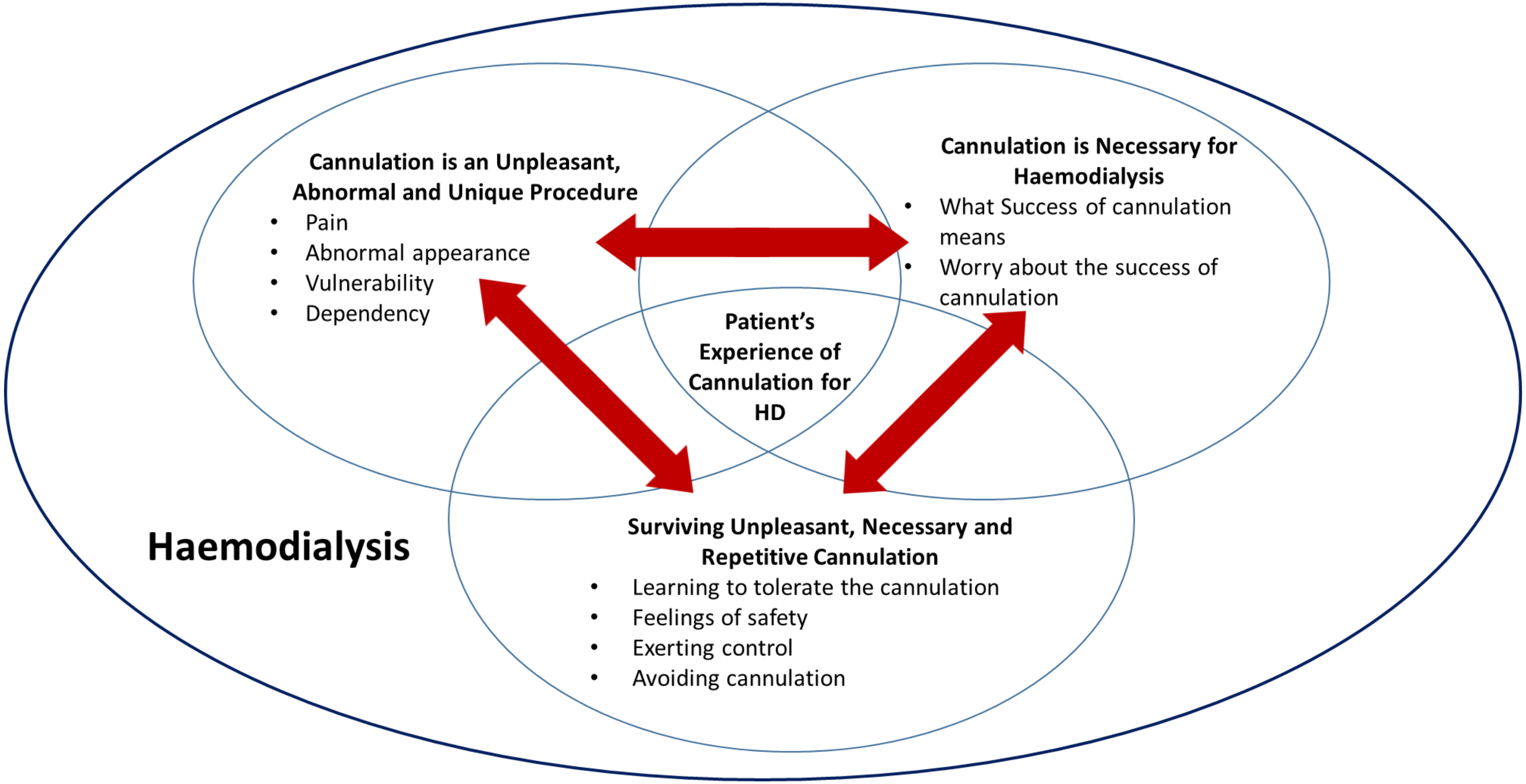


Figure 3: Patients' Experiences of Cannulation for Haemodialysis

2.5.4.1 Synthesised Finding 1: Cannulation is an Unpleasant, Abnormal and Unique Procedure

Cannulation creates unpleasant feelings and is not a normal procedure for patients to experience regularly: ‘*Cannulation is not normal, sticking a needle in. But my life depends on it. It’s just psychological. … Every time I get the needle ready I hear the music from Jaws.*’ (Hanson et al., 2017). It is associated with the categories of pain, concern about the abnormal appearance of the AV access, vulnerability and dependency. The context of regular haemodialysis makes this a unique procedure that is not similar to other one-off cannulation events.

Pain was regularly associated with cannulation: *‘Then I would feel the big needles being pushed in … I still feel pain when they [the nurses] hit a nerve, whoa that is painful.*’ (Mafara et al., 2016). Pain was a common theme in studies, but the extent of the pain and how much this affected individual patients varied. Whilst not all studies developed themes associated with pain, all acknowledged that cannulation was painful, which was evident in illustrations used throughout all synthesised findings. For some, the pain was short-lived or minor: ‘*It hurts, but it only hurts when the skin is punctured, after that, it doesn’t hurt anymore.*’ (Da Silva et al., 2015). However, it appeared that whilst some patients were not bothered by the pain now, patients often mentioned how this had improved over time, indicating this had been an issue at some point in the past: ‘*I used to dread coming to dialysis due to the fear of the painful needles but now I am getting better*’ (Mafara et al., 2016). For others pain progressed beyond the cannulation procedure or the pain was excessive: *‘How can these big needles not hurt when they pierce my skin huh? They are the biggest needles I have ever seen in my life ….*’ (Mafara et al., 2016).

Patients also worried about the **abnormal appearance** of their AV access, with cannulation creating scars, bruising and lumps:

‘*Only the deformation of my arm (...) my arm is covered in ugly cuts, covered in lumps* ’(Furtado and Lima, 2006).

‘It’s really awful because our veins become dilated, one arm is thicker than the other, and that bugs me a lot because of these lumps in my arm’ (Da Silva, Silva, Pereira, Ferreira, De Alcantara and Da Silva, 2018).

For some it was not just about how they felt about their appearance, but also how others reacted to it, thus they would try to cover their AV access when going out to hide the marks from cannulation: *‘I used to wear short-sleeves and now I wear long-sleeves because I don’t want people to see me with this thing here, this thing inside my arm, because you can see it…. Every time that I go out now, I gotta [sic] wear long-sleeve because I don’t want people to see my arm and say oh look at that guy what does he have in his arm, holes or what?’* (Wells, 2009).

The cannulation procedure itself induced feelings of **vulnerability** in some patients as they ‘*surrendered their arm to the nurse*’ (Mafara et al., 2016). They viewed it as a ‘*form of self-torture, self-mutilation*’ (Taylor et al., 2016), with the needle invading their body: *'I feel like the Bionic Woman. It's like that movie in which you have something strange in your body, and it bugs you. My looks bug me... My looks as a woman... the looks of the arm, which is ugly, those changes in the arteries.'* (Da Silva et al., 2018). How they were treated by the cannulator exacerbated this vulnerability: '*They should be concerned that you are a human being and that you're still alive. Instead, they come in there and punch you like you'd punch a tyre. They bruise you all over like that with no concern at all* ' (Whittaker and Albee, 1996). However, not all patients appeared to reflect this vulnerability which is later explored in Synthesised Finding 3: Surviving unpleasant, necessary and repetitive cannulation (Section 2.5.4.3).

Some patients felt the cannulation procedure created **dependency** on others. This was not viewed positively and emphasised their vulnerability: *'I have to depend on nurses to stick the needles in my arm … you know it just sucks to lose your independence and keep on wondering what the future holds for you ….*' (Mafara et al., 2016). However, this dependency was often viewed more positively if the cannulator was not a healthcare professional but a family member or friend: '*I couldn't do the cannulation. The fistula is in my left hand. I'm left handed. My husband did the cannulation and I would have to put the numbing cream on it because it hurt like hell and fortunately he was very good at it ... I can get on and off myself but this I needed him to help me...* (Cafazzo et al., 2009; Cafazzo, 2007)*.'*

2.5.4.2 *Synthesised Finding 2: Cannulation is Necessary for Haemodialysis*

Patients recognised that cannulation is essential for haemodialysis: ‘*I come here to live. That’s the short story. So whatever happens to me, thinking I am not going to like those needles put in, that is a fact.*’ (Wilson and Harwood, 2017). The cannulation ‘*keeps me alive. If it wasn’t for it, I wouldn’t be here*‘ (Da Silva et al., 2018). This link with a life-sustaining treatment changes what success means and leads to worry about whether it will be successful.

What does successful cannulation mean to patients? Wilson and Harwood’s study (2017) explored this concept directly and contributed heavily to this category. However, other studies also provided insight in this area. Success was getting the needle in easily with the minimum amount of pain, but also more than this, as the needles were then involved in delivering a successful haemodialysis treatment: *’If I get started on time, and they have no problems putting the needles in, and it only hurts initially like it always does, and then the pump starts up, and everything looks good. And then, I am ready for a nap, and that’s a good experience.’* (Wilson and Harwood, 2017).

Due to its link with haemodialysis, a life-sustaining procedure, patients **worried about the success of cannulation**. If the cannulation was difficult and thus not successful first time, patients ‘*feel like you didn’t get something done properly; you didn’t get the dialysis done properly*’ (Wilson and Harwood, 2017), viewing difficult cannulation as making their haemodialysis treatment less effective. They also worried that difficult cannulation could damage their AV access: *‘It is the feeling of fear, not really the pain ….. more that something would go wrong. The fistula would brake [sic].*’ (Herlin and Wann-Hansson, 2010). Patients also worried that the needle would not go in on the first attempt, which would lead to multiple cannulation attempts. It was often difficult for patients to cope with the pain, the uncertainty of whether it would be successful and the time the cannulation takes:

> *‘When he would do it [insert needles], it was...very uncomfortable because he couldn’t see the vein and here he would move, take it out, push it back in, take it out, push it back in a different way. And you know, that gets uncomfortable after a while...that needle, that big old nail going in and out... He blew up my arm which, what that means is that he would stick the needle in thinking that it’s going in the vein, but it’s going past the vein, going on the other side of the vein... And then the blood...well, right away when the machine starts up, it’s going to push the blood all the way on the other side, and it’s going to make a big old bubble on the inside of your skin. … the way I’m going, they’re going to kill my arm.’* (Richard and Engebretson, 2010)

> *‘I don’t want somebody poking at my arm every time I come here. . . I’ve seen one nurse will take forever to try and the next thing you know she’s got somebody else there trying so they’re poking at your arm.’* (Xi et al*., 2011)*

2.5.4.3 *Synthesised Finding 3: Surviving Unpleasant, Necessary and Repetitive Cannulation*

The necessity and link to haemodialysis, a life-sustaining treatment, created a need for patients to survive the procedure regardless of how unpleasant it is: *'I was very scared the first time, but now I can take it [needle insertion]*. *Otherwise I cannot be treated. It [needle insertion] saved my life; so I don't feel anything now. Well, it extends my life… If I don't do it [needle insertion] I get oedema and can be shocked. Pulling out water from my body is saving my life.*' (Yodchai et al., 2014). This theme illuminates how patients manage this unpleasant procedure not just once, but on a frequent and regular basis: *'I've learned to deal with it. I mean it's nothing nice, I wouldn't wish it on anybody because I mean who likes to get stuck 3 times a week, with big needles'* (Wells, 2009). This includes learning to tolerate the cannulation, feeling safe, exerting control and avoiding cannulation.

Patients often **learned to tolerate cannulation**, recognising it was an essential part of haemodialysis and describing becoming 'used to it': '*Because I've accepted I know … it's my way of life, it's how I'm going to live … It's just part of life.*' (Moore et al., 2018). However, this does not mean the procedure becomes more pleasant, but that they have to learn to tolerate the unpleasantness due to the necessity to have haemodialysis. For some, the cannulation remained '*exceedingly painful* ' (Yodchai et al., 2014), but they learned to '*bear the pain* ' (Yodchai et al., 2014) and tolerate the unpleasantness. For others the pain and procedure was more manageable: *'The needle punctures are only bothersome at first (...) after that, you get* *used to them.'* (Furtado and Lima, 2006). Some patients coped by reframing the stressor: '*Well I sort of get in the mindset that I'm going to the 'office' [his dialysis room] … Still slightly apprehensive that the needles won't work …. Slightly. But obviously it diminishes ….*' (Moore et al., 2018). However others continue to struggle with the cannulation:

'*I put my arm out, think of a tropical island, and try not to think about how scared I am'* (Romyn, Rush and Hole, 2015)

'They use bad needles and sometimes I get big balls [on my arm] and they have to go to the same spot and you just have to stand the pain' (Wells, 2009).

Some patients **exerted control** to help them survive the cannulation procedure. Self-cannulation was often a way to control cannulation. This enabled them to avoid problems with cannulation from others doing this badly: '*I trust myself rather than trusting somebody else going into the vein. I'm always worried they'll pop it [the vein]. But if it's yourself you feel it straight away and you can ease up a bit.'* (Hanson et al., 2017). Self-cannulation also provided patients with a sense of achievement, creating independence and self-efficacy: '*It's very good and you feel that you are independent, you don't need help from anyone else…. So, in that way you're sort of thing, you're not depending on someone else, or you're not depending on the hospital or anything, you're doing it yourself. So I think that is a very good thing'* (Moore et al., 2018).

Whilst self-cannulation was a way of exerting control, this also produced unique challenges for patients. Patients took time to learn how to self-cannulate, but felt it was worth persevering:

‘*I was thinking that I have to condition my mind, that nobody would do it for me. First time I was shaking but I said “why are you shaking? Nobody will do it for you. You have to do it yourself’* (Hanson et al., 2017).

‘They’ve got to go through this process of either being frightened of needles, or overcoming it, learning how to do it – and as I say that’s going to be a 6 month process’ (Moore et al., 2018).

‘As the time goes by, it seems a little by little, actually we somehow mastered [cannulation training].’ (Taylor et al., 2016)

However, patients who self-cannulated often still needed continuing support:

‘Like I say it’s very good for self- confidence … as long as I’m healthy, needling was no problem and everything was going well … it’s just when your health goes down and needling becomes a problem that you find confidence goes down … it’s been difficult every second or third time I can’t do it … so that’s why you lose confidence sometimes.’ (Moore et al., 2018)

‘My needles are fine. I can do that but I need somebody here to watch just in case I panic.’ (Hanson et al., 2017)

However, some patients were unable to overcome the challenges associated with self-cannulation: ‘*Interviewer - What didn't you like about the idea [of* *adopting NHD]? Patient - The barrier was putting in my own needles. Interviewer - That was the number one reason? Patient - That was the number one thing. Interviewer - So, that's interesting because you go through this three times a week and someone else is doing it for you. Patient - You become dependent. Interviewer - But you'd rather have someone else do it and look away than doing it yourself. Patient - Oh yes, it's fear. It's the fear of the unknown and the new situation.*' (Cafazzo et al., 2009; Cafazzo, 2007).

Patients recognised the necessity of cannulation, so wanted to feel safe in the cannulation procedure. **Feeling safe** was important and made the cannulation procedure easier for the patient to tolerate. The environment made patients feel safe: '*It's a nice environment here. I find it really comforting to be here.*' (Wilson and Harwood, 2017), as does the cannulation technique used: '*I came here to this clinic because I knew it used the buttonhole technique. This technique is the best.*' (Da Silva et al., 2015). A good team also often made the patient feel safer: *'Well, there is a good team here. There is good support, so if one nurse was having a difficult time, they would all rally and come to her aid, and I found that really comforting that I was getting good treatment.'* (Wilson and Harwood, 2017).

Whilst feeling unsafe was often due to problems with cannulation, the patient's relationship with the cannulator helped alleviate concerns, invoking feeling safe. Patients had '*more confidence in somebody that you know is going to do it well'* (Sanz Turrado, Perez, Dominguez, 2017). If the patients trusted the cannulator, they felt more relaxed and expected the cannulation to be better, being more tolerant of any problems encountered: *‘There are times when the supervisor or someone like him inserts the needle and you think it's like God for you at that moment and you say: uh! How good that it is his turn with us. And if that day he does it badly, and you say, well, if he has done it badly, imagine what the other one, that has never inserted it in me would have done.’* (Sanz Turrado et al., 2017). Whereas patients often worried if they did not trust the cannulator: ‘*I was in non-stop panic because she’d stuffed up my buttonhole, my access.*’ (Taylor et al., 2016). The cannulator could also do things to make patients feel safer: ‘*Just talking through it, I think that really helps. You know? I really do. It makes you feel more comfortable and makes you feel more confident in the nurse, and so it helps. It really does.*’ (Wilson and Harwood, 2017).

However, not all patients were able to cope with the unpleasantness of cannulation, leading to some **avoiding cannulation**. Some did this by reducing the frequency of haemodialysis: ‘*… and that is less time and that you’re getting cannulated 3 times, 3 out of 7 days as opposed to almost every day.*’ (Cafazzo et al., 2009; Cafazzo, 2007). Others felt ‘*it would be easier to do it having line access because of the way that the hookups work*’ (Cafazzo et al., 2009; Cafazzo, 2007). However, where possible some patients completely avoid haemodialysis due to the thoughts of the cannulation: *‘I’m a terrible coward when it comes to needles, so hemo[dialysis] wasn’t really even on the table for me.*’ (Wells, 2009).

2.5.5 Assessment of Accumulated Findings

The results of the CERQual assessment of accumulated findings are summarised in Table 5 and Table 6. There were some concerns about methodological limitations related to incongruency between the methodology and the research question, methods, analysis and / or interpretation of results. Concerns about coherence related to a lack of clarity of how conclusions of studies flowed from their results. In some studies, this was related to a lack of detailed description, so was difficult to determine. However, there also appeared to be a lack clarity about what was related to haemodialysis, what related to their vascular access and what related to cannulation. Whilst not all studies were about cannulation experience, there was often an assumption made that whatever was discovered was directly related to the phenomenon of interest of the study only. However, cannulation experience does happen in the context of haemodialysis. Therefore, studies do need to acknowledge this accepting they may not be able to differentiate between these experiences. Only one study acknowledged this (Moore et al., 2018). The adequacy assessment indicated there was a lack of richness of data represented, but this may have been limited by reporting guidelines of journals. In particular, the categories of vulnerability and feeling safe lacked richness in the data that supported them. The relevance category identified that some studies which influenced findings did include participants who did not have direct experiences of cannulation but had observed this in others, including carers performing cannulation or participants with CVCs who had previously had AV access. When we examined how many illustrations this influenced, this was minimal.

Whilst the CERQual assessment raised minor concerns about studies included, there was a consistency in findings across all included research studies that did not seem to vary with the methodological quality, coherence, adequacy or relevance of studies. This increased our confidence in findings and indicated the limitations identified had minimal effect on our findings, leading to moderate to high confidence in the accumulated findings.

Summary of Review Finding	**Studies contributing to Review Finding**	**Methodological Limitations**	**Coherence**	**Adequacy**	**Relevance**	**CERQual assessment of confidence in the evidence**	**Explanation of CERQUal Assessment**
Cannulation is an unpleasant, abnormal and unique procedure	Bourbonnis, Cafazzo (2009 and 2007), Da Silva (2018 and 2015), Furtado, Hanson, Lin, Mafara, Moore, Richard, Taylor, Wells, Whittaker, Wise, Xi, Yodchai	Minor concerns (5/16 studies lacked clarity on important methodological points)	Minor concerns (5/16 studies lacked clarity as to how conclusions flowed from the results analysis)	Minor concerns (5/16 studies lacked clarity on whether findings were representative of all participants.)	Minor concerns (8/57 illustrations (5/16 studies) had indirect or partial relevance)	Moderate confidence	Due to 'Minor concerns' for: • Methodological design • Whether conclusions flowed from the results analysis • Whether findings were representative of all participants • Relevance of findings.
Cannulation is necessary for haemodialysis	Cafazzo (2009 and 2007), Da Silva (2018), Giles, Hagren (2001 and 2005), Hanson, Herlin, Richard, Taylor, Tong, Xi, Wilson	No or very minor concerns	No or very minor concerns	Minor concerns (5/12 studies lacked clarity on whether findings were representative of all participants.)	Minor concerns (3/30 illustrations (3/12 studies) had indirect or partial relevance)	High confidence	-
Surviving unpleasant, necessary and repetitive cannulation	Cafazzo (2009 and 2007), Da Silva (2015), Furtado, Hagren (2005), Hanson, Herlin, Lima, Moore, Picoli, Richard, Romyn, Sanz Turrado, Taylor, Xi, Wells, Whittaker, Wise, Wilson, Yodchai	Minor concerns (6/19 studies lacked clarity on important methodological points)	No or very minor concerns	Minor concerns (8/12 studies lacked clarity on whether findings were representative of all participants.)	No or very minor concerns (4/75 illustrations (4/19 studies) had indirect or partial relevance)	High confidence	-

Table 5: CERQual Evidence Profile

Summary of Review Finding	Studies contributing to review finding	CERQual Assessment of confidence in the evidence	Explanation of CERQual Assessment
Cannulation of an unpleasant, abnormal and unique procedure	Bourbonnis, Cafazzo (2009 and 2007), Da Silva (2018 and 2015), Furtado, Hanson, Lin, Mafara, Moore, Richard, Taylor, Wells, Whittaker, Wise, Xi, Yodchai	Moderate confidence	'Minor concerns' for: • Methodological design • Whether conclusions flowed from the results analysis • Whether findings were representative of all participants • Relevance of findings.
Cannulation is necessary for haemodialysis	Cafazzo (2009 and 2007), Da Silva (2018), Giles, Hagren (2001 & 2005), Hanson, Herlin, Richard, Taylor, Tong, Xi, Wilson	High confidence	-
Surviving unpleasant, necessary and repetitive cannulation	Cafazzo (2009 and 2007), Da Silva (2015), Furtado, Hagren (2005), Hanson, Herlin, Lima, Moore, Picoli, Richard, Romyn, Sanz Turrado, Taylor, Xi, Wells, Whittaker, Wise, Wilson, Yodchai	High confidence	-

Table 6: Summary of Qualitative Findings

2.6 Discussion

This systematic review aims to explore patients' experiences of cannulation for haemodialysis, developing an in-depth description of this using findings from current studies. Synthesising findings from these 26 studies broadens what we know from individual studies, into one cohesive description. Using qualitative findings to do this, maintains the focus on what patients' feel and experience, rather than imposing healthcare professionals' assumptions and preconceptions by measuring a specific concept e.g. only pain. This approach gives us greater understanding of what current research tells us about patients' experiences of cannulation, highlighting how we can improve this for patients and indicating where future research is needed.

From our synthesis, we have identified that cannulation is an unpleasant, abnormal and unique procedure that is difficult to face. However, despite its unpleasantness, the necessity of successful cannulation for haemodialysis introduces extra emphasis on the procedure, creating worry about the success of the cannulation and whether multiple needle attempts will be needed. This necessity also drives a need to survive this unpleasant, repetitive procedure. Patients learn to tolerate the needle insertion and attempt to exert control over the procedure as a means to survive this. Feeling safe makes the cannulation easier to tolerate. Despite this, the procedure often remains unpleasant, which can lead to patients avoiding needle insertions. Whilst we previously knew that cannulation was associated with challenges, this aggregation of findings starts to fully describe the trauma cannulation can cause to patients, how the link to a life sustaining treatment exacerbates this and how patients survive this unpleasant procedure on a regular basis.

To meet the objective of this study, the discussion explores each of the synthesized findings, adding what might be known from other studies and extending our understanding of this. This exploration also identifies where cannulation practice could improve and gaps in our understanding that can guide further research. These gaps are summarised in recommendations at the end of this chapter.

2.6.1 Cannulation as Part of Haemodialysis

Our analysis has identified that cannulation is an inherent part of haemodialysis using AV access. Of the 26 included studies, only four were directly about cannulation for haemodialysis, with 19 included studies exploring the broader subjects of vascular access or haemodialysis experience. This demonstrates that cannulation is a part of broader experiences of having vascular access for haemodialysis and haemodialysis itself. Other studies beyond this systematic review also demonstrate this. Casey et al’s (2014) systematic review on patients’ experiences of vascular access for haemodialysis identified ‘Fear of cannulation’ as a sub-theme, which they stated was a key area of concern. Other studies have also explored patients’ satisfaction with their vascular access, using a validated questionnaire. They found patients with AV access were more likely to be bothered by symptoms associated with cannulation, namely the appearance of their access, pain, bruising and swelling (Field, Khawaja, Ellis, Nieto, Hodson and Inston, 2019; Kosa et al., 2016; Kosa, Bhola and Lok, 2015). Since completion of our systematic review, Kuo et al. (2020) completed a qualitative study exploring what patients believe to be a ‘bad run’ for haemodialysis. Again, cannulation was highlighted as one of four main issues for patients on haemodialysis, alongside cramps, ‘crashing’ and clotting. The consistency with which cannulation is highlighted in studies examining haemodialysis and VA experience indicates it is not just an inherent part of haemodialysis but is a pervasive issue that forms part of their haemodialysis experience.

2.6.2 The Unpleasantness of Cannulation

This systematic review has identified the unpleasantness of cannulation, which includes pain, abnormal appearance, feelings of vulnerability and dependency. Pain associated with cannulation was core to the unpleasantness theme. This concept has also previously investigated in quantitative studies not included in this review. These studies illuminate not just that pain is an issue, but the extent of this problem. Figueiredo, Viegas and Monteiro (2008), using a 10-point visual analogue scale (VAS) with 47 haemodialysis patients, found the overall pain score for cannulation was 2.7 out of 10 (Standard Deviation (SD) +/- 1.9). They concluded that the pain from cannulation was mild, however despite this still recommended that further effort should be made to reduce this pain. Aitken, McLellan, Glen, Serpell, MacTier and Clancy (2013) assessed pain in 461 haemodialysis patients using the 10-point VAS, but also the McGill's pain score. They found 24.4% of patients on haemodialysis experienced severe acute pain (defined as VAS score >5, with acute or chronic pain defined by the McGill pain score) and 3.2% experienced chronic pain with cannulation, indicating this was a frequent and severe problem. They believed pain from needling was often poorly recognised and under-reported. RCTs comparing buttonhole to rope ladder cannulation have also evaluated pain related to cannulation techniques, but meta-analysis of these studies failed to find a difference (Wong, Muneer, Wiebe, Storie, Shurraw, Pannu, Klarenbach et al., 2014). However, a lack of sensitivity to the methods used to measure pain (10 point VAS) alongside limitations in the way the RCTs were conducted, limits conclusions about the effect of cannulation technique on reports of pain (Fielding, Hadfield, White, Waters, James, Buchanan, Fluck and Selby, 2022a). Indications are that cannulation pain is a significant issue not just for individual patients, but also has a high incidence within the population.

However, within the studies included in this review the exploration of cannulation pain was surprisingly limited, lacking depth and avoiding descriptions, solely acknowledging pain from cannulation existed. There was no exploration within studies about whether pain varied and what this felt like for the individual patient. Future studies need to consider that cannulation is painful and we need to understand more about this pain rather than just accepting it happens.

This systematic review also found that unpleasantness is not just about pain, but included abnormal appearance, feelings of vulnerability and dependency. The previously mentioned systematic review into patients' experiences of vascular access (Casey et al., 2014) again provides additional insight into this. They found the invasive nature of vascular access and the risk of complications created emotional vulnerability. Fear of cannulation developed from anxiety about pain, the size of the needles and complications from cannulation that interfered with their ability to have haemodialysis. Dependency was created by having others needle you (Casey et al., 2014). Disfigurement from vascular access was a further theme within this review, with sub-themes around preserving normal appearance, avoiding stigma and having a visual reminder of the disease. These themes and sub-themes resonate with the systematic review described in this chapter, reinforcing the findings of this review, particularly around the unpleasantness of cannulation.

However, there remains a paucity of quantitative studies exploring other elements of unpleasantness other than pain. These elements of the unpleasantness of cannulation are complex concepts, so maybe harder to measure in quantitative studies, but these are also poorly recognised. Future studies that claim to measure patients' experiences of cannulation need to consider all the factors that contribute to the unpleasantness of cannulation, not just pain. The CERQual assessment of our synthesised findings highlights that vulnerability was a sub-theme that lacks depth of understanding and requires further exploration.

2.6.3 The Necessity of Cannulation for Haemodialysis

The necessity of cannulation and its link to receiving a life-sustaining treatment appears to have a significant impact on patients, causing them to have a heavy burden of worry about whether cannulation will be successful. Our findings indicate that unsuccessful cannulation can be a difficult procedure for patients to tolerate, increasing the trauma of cannulation both physically and psychologically.

In quantitative studies, unsuccessful canulation is often defined as ‘miscannulation’, where there is more than one attempt to insert either the arterial or venous needles or both needles. Despite the importance of avoiding miscannulation, it continues to occur frequently, happening in approximately 4% of haemodialysis treatments (Coventry, Hosking, Chan, Coral, Lim, Towell-Barnard, Twigg et al., 2019; White, Fielding, Rhodes, Chesterton, Fluck and Taal, 2018). One study found miscannulation was identified as the second most frequent harm event during haemodialysis (Fielding, Rhodes, Chesterton, Fluck, Lambe, Inacay and Taal, 2016b). During a six-month period, another study found that 31.5% of their patients on haemodialysis experienced at least one event of missed cannulation (Coventry et al., 2019). Whilst this often led to one further cannulation attempt, on occasions this led to three to six attempts to insert one needle

(Coventry et al., 2019). Cannulation of new AV access is particularly susceptible to miscannulation, with one study finding 37% of patients with new AV fistulae and 19% of patients with new AV grafts experienced more than 10 miscannulations (van Loon, Kessels, van der Sande and Tordoir., 2009). Only less than 5% of patients with new AV fistulae and approximately 30% of patients with AV grafts do not experience miscannulation (measured over a two-year period, with a minimum follow up time of 6 months) (van Loon et al., 2009). These findings demonstrate that miscannulation is a frequent event for patients using AV access for haemodialysis, particularly new AV access. In practice, miscannulation can be considered a ‘normal’ event, where healthcare staff accept it as inevitable. However, as our review highlights, miscannulation is traumatic for patients and efforts need focus on preventing this.

There is indication that use of ultrasound to guide cannulation may help reduce the rate of miscannulation or avoid it completely. This is often known as POCUS (Point of Care Ultrasound). A scoping review identified that POCUS was used for a number of reasons included increasing cannulation accuracy, performing new AV fistula cannulation and performing difficult cannulations (Schoch, Bennett, Currey and Hutchinson 2020). However evidence as to its efficacy is limited (Schoch et al., 2020). A few small RCTs have tested the use of POCUS in standard haemodialysis patients (Schoch, Bennett, Currey, Smith, Orellana and Hutchinson, 2022), patients with new AV fistulae undergoing cannulation (Kumbar, Soi, Adams, Brown Deacon, Zidan and Yee, 2018) and patients on haemodialysis with difficult to cannulate AV access (Eves, Cai, Latham, Leung, Carradice, Chetter & Smith, 2021). Currently sample sizes (10-32 patients) are too small to draw any definitive conclusions.

An observational study also found that miscannulation rates dropped from 15.5 per 1,000 cannulations to 4.9 per 1,000 cannulations after implementation of ultrasound guided cannulation (Luehr, 2018). Whilst this study observed approximately 1000-4000 cannulation events (numbers varied between the four stages of the study), only small numbers of individual patients were in the study (17-38 individual patients). They noted that miscannulation events seemed to cluster in individual patients, indicating that individual patients had a trend to no problems with cannulation or miscannulation. These results could have been influenced by the small numbers of individual patients within an observational study design. Therefore, this study still only suggests that POCUS may reduce the rate of miscannulation in individual patients, rather than provide definitive evidence. Interestingly, Coventry et al's (2019) observational study found that non-ultrasound use was associated with cannulation success. However, current practices only utilise ultrasound after cannulation difficulties rather than using it proactively to prevent cannulation problems. Therefore, this may be a reflection of practice patterns where POCUS is used to solve miscannulation after it has happened, rather than POCUS causing miscannulation.

Considering the trauma and frequency of miscannulation, if POCUS is shown to reduce this problem, then practice needs to change to using ultrasound pre-emptively to prevent problems, rather than retrospectively once problems have been experienced.

2.6.4 Surviving Unpleasant, Necessary and Repetitive Cannulation

Whilst patients may learn to survive unpleasant, necessary and repetitive cannulation for haemodialysis, this does not necessarily mean cannulation improves but that they learn to tolerate cannulation out of necessity for survival.

Control appears to improve patients' experiences of cannulation. Four studies included in our review specifically explored home haemodialysis (Hanson et al., 2017; Wise, Schatell, Klicko, Burdan and Showers, 2010; Cafazzo et al., 2009; Cafazzo, 2007; Giles, 2004), generating themes around self-cannulation, with two further studies exploring self-cannulation directly (Moore et al., 2018; Taylor et al., 2016). SHARED HD is cluster randomised controlled trial that aimed to promote and evaluate patient involvement in their haemodialysis care (Fotheringham, Barnes, Dunn, Lee, Ariss, Young, Walters et al., 2021). This promoted ten self-care activities for patients on haemodialysis, including setting up the equipment for cannulation and inserting their own needles (Fotheringham et al., 2021). This demonstrates one way that patients can have control and become involved in cannulation.

However, this study did not have any impact on patients’ quality of life (Fotheringham et al., 2021).

Whilst it is tempting to believe that self-cannulation will improve cannulation experience for many patients and should be promoted, our review indicates that self-cannulation is also difficult to achieve. The benefit of self-cannulation is only found in studies that explored experiences of patients’ who self-cannulate. Thus, it is difficult to know if these benefits would translate to patients who do not self-cannulate. However, control during cannulation is also evident in non-self-cannulation (Richard and Engebretson, 2010). Controlling who cannulates you or where they cannulate could be a form of gaining control over the procedure. The ‘BRS and VASBI Needling Recommendations’ for the UK, describe the many different ways patients can become involved in cannulation and also how a gradual process of learning parts of the procedure may allow patients to eventually self-cannulate (Fielding et al., 2018a). Whilst it is good to promote self-cannulation, when it is not possible, we need to think beyond self-cannulation, considering how the patient could be involved in cannulation and how the dynamic between the cannulator and canulatee can promote the patient feeling in control.

Feeling safe can also make cannulation easier to tolerate, with the cannulator, environment and cannulation technique particularly influencing this. Whilst there is broad acceptance that cannulation varies with different cannulators, there is a paucity of studies exploring this variation or how we can reduce this and promote ‘good’ cannulators. Harwood, Wilson and Oudshoorn (2016) conducted a qualitative study with nurses, to identify what led to successful cannulation. They found this went beyond just technical skill, including patient-centred care, teamwork and the cannulator’s self-awareness of their own skill in cannulation. Our review reflects this, where the attitude and communication of the cannulator can improve or adversely affect the patients’ experiences. Training of cannulators needs to consider not just the development of the technical skill to be able to cannulate, but also the social interaction during cannulation.

The environment also plays a part in patients feeling safe, which was a theme within one study included in the review (Wilson and Harwood, 2017). This identified that a calm, relaxed environment improved patients’ experiences of cannulation, whereas a chaotic environment had the opposite effect (Wilson and Harwood, 2017). Haemodialysis units are often busy, with appointment schedules arranged to maximise the number of haemodialysis treatments, leading to a pressured work environment. Cannulators, but also managers who influence nursing schedules and workloads, should aspire to create a calm haemodialysis unit that makes patients feel safe to undergo cannulation and survive its unpleasantness.

The cannulation technique used also appears to affect whether patients feel safe. This was particularly evident in one included study that explored buttonhole cannulation, where patients appeared to feel safer with this technique (Da Silva et al., 2015). However, there were no studies exploring any other cannulation techniques. It is difficult to determine whether buttonhole technique truly leads to a better cannulation experience, as other techniques have not been explored. Further research is needed into how cannulation techniques make patients feel safe during cannulation.

Whilst control and feeling safe appear to improve patients' experiences of cannulation, it is unclear how they do this. Further research is needed to understand these elements in more depth, understanding how they improve patients' experiences and thus how improvements may then facilitate these feelings.

2.6.5 Strengths and Limitations of the Systematic Review

A strength of our review is that we have included articles in any language, encompassing a breadth of cultural backgrounds. The systematic process with how the review was conducted and the methods used were also a strength, adhering to PRISMA (Page et al., 2021), PRISMA-P (Shamseer et al., 2015) and ENTREQ (Tong et al., 2012) guidance. As with all systematic reviews, the strength of findings is limited by the quality of studies included. We did not exclude any studies due to quality, to enable exploration of the breadth of findings available. This means we have included studies of varying quality. However, the CERQual assessment (Table 4) indicates high confidence in our findings, with moderate confidence in the first theme, ‘Cannulation is an unpleasant, abnormal and unique procedure’. The moderate confidence in the first theme indicates a lack of understanding of the unpleasantness of cannulation, particularly around vulnerability and pain. Further research needs to really explore how canulation is unpleasant for patients and what this means to them.

2.7 Conclusions

In conclusion, this systematic review provides in-depth insight into patients’ experiences of cannulation for haemodialysis. The synthesis of qualitative findings provides a richness and depth of understanding of this phenomenon, which would not be possible to achieve through an examination of quantitative studies. Cannulation is an essential procedure that impacts on patients’ experiences of haemodialysis. The unpleasantness of the cannulation procedure for patients is evident and includes issues related to pain, abnormal appearance, vulnerability and dependency. However, we still need further understanding of this unpleasantness, particularly understanding pain in greater depth. Other elements of unpleasantness need to be considered when assessing the impact of interventions on patients’ experiences of cannulation. The necessity of cannulation for haemodialysis emphasises the unpleasantness of the procedure, leading to worry about whether it will be successful. Worry about unsuccessful cannulation is an issue for patients, and the frequency of this event means there needs to be exploration of how we minimise this. POCUS appears to be a promising intervention to minimise miscannulation but needs further evaluation.

Findings show that patients learn to survive repetitive cannulation, where feeling safe and in control can improve their experiences. This indicates cannulation is not just a technical skill, but also a social process. Consideration needs to be given to how to make patients feel safe and in control, particularly during training of cannulators and when organising haemodialysis environments. However, further exploration is needed as to what feeling safe actually means. Cannulation techniques may also influence these elements, but further research is needed to determine how. Whilst this review has helped further develop our understanding about patients' experiences of cannulation for haemodialysis, there is still much to understand about this, to continue to improve this necessary but unpleasant procedure for patients.

2.7.1 Summary of Recommendations

2.7.1.1 Clinical Practice

- Strategies need to be developed to minimise miscannulation, including the evaluation of the efficacy of POCUS (discussed Section 2.6.3)
- Training of cannulators needs to recognise the social interaction that happens during cannulation as well as technical aspects (discussed Section 2.6.4, paragraph 4)

- Haemodialysis units and staffing schedules need to be designed to create a calm environment for cannulation to occur (discussed Section 2.6.4, paragraph 5)

2.7.1.2 Future Research

- Future qualitative studies into patients' experience of cannulation for haemodialysis need to explore specifically how cannulation is unpleasant, including an in-depth exploration of pain and further exploration of vulnerability, rather than just identifying that the procedure is unpleasant (discussed Section 2.6.2, paragraphs 2 and 4)
- Studies that claim to explore or measure patients' experience of needling when evaluating interventions to improve this, need to include all the elements of unpleasantness, not just pain (discussed Section 2.6.2, paragraph 4)
- The concepts of feeling safe and control during needling requires further exploration, particularly considering the effect of the cannulator, the environment and needling technique on feeling safe, as well as how to facilitate control in cannulation (discussed Section 2.6.4, paragraph 6)

This now concludes this chapter on the systematic review exploring patients' experiences of cannulation for haemodialysis. The next chapter will describe the development of a questionnaire to measure this concept, using the findings from the systematic review to provide structure to this.

3 Chapter 3: Measuring Patients’ Perspectives of Cannulation: Developing and Evaluating a Questionnaire

3.1 Introduction

The previous chapter develops an understanding of patients’ experiences of cannulation from what is known in current research. Having developed this understanding, the next step is to consider how to measure patients’ experiences of cannulation for haemodialysis from their perspective using a patient reported tool, thus enabling this to be included as an outcome in research studies evaluating interventions to improve cannulation. The findings in the systematic review in the previous chapter indicate potential content for this patient reported tool, which the application of is discussed further in section 3.2.2.

3.1.1 Research Aim, Question and Objectives

To provide further focus for this study, the following aims and objectives are outlined below:

Research Aim (same as Objective 2 for the thesis): To develop and evaluate a robust patient reported outcome to measure patients’ experiences of cannulation for haemodialysis undertaken by healthcare professionals, based on current understanding from research

Research Question: What is optimal content for a patient reported outcome to measure patients’ experiences of cannulation for haemodialysis in a valid and reliable manner within research?

Research Objectives:

1) To develop a ‘draft questionnaire’ with patient representatives, using themes from Chapter 2 to facilitate the initial discussion
2) To test the validity and reliability of the ‘draft questionnaire’
3) To identify how to best interpret scores from the questionnaire
4) To extend understanding of patients’ experiences of cannulation from the results of the questionnaire

The rationale for this approach and the need for this tool is explored in the remaining sections of this introduction.

3.1.2 The Importance of Measuring Patients’ Experiences of Cannulation

Numerous trials and observational studies have explored how to improve cannulation. Various systematic and scoping reviews highlight multiple interventions that could influence patients’ experiences of cannulation, including cannulation technique (Fielding et al., 2022a; Ren, Han, Huang, Yuan, Cao, and Yang, 2016; Wong et al., 2014; Grudzinski, Mendelssohn, Pierratos and Nesrallah, 2013), the use of ultrasound to improve cannulation (Schoch et al., 2020) and methods to reduce pain and anxiety related to cannulation (Harwood et al., 2017). However, assessment of the impact of these interventions on patients’ experiences is often limited or completely absent. Patients have to live with cannulation thrice weekly for years, often until the end of their life, to be able to receive a life sustaining treatment. The decisions they make about their vascular access are often based on their experiences, rather than hard clinical outcomes (Axley and Rosenblum, 2012; Xi et al., 2011). Therefore, their experiences of this unpleasant, repetitive yet necessary procedure must be considered within studies aimed to improve cannulation.

The most common aspect of patients' experiences of cannulation included in previous studies is pain assessed by a pain VAS. However, this measure often lacks sensitivity in this context (Fielding et al., 2022a) and only measures one dimension of patients' experiences of cannulation, intensity of pain. As discussed in the previous chapter, pain is also only one element of patients' experiences of cannulation. Future studies to compare interventions to improve cannulation, need to capture the impact on patients' experiences. Therefore, an accurate and reliable measure is required to measure patients' experiences of cannulation for haemodialysis.

3.1.3 Current Measures of Patients' Experiences of Cannulation for Haemodialysis

There is no current published measure to capture patients' experiences of cannulation. However, three measures were identified that relate to this:

1) The SF-VAQ captures patients' experiences of vascular access for haemodialysis. This questionnaire was developed across multiple studies, using interviews with patients to develop the content and refine items (Kosa et al., 2016 and 2015; Quinn, Lamping, Lok, Mayer, Hiller, Lee, Richardson et al., 2008), indicating content validity although no specific data are available to confirm this. The final

questionnaire contained 13 items, with one item about patient satisfaction, four items about physical complications, four items about the impact on social functioning and four items about dialysis complications. Testing demonstrated it had good internal consistency (0.84) and test-retest reliability (0.92) (Kosa et al., 2015). However, there appears to be an unrecognised problem with floor effects, with 11 items producing a mean score between one to three on a seven point Likert scale and 12 items with medians scores between one to two (results from Kosa et al., 2015).

2) The VASQoL questionnaire focusses on the impact of vascular access on the patient's quality of life (Greenwood, Kingsmore, Ricarz, Thomson, Bouamrane, Meiklam, Dunlop et al., 2022; Richarz et al., 2021). It was developed through interviews, focus groups and cognitive interviews with patients on haemodialysis, confirming content validity. This produced a questionnaire with 11 items across three domains – physical, vascular access function and capabilities. Construct validity was confirmed through a factor analysis and the questionnaire demonstrated good internal consistency (0.858) and test-retest reliability (0.916). Again, ceiling effects from their 10-point scale appeared to be an issue, although this effect reduced when examining patients who experienced vascular access problems. Of note, this questionnaire was not published at the time of designing the studies in this thesis.
3) The 'Dialysis Fear of Injection Questionnaire' (D-FIQ) (Mulder, De Vries, Op't Hoog and Buytene, 2013), is an adaption of the Diabetes

Fear of Injection and Self-Testing Questionnaire (Snoek, Mollema, Heine, Bouter and van der Ploeg, 1997). This questionnaire has 18 items, assessing patients' fear of injections. The D-FIQ demonstrated good validity and reliability, particularly predictive validity (Mulder et al., 2013). Unfortunately, a copy of this questionnaire could not be sourced, despite attempting to contact authors directly.

Whilst these three questionnaires provide some measure of experience that may relate to cannulation, none provide a comprehensive measure. The SF-VAQ and VASQoL both measure vascular access experience. Whilst this includes the experience of having AV access which undergo cannulation, this also includes CVCs, which does not undergo cannulation, changing the focus. Both questionnaires focus on the impact on the patients' life rather than vascular access procedures. Therefore, cannulation experiences may not be captured. The D-FIQ measures anxiety related to cannulation. Whilst this focusses on patients' experience of cannulation, anxiety is only one element of this experience. Therefore, this questionnaire does not provide a full picture of patients' experiences of cannulation. To measure this concept requires development of a new measure.

3.1.4 Purpose of the Questionnaire

Before designing the questionnaire, it is important to be clear on its purpose, defining the concept it will measure (DeVellis, 2012). Whilst the systematic review (Chapter 2) provides definition of the concept, this did not define exactly what the questionnaire would be measuring or how it would do this.

The concept of patient experience itself is vague and has become a term that is often used as a ‘catch-all’ for numerous concepts. Wolf, Niederhauser, Marshburn and LeVela (2014) debate the varying ways the term ‘patient experience’ is applied within healthcare, including whether it is a one off event or a continued experience, whether patient satisfaction surveys are adequate and whether patient experience should be formed by patients’ expectations or more concrete concepts (Wolf et al., 2014). Whilst their conclusions determine that patient experience is more than just satisfaction with healthcare services, they provided no single definition for patient experience, often straying into defining what care equates to a good patient experience rather than defining what patient experience is. This demonstrates the debate, showing the importance of defining the concept the questionnaire is measuring.

How the questionnaire is to be used assists in providing some definition of what it needs to measure. As discussed earlier, the questionnaire is to be used in research to enable comparison of interventions and measure patient experience as an outcome, alongside other clinical outcomes. This requires a questionnaire that is evaluative and able to define between interventions that improve, do not alter or worsen experiences of cannulation. On reflection, the questionnaire also needs to capture what patients’ actually experience because of cannulation (i.e. symptoms). These characteristics are typical of Patient-Reported Outcomes Measures (PROMs) used within research (Aiyegbisi, Kyte, Cockwell, Anderson and Calvert, 2017). Whilst the focus of our the questionnaire is experience, PREMs tend to be more global, focussing on the quality of care and individual experiences influenced by local context (Aiyegbisi et al., 2017). When comparing interventions within research, this context to the procedure needs to be controlled rather than measured as an outcome, making a PROM rather than PREM more relevant to the purpose of the questionnaire. However, Aiyegbisi et al (2017) define a PROM as measuring the effect on patient's quality of life. This could lead to a concept that is too broad for cannulation, as there are many aspects of the patient's life that happen outside of cannulation. On reflection, the questionnaire aims to evaluate patients' experiences of a medical procedure, cannulation. This defines the questionnaire as a PROM of a medical procedure, focussing on the cannulation procedure.

One further point of definition is to clarify which population the questionnaire is relevant to. Patient representatives felt cannulation performed by healthcare professionals was a separate concept to that performed by the patient or carer. The systematic review in Chapter 2 also highlights this, where both control and the cannulator (under Feelings of Safety) define experiences of self or carer cannulation as a different and distinct concept to cannulation by a healthcare professional. Therefore, the questionnaire aims to measure patients' experiences of healthcare professional cannulation, rather than all cannulation.

To summarise, the questionnaire to be developed is an evaluative PROM measuring the consequences of cannulation for haemodialysis for the patient i.e. the symptoms they experience. The focus is on cannulation performed by healthcare professionals for haemodialysis. This provides an appropriate PROM to be used in research, to evaluate interventions designed to improve cannulation in this population.

3.1.5 Assessing Measurement Properties of Questionnaires

When a developing a questionnaire, it is good practice to assess the measurement properties (Da Souza, Alexandre and Guirardello, 2017; Polit, 2015; Mokkink, Terwee, Patrick, Alonso, Stratford, Knol, Bouter et al., 2010a). This is important when developing questionnaires based on subjective criteria, like PROMs or PREMs, to ensure the questionnaire measures what it claims to measure in a reliable way (Mokkink et al., 2010a). If the results of questionnaires are used to guide patient care, then results need to be as close to reality as is possible.

Classical test theory is one approach to assess measurement properties. This assumes that questionnaire scores are the sum of the concept being measured combined with error. It is a simple approach requiring small sample sizes to complete tests (Cappelleri, Lundy and Hays, 2014; Erguven, 2013). The assumptions of classical test theory are unidimensionality (changes in the concept fully account for changes in the item scores) and monotonicity (item scores change to reflect the person’s location within the concept being measured) (Cappelleri et al., 2014). The questionnaire to be developed aims to fit these assumptions and thus classical test theory was an appropriate approach to use.

Classical test theory incorporates the concepts of assessing validity and reliability of the total questionnaire, in opposition to item response theory which examines the relationship of individual items to the concept they are measuring (Cappelleri et al., 2014; Erguven, 2013). Validity is whether the questionnaire measures what it is intended to measure (Da Souza et al., 2017; Polit, 2015; Mokkink et al., 2010a). Reliability is whether it measures this consistently. This often equates to stability of the questionnaire, ensuring scores only change when there is change in the construct they are measuring, and not due to error (Da Souza et al., 2017).

There are many different approaches and elements that can be measured to determine the questionnaire's validity and reliability. The COSMIN taxonomy (stands for COnsensus-based Standards for the selection of health Measurement INstruments) (Mokkink et al., 2010a; Mokkink, Terwee, Knol, Stratford, Alonso, Patrick, Bouter et al., 2010b). defines what tests can be used to assess the quality of a health-related PROMs and PREMs, including:

- Validity
    - Content validity, which also includes face validity
    - Criterion validity including concurrent and predictive validity

    - Construct validity including structural validity, hypothesis testing and cross-cultural validity
- Reliability
    - Internal consistency
    - Reliability – test-retest, inter-rater and intra-rater
    - Measurement Error
- Responsiveness

However, this does not state which tests should be completed or at what point (Mokkink et al., 2010a). For this study, there needs to be consideration of what tests are appropriate to complete, rather than completing all tests with no sense of rationale.

Guidance from the Food and Drug Administration in the United States provides focus for the required tests to assess measurement properties, defining essential tests for patient reported outcomes in trials as content validity, internal consistency, test-retest reliability and responsiveness later adding criterion validity (or if not possible, convergent and discriminatory validity (US Department of Health and Human Services Food and Drug Administration, 2009)). Therefore, the original planned validity and reliability tests were face validity, internal consistency, convergent validity and test-retest reliability. These appeared to be the most essential tests to reassure of validity and reliability of the questionnaire within research. The sample size for this study was formed to be adequate for these tests. Once the data were collected, other tests were added to further understand the measurement properties of the questionnaire. Whilst these tests were planned after data collection, these analyses were defined before completing them, and only performed if the sample size was considered adequate for the test. Assessing floor and ceiling effects, sensitivity analyses and a minor hypothesis test were added and interpretation of the questionnaire score was explored. A confirmatory factor analysis was considered, but this was not conducted as the sample size was not adequate.

3.2 Methods

As this is a questionnaire development study, this methods section has been divided into the phases of the questionnaire development and testing:

1) Development of the Draft Questionnaire
2) Face Validity Testing
3) Other Measurement Properties

Each section defines its own sample, data collection and analysis. Ethical considerations are similar in each section of the study, so covered in one section.

Prior to commencement of the study, the protocol was registered on the research registry (researchregistry5243).

3.2.1 Ethical Considerations

The study received approval from the Health Research Authority (HRA) which authorises research conducted within the National Health Service (NHS) in the UK (IRAS No: 269188). This study was conducted in accordance with this approval.

.

3.2.1.1 Recruitment and Informed Consent

Potential participants for the face validity and other measurement properties phases were identified by the clinical care team with reference to the inclusion and exclusion criteria. Eligible patients were approached by a member of the clinical team and asked if they are willing to discuss participation in the study whilst attending for their regular haemodialysis treatment. Patient representatives identified that this was the optimal time to discuss this, without adding any burden to the current treatment regime. If participants were deemed to lack capacity to provide consent, they were not approached as they were ineligible to complete the questionnaire.

Each eligible participant was provided with a participant information sheet and an opportunity to discuss participation in the study. Patients were given verbal information on the study, the opportunity to ask questions and time to consider the information provided, before deciding whether to participate in this study. At a later haemodialysis treatment, patients were then asked if they are willing to consent to the study. During verbal discussions about the study during the consent process, the following aspects were discussed:

- Involvement in the study was voluntary and they could withdraw consent at any point. Whether they chose to take part in the study would not affect their normal care in anyway.
- Involvement in the study involved:
    - For face validity phase, completing two questionnaires
    - For the other measurement phase. completing three questionnaires at two different time point.

    Whilst questionnaires were provided during their haemodialysis treatment, they could complete these at home if they would prefer.
- Information would also be collected from their medical records.
- All information they provided or collected from their medical records would be anonymised and the only people who would know they had taken part in the study would be the clinical care team.
- If they withdrew consent after completing questionnaires, then the information they had provided so far would be retained in the study, but no further information would be collected.

Consent was obtained using a written consent form. Informal consent was re-confirmed at each interaction throughout the study, with the opportunity for participants to ask questions or withdraw from the study if they wished to. Following provision of informed consent, arrangements were made to provide participants with the questionnaires and collect these.

3.2.1.2 Anonymity of Participant Information and Data Security

All data were handled in line with the UK General Data Protection Regulation (UK GDPR) (Information Commissioner’s Office, 2018) and adhered to the local hospital policies for data protection and information governance.

On consent each participant was assigned an individual participant identification (ID), to enable anonymisation of questionnaires, clinical and demographic data, and other electronic data. At each site, a separate enrolment log was kept containing the participant’s name, date of birth and participant ID, to permit identification of all participants enrolled in the study. The participant ID enabled linkage of data during analyses, eliminating personal identifiers outside of the enrolment log.

All paper documents were treated as confidential documents, stored onsite securely with restricted access in line with the local hospital policy. All paper data were transcribed to electronic databases before leaving the site and thus not removed from each hospital site. Computer held data, including the study database, were held on a secure computer drive at the University of Nottingham, which is subject to regular back up procedures and password protected.

Any data used for dissemination purposes were anonymised, ensuring participants could not be identified from data. Anonymised data transported outside the University of Nottingham were stored using only encrypted data storage.

3.2.2 Development of the Draft Questionnaire

A total of six patient representatives were involved in the initial development of the questionnaire (see section 1.4.3, for further information), with one patient's spouse also joining some discussions. This started with a group meeting held for five hours on a Sunday. To enable them to prepare, patient representatives were provided with information before the meeting, which included information on cannulation for haemodialysis and a brief description of the findings from the systematic review (Chapter 2), as well an agenda and aims of the meeting. Prior to the meeting, one patient representative who was involved in the development of the Kidney PREM (Hawkins et al., 2022), provided advice to myself on how to run the meeting and reviewed the information outlined above.

Ground rules were set at the start of the meeting, to prevent conflict between patient representatives and encourage a positive atmosphere. The meeting agenda was designed with lots of breaks, to prevent fatigue. Refreshments were provided throughout the meeting. I chaired the meeting, with a colleague present to assist in facilitating discussions. Throughout, explanations of various planned activities were used to create clarity and facilitate discussion. This included a presentation summarising and explaining the research plan. I took an informal, relaxed approach to chairing the meeting, encouraging patient representatives to drive the discussion and using questions to explore content as it arose. Throughout, the aim was to make patient representatives feel comfortable to disclose their thoughts and opinions and discuss things openly, respecting each other’s opinions. Discussion of individual patient’s experiences, alongside the findings of the systematic review, gradually identified the main issues to include in the questionnaire. The structure of the questionnaire was then discussed. A copy of other questionnaires were provided as examples and patients representatives discussed what they liked and did not like about these questionnaires. It was agreed at the end of the meeting, that another group meeting was not needed. Whilst patient representatives had found meeting as a group helpful and enjoyable, they felt they could progress work through one-ot-one meetings with myself. It was agreed that if queries were not resolved in one-to-one meetings, then another group meeting could be considered. After the meeting, a summary was provided to all attendees and all agreed it was an accurate summary.

Following the meeting, the discussion was used to form a draft questionnaire for patient representatives to review. I then conducted one-to-one meetings with each patient representative to review this. During this period, the draft questionnaire was altered and revised three times towards the final draft questionnaire. This was named the ‘Patients’ Perspectives of Needling’ (PPN) questionnaire and a scoring system was developed to create an overall PPN Score. This version of the questionnaire was ready to be used in face validity tests.

3.2.3 Face Validity Tests

Face validity is a form of content validity that determines whether the questionnaire appears to adequately reflect the concept it is designed to measure (Da Souza et al., 2017; Polit, 2015; DeVellis, 2012; Mokkink et al., 2010b). Whilst there is much debate as to the difference between content and face validity, many describe content validity as a process where the questionnaire content is endorsed by experts, who make a judgement about relevance and comprehensiveness of items (Polit, 2015; Mokkink et al., 2010b). However, this needs to be judged from multiple perspectives, not just that of the patient (Mokkink et al., 2010b). Therefore, as this study has only used the patient perspective to judge the content of the questionnaire, and no other experts in this area (e.g. healthcare professionals), this was deemed a face validity test.

3.2.3.1 Sample

To test the questionnaire for face validity, twelve patients at two renal centres were recruited. A small sample was used to gain detailed and varied feedback on the questionnaire. Purposive sampling was used to identify and recruit patients with varying demographic and clinical backgrounds, aiming for variation in:

- Renal centre
- Gender, ethnicity and age
- Location and type of AV access
- Patients with and without diabetes

Variation across the two renal centres was key, as each renal centre used different cannulation techniques, ensuring the PPN was valid for both techniques. To avoid confusion, as area puncture and rope ladder are cannulation techniques that are difficult to define between (Fielding et al., 2022a; Fielding et al., 2018a), they were classified together.

Eligibility criteria included patients who met the following criteria:

- 18 years of age or older
- Using an AV fistula or graft for regular haemodialysis, including HDF
- Receiving healthcare professional cannulation
- Able to complete the questionnaires in English, either independently or with support from a family member, carer or member of the research team

To ensure the questionnaire was valid for the relevant patient population, the following patients were excluded:

- Self-cannulating or under-going carer cannulation
- Performing home haemodialysis
- Receiving haemodialysis via a CVC
- Using atypical AV access, not located in their arm or their leg
- Undergoing regular ultrasound cannulation for haemodialysis i.e. used three times in the week preceding recruitment
- Undergoing haemodialysis in an in-patient setting.

3.2.3.2 Data Collection

For each participant, clinical and demographic data were collected on:

- Gender, age and ethnicity
- Type of AV access used for haemodialysis
- Haemodialysis and cannulation vintage
- Cannulation technique used
- Cause of CKD
- Current vascular co-morbidities that may affect the quality of the AV access.

Each participant was asked to complete the PPN questionnaire and then complete another bespoke questionnaire alongside the PPN, the face validity questionnaire (FVQu). The FVQu asked their opinions on the PPN, covering:

- How easy the questions were to understand, particularly asking if there any specific questions or words they did not understand
- How relevant and comprehensive they felt the content of the PPN was, particularly exploring whether the PPN included anything irrelevant or whether anything was missing
- Any general comments on the PPN.

The FVQu included closed questions, where they scored elements on a scale from one to seven, and open questions, where they could add free text on their own opinions. Closed questions had a scale scoring between one and seven, with a higher score meaning it was easier to understand, relevant or comprehensive, depending on the question. The FVQu was reviewed by patient representatives, to ensure it was easy to understand.

Both questionnaires were given to participants whilst on haemodialysis and they were given a choice as to whether to complete these questionnaires at home or whilst on haemodialysis. Patient representatives felt this option minimised burden to participants, who were already undergoing a burdensome treatment, and they did not feel it would affect participants answers to questions. If the participant took the questionnaires home to complete, I arranged to collect them at a future haemodialysis treatment. They were asked to complete the PPN first and then the FVQu. If the participant required assistance completing the questionnaire, this was not done by myself, but a research nurse who was encouraged to write the participant’s verbatim responses in answer to questions. As I had invested in the questionnaire, it was felt I could unduly influence the data collection process if I assisted in questionnaire completion. All questionnaires were anonymised using a participant ID.

3.2.3.3 Data Analysis

The clinical and demographic data, results of the PPN questionnaire and FVQu questionnaire were transcribed into an excel database and SPSS to enable analysis. Once in SPSS, the data were randomly checked for accuracy. Missing answers to questions were not replaced but acknowledged as missing.

PPN scores were calculated. Frequencies and percentages were used to describe nominal and categorical data from clinical and demographic characteristics. Descriptive statistics were used to describe PPN scores and results of the FVQu. As there were data from only twelve participants, it was assumed the criteria for normal distribution would not be met. Medians and inter-quartile ranges were used to describe the distribution of questionnaire answers and continuous data. Free text comments on the content of the PPN were used to guide modifications to the PPN and patient representatives were consulted on all modifications made. If more than 40% of the PPN was modified at this stage, success thresholds stated that further face validity testing would be needed. However, if less than 40% of the PPN was modified, it could progress onto the next stage. Some free text comments were also provided on patients' experiences of cannulation for haemodialysis, thus were incorporated into the thematic analysis of comments described in section 3.3.5.

3.2.4 Other Measurement Properties

As mentioned earlier (section 3.1.5), three other validity and reliability tests were identified as suitable for this study, described below:

1) Internal consistency is a reliability measure, examining the homogeneity or inter-relatedness of the questionnaire (Da Souza et al., 2017; DeVellis, 2012; Tavalok and Derrick, 2011; Mokkink et al., 2010b). It explores the correlation between answers to items within the questionnaire, examining whether they behave in a manner that indicates they measure the same concept (DeVellis, 2012).

2) Convergent validity involves the assessment of the PPN against another questionnaire that measures a similar concept, to see if the PPN had expected convergence with the other questionnaire (Da Souza et al., 2017; Polit, 2015; DeVellis, 2012). Convergent validity is a type of construct validity (Mokkink et al., 2010a). It is often used to replace criterion validity, when there is no gold standard available to assess the questionnaire against (Da Souza et al., 2017; Polit, 2015; Mokkink et al., 2010b).
3) Test-retest reliability is used to assess stability and reproducibility of the questionnaire, ensuring that questionnaire scores change only when there is a change in the concept (Da Souza et al., 2017; Polit, 2015; DeVellis, 2012). It assesses what happens to the questionnaire score when there no change in the concept being measured, through repeated measures (Da Souza et al., 2017; Polit, 2015; DeVellis, 2012).

Data collection was designed to gather data required to complete the above tests. As mentioned previously, after the data collection was completed, further tests were added to the analysis of this:

1) Assessment of floor and ceiling effects, assessing the number of participants who achieved the highest or lowest possible score. This could indicate a lack of an ability to distinguish between those with different experiences or a redundancy of items (Terwee, Bot, De Boer, van der Windt, Knol, Dekker, Bouter et al., 2007).

2) Sensitivity analyses, recalculating validity and reliability tests when altering the questions included in the PPN and the sample included in the analysis. These analyses explored how the PPN behaved when altered and assisted in determining the optimal format.
3) Hypothesis testing, which is a form of construct validity that can be used to understand whether the questionnaire behaves in an expected manner (Polit, 2015; Mokkink et al., 2010a; Mokkink et al., 2010b). This can take many forms, testing results between known groups or examining relationships between individual questions (Mokkink et al., 2010b). For this study, this examined the relationship between individual questions.
4) Exploring the interpretation of PPN scores, which used two techniques:
   a. An item discrimination index, which identifies questions that discriminate well between individuals who have different cannulation experiences (Cappelleri et al., 2014). It provides a hierarchy of questions, with the higher scoring items in the discrimination index indicating that a question discriminates well between those with different experiences.
   b. Calculation of the standard error of measurement, which is an absolute figure to determine how much variation in PPN score is due to error (Mokkink et al., 2010a). The smallest detectable change was also calculated from this this, which is the lowest score that can be attributed to a change in the concept and not attributed to error (Mokkink et al., 2010b).

3.2.4.1 Sample

Whilst there are no strict criteria for sample sizes for these tests, there is indication that a sample size of above 50 is required for test-retest reliability (Da Souza et al., 2017). To allow for attrition and missing data, it was determined that a sample size of at least 80 participants was needed. It was also felt a sample size between 80 to 100 across two renal centres would allow natural variation in participants, to ensure the population was representative of the majority of patients on in-centre haemodialysis. Convenience sampling rather than purposive sampling was used, assuming there would be natural variation in participants' demographic and clinical backgrounds. Again, recruitment aimed for equal numbers across the two sites to ensure variation in cannulation technique across the study sample.

Eligibility criteria were the same as those defined for the face validity phase (Section 3.2.3.1).

3.2.4.2 Data Collection

For each participant, clinical and demographic data were collected as described in the face validity phase (Section 3.2.3.1), with the addition of local anaesthetic use before cannulation, following feedback from participants in the face validity phase.

Each participant was asked to complete three questionnaires. They were asked to complete the PPN on two separate occasions, named time 1 (T1) and time 2 (T2). This provided data for both internal consistency and test-retest reliability tests. The time in between completion of questionnaires was set as a minimum of the time in between two haemodialysis sessions (normally 48 to 72 hours) and a maximum of 14 days. This time period was short enough to ensure there was no change in the concept being measured in the majority of participants, whilst instigating a break in between questionnaire completions to reduce the likelihood participants remembered their previous answers. However, there was concern that even within 14 days, there could still be changes in their cannulation, as it is an unstable procedure. This is not an uncommon concern with medical procedures and can affect the test-retest results (Polit, 2015). Therefore, before completion of the PPN at T2, participants were asked if they felt their cannulation had changed since the last completion of the PPN.

Alongside the PPN at T1, participants were also asked to complete the SF-VAQ (Kosa et al., 2015) (as described in section 3.1.3) to enable a comparison to test convergent validity. Permission was gained from the University of Toronto in Canada to use this questionnaire within this study. Patients' experiences of vascular access were considered a similar but broader concept to experiences of cannulation for haemodialysis. This therefore provided a similar measure to the PPN but did not provide the gold standard measure required for criterion validity.

As per the face validity phase, the questionnaires were given to participants whilst on haemodialysis and they were given a choice as to whether to complete these questionnaires at home or whilst on haemodialysis. If the participant required assistance completing the questionnaire, this could be done by myself, but the clinical team were not allowed to assist in questionnaire completion. As the clinical team cannulated patients, it was felt they could unduly influence the data collection process if they assisted in questionnaire completion. All questionnaires were anonymised using a participant ID.

3.2.4.3 Data Analysis

The clinical and demographic data, the results of the PPN at T1 and T2, and SF-VAQ were transcribed into an excel database and imported into SPSS to enable analysis. Once in SPSS, the data was randomly checked for accuracy.

Missing answers to the PPN and SF-VAQ were replaced as followed:

- If one or two question answers were missing, then these were replaced with the mean for the section
- If more than two question answers were missing, then the questionnaire was removed completely from the analysis
- As analyses were conducted for questionnaire sections as well as the total questionnaire score, sections with one to two missing answers

were retained for the section analysis, even if the full questionnaire was not used

Success criterion was also set for missing data, where if more than 20% of data was missing from the PPN questionnaire dataset, then this may be an indication that there was problem with the questionnaire, requiring modifications.

PPN scores were collated as per the scoring system. Frequencies and percentages were used to describe nominal and categorical data from clinical and demographic characteristics. Descriptive statistics were used to describe PPN scores. Data were tested for normality by observing plots and using skewness, kurtosis tests and Shapiro-Wilk test. The distribution of normally distributed data was described using means and 95% confidence intervals and non-normally distributed data using medians and inter-quartile ranges.

Each test was completed on the total PPN score and each section. *A priori s*uccess thresholds defined whether the PPN met the desired criteria for the test. The analysis process and success thresholds for each individual test are described in the sections below. In this phase, the aim was to minimise changes to the questionnaire. However, if success thresholds were not met, modifications would be considered to the questionnaire. Again, any modifications would be reviewed by patient representatives and if more than

20% of the questionnaire was changed at this stage, then this phase would be repeated.

3.2.4.3.1 Internal Consistency

Cronbach alpha was used to calculate internal consistency for the PPN and individual sections, which is the recommended statistic (DeVellis, 2012; Mokkink et al., 2010a). Where a PPN T1 was removed for an individual participant due to missing data (see section 3.3.3.2), the PPN T2 was used. If both PPN T1 and T2 were missing, then the participant was excluded from the analysis. As the time between T1 and T2 was small, with some participants completing their PPN T2 before other participants had completed their PPN T1, this was considered reasonable. This provided the most complete dataset for the analysis. This dataset was named the ‘Internal Consistency dataset’ and where indicated and appropriate, used for other analyses.

The success threshold for Cronbach Alpha and internal consistency was set at above 0.7. This is considered a reasonable threshold for internal consistency, with a higher level indicating better reliability up to a maximum of 1.0 (Tavalok and Derrick, 2011; Mokkink et al., 2010b). Some recommend an upper threshold of 0.9 or 0.95 for Cronbach alpha, as this may indicate redundant items (Tavalok and Derrick, 2011). This approach was considered but not set as a success threshold. It was felt that redundant items should not just be identified purely from a statistic, but also through face validity testing and the opinion of patient representatives.

As SPSS does not calculate confidence intervals for internal consistency, these were calculated using intra-class correlation, using the upper and lower bounds for the upper and lower confidence interval. This is a common way to calculate internal consistency confidence intervals, based on an article that demonstrates internal consistency and mixed model intra-class correlation looking for consistency are the same (Bravo and Potvin, 1991).

3.2.4.3.2 Convergent Validity

To complete correlations, the results of the SF-VAQ were compared to the results of the PPN T1. The SF-VAQ was divided into two sections:

1) An overall general satisfaction question (Question 3)
2) The three domains that make the other 12 questions in the SF-VAQ, comprising of a composite score of 12 questions (Questions 4-15).

If one of the questionnaires was missing or removed due to missing data, then the participant was removed from the analysis. Pearson's, Spearman's Rho or kappa correlation coefficients were to be used to determine correlation, dependent on whether the scores were normally distributed or not and whether they were categorical or continuous data (Schober, Boer and Schwarte, 2018; Altman, 1991,). These tests were performed with two tail significance, aiming for a p value below 0.05. Where one or both questionnaires were missing, the participant was excluded from the analysis.

The success threshold aimed for a correlation between 0.4-0.7. This would demonstrate a moderate correlation between the PPN and SF-VAQ (Schober et al., 2018; Altman, 1991). A moderate correlation was chosen as the SF-VAQ is not a validated measure of cannulation experience, only vascular access experience. This is a broader concept than cannulation experience. Therefore, we did not expect or desire a strong correlation which could indicate the PPN was measuring a concept different from cannulation experience. The direction of correlation could not be defined until the PPN had been designed and the direction of PPN scoring defined. However, once the PPN scoring had been set, the following expectations were set:

1) The PPN had a negative correlation with Question 3 of the SF-VAQ
2) The PPN had positive correlation with Questions 4-15 of the SF-VAQ.

3.2.4.3.3 Test-Retest Reliability

Correlations between the PPN T1 and T2 were completed using intra-class correlation coefficient, which is the preferred measure for test-retest reliability, above other correlation coefficients (Da Souza et al., 2017; Polit, 2015). The intra-class correlation coefficient takes account of random measurement error, which Pearson and Spearman’s rho do not (Da Souza et al., 2017). There are different types of intra-class correlation coefficient, but the two-way mixed effects model was chosen with absolute agreement (Koo and Li, 2016; Polit, 2015). This is an appropriate test to assess correlation between multiple scores from the same rater, allowing for the non-random allocation between repeated measures (Koo and Li, 2016). As with convergent validity, where one or both questionnaires were missing or removed due to missing data, the participants were excluded from the analysis.

The threshold aimed for an intra-class correlation coefficient of 0.5 or above. This is a moderate correlation, with above 0.7 or 0.75 being considered a good correlation that demonstrates good reliability (Da Souza et al., 2017; Koo and Li, 2016). However, as cannulation is an unstable procedure, there was concern that aiming for a good correlation could be misleading when measuring a concept with poor temporal stability (Polit, 2015). There was concern this may lead to incorrect or unnecessary changes to the PPN. However, whilst a moderate correlation was considered adequate, no upper limit was applied to the success threshold.

3.2.4.3.4 Floor and Ceiling Effects

Floor and ceiling effects were assessed for the individual questions, as well as the total PPN and each section. The distribution of answers was explored, counting the number of respondents to each category of each question. Section and total PPN data provided a continuous variable rather than a categorical data. Therefore, to assess respondent answers in continuous data, the number of respondents who answers between 1.0-1.99, 2.00-2.99, 3.00-3.99 etc. up to 6.00-7.00 were collated. Traditionally, more than 15% of respondents in the low or high categories indicates floor or ceiling effects

(Terwee et al., 2007). However, in a seven-point scale, 15% indicates an equal distribution across each answer. Therefore, it was decided that 30% of respondents in the low or high categories indicated minor floor or ceiling effects (i.e. 15% above equal distribution of answers), with over 40% giving cause for concern. These analyses used the ‘Internal Consistency’ dataset.

3.2.4.3.5 Sensitivity Analyses

Sensitivity analyses were performed to determine the effect of alterations on. internal consistency, convergent validity and test-retest reliability. Alterations included were:

- Any questionnaires with missing data were removed
- Question 18 included in the PPN
- Test-retest reliability only including those without changes in their cannulation during this phase.

The validity and reliability tests were performed as described in previous sections and the results assessed to identify the optimal format.

3.2.4.3.6 Hypothesis Testing

Questions 1, 2 and 3 in the final PPN were worded in a manner that if participants answered these correctly, the following hypothesis would be true:

Q2 score ≥ Q1 score ≥ Q3 score

COSMIN describes hypothesis testing as an in-depth analysis, with correlations between scores calculated and assessed against pre-determined thresholds defining the magnitude of difference expected (Mokkink et al., 2010b). However, this hypothesis is simpler, where the magnitude of difference is less important than the direction of difference. Therefore, no threshold was set beyond the above equation.

To determine whether this hypothesis was met, the frequencies of PPN that met the following criteria were calculated:

- Q2 was lower, equal to or higher than Q1
- Q1 was lower, equal to or higher than Q3
- Q2 was lower, equal to or higher than Q3

The difference between the questions was calculated, with either means and 95% confidence intervals or medians with inter-quartile ranges used to describe the distribution, depending on the normality of the data. The difference between question answers was compared. Two way ANOVA or Friedman ANOVA was used to compare the difference between all three questions, depending on whether the data were normally or non-normally distributed (MacFarland and Yates, 2016). Paired t-test or Wilcoxon signed rank was used to compare pairs of questions, again depending on whether the data were normally or non-normally distributed (Whitley and Ball, 2002). This analysis used the Internal Consistency dataset.

Success criteria defined that at least 80% of participant should meet the hypothesis. This purely an arbitrary threshold, determined by what was felt to be acceptable. When comparing means or medians, we aimed for a p value below 0.05.

3.2.4.3.7 Interpretation of PPN Scores

An item discrimination index was created using the extreme group method, as described by Cappelleri et al (2014). This involved:

1) Identifying the participants scoring the top 25% (H) and bottom 25% (L)
2) For each item determining the number of participants in the H group who score 4-7 (=endorsement)
3) For each item determining the number of participants in the L group who score 4-7 (=endorsement)
4) Subtract the proportion (%) of H that endorses an item from the proportion of L that endorse an item.
5) Place each item in order of the magnitude of discrimination in a table (Table Headings: Item, Proportion endorsed from H, Proportion endorsed from L, Item discrimination index). A negative item is lower than all positive numbers and the more negative, the lower it goes.

As the item discrimination index provides a hierarchy of items, no success threshold was set. However, it was determined that any questions scoring 0 or negative in the index demonstrated poor discrimination and consideration would be given as to whether to remove them. This analysis used the Internal Consistency dataset.

Standard error of measurement was calculated using the following equation, recommended by Geerinck, Alekna, Beaudart, Bautmans, Cooper, De Souza Orlandi, Konstantynowicz et al. (2019):

$$\text{Standard Error of Measurement} = \text{SD Difference}/\sqrt{2}$$

To complete the analysis, the difference between PPN scores at T1 and T2 was calculated for each participant and then the standard deviation of this difference was calculated, creating the ‘SD Difference’. A square root of two was used, as the questionnaire was administered on two different occasions.

The smallest detectable change is easily calculated from the standard error of measurement (Darter, Rodriguez and Wilken, 2013; Hinman, Dobson, Takla, O'Donnell and Bennell, 2013; Mokkink et al., 2010a; Terwee et al., 2007):

$$\text{Smallest Detectable Change} = \text{Standard Error of Measurement} \times \text{z score interval} \times \sqrt{2}$$

The smallest detectable change was calculated for 90%, 95% and 99% z score intervals (i.e. 1.65, 1.96 and 2.58 respectively). This provided the smallest detectable change for individual participants. The smallest detectable change was also calculated for the group by dividing the smallest detectable change by the square root of the sample size (Darter et al., 2013; Hinman et al., 2013; Terwee et al., 2007).

As these analyses used the difference between the PPN scores at T1 and T2, the dataset used for test-retest reliability was used for this analysis. Success thresholds were set for the smallest detectable change, aiming for a group smallest detectable change (using 95% z score) of less than one. The standard error of measurement and smallest detectable change provide figures that are absolute and relate directly to PPN scores. Again, this figure was arbitrarily set according to what was judged to be a reasonable limit.

3.2.5 Qualitative Thematic Analysis of Free Text Comments from the PPN

Free text comments from the PPN were downloaded into NVivo for analysis. A basic thematic analysis was completed on these comments, following the procedure described by Braun and Clarke (2006):

1) Familiarise yourself with the data
2) Generate initial codes
3) Search for themes
4) Refine and review themes
5) Define themes
6) Provide a report of findings describing the themes using direct quotes form participants.

Whilst this analysis process was followed, it was recognised that this was likely a superficial thematic analysis, lacking the depth used to define reflexive thematic analysis by the same authors (Braun and Clarke, 2020). This level of analysis was driven by the type of data used, where short written comments consisting of a maximum four to five sentences from individual participants were analysed.

3.3 Results

The results section is structured according to the results generated by the different sections of the study, including how the PPN changed and developed through the study, with a section describing the final PPN. A brief description of what the PPN results tell us about patients' experiences of cannulation is also included.

3.3.1 PPN Version 1

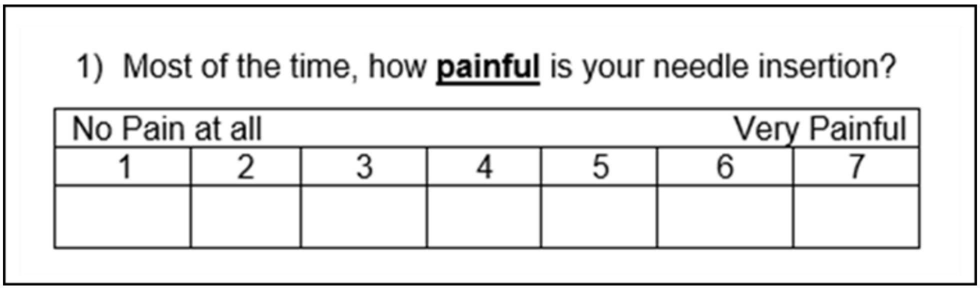
The PPN Version 1.0 (PPN v1) is the version of the PPN developed with patient representatives, as described in section 3.2.2. This version was then assessed in the Face Validity phase of the study.

The PPN v1 contained 22 items, split into four sections:

1) Pain – 5 items
2) Worry – 9 items
3) Problems – 4 items
4) Interaction during Needling – 4 items

The patient representatives felt these 22 items covered the most important and common aspects of patients' experiences of cannulation. The items were a mixture of questions and statements. Items were kept short and simple, with patient representatives reviewing them for relevance and simplicity of wording.

All questions were unipolar, using a scale between one to seven. The description of the scale varied, to fit individual questions. The extremes of the description of the scale were labelled at each end, with 7 unlabelled boxes underneath, as demonstrated in Figure 4. Patient representatives felt this was the clearest and most relevant way to demonstrate the scale.



1) Most of the time, how **painful** is your needle insertion?

No Pain at all						Very Painful
1	2	3	4	5	6	7

Figure 4: Example of a question from the PPN, to demonstrate the scale

A brief introduction was included in the questionnaire explaining what the questionnaire was and a section to insert the participant ID, to anonymise the questionnaire. The introduction clarified that participants should consider their experiences of cannulation over the last four weeks. It reassured them of the anonymity of the questionnaire and encouraged them to be honest in their answers. Each section of the PPN v1 had a brief introduction to explain the section. A free text comments box was inserted at the end of the PPN.

Patient representatives felt this was important, so patients could add unique elements of their experience or clarify their answers. Patient representatives reviewed the content of the questionnaire throughout for relevance and ease of understanding.

A scoring system was developed, using the mean of the means of each section to create a composite score for each participant, between one and seven. This approach meant each section had equal weighting regardless of the number of questions. As experience of cannulation was deemed something that was an inherently negative and unpleasant experience, the score indicated how poor their needling experience was. Therefore, a high score indicated a worse experience with a low score indicating a less worse experience. Questions 17 to 22 worked in the opposite direction, where a higher number indicated a less worse experience. Therefore, the scores for these questions were reversed (i.e. 1=7 and 7=1) before being collated into the final PPN score.

3.3.2 Face Validity Tests

3.3.2.1 Participant Characteristics

Participants were recruited from two renal centres, with a total of twelve participants recruited. An even split was achieved across both sites with six participants at each site. There were slightly more males (n=7) in comparison to females. A wide age range was captured, with the youngest participant being 31 years old and oldest 90 years old. A range of ethnicities was covered including those from Afro-Caribbean (n=2) and South Asian (n=2) backgrounds. A range of haemodialysis and cannulation vintage, vascular access types and those with and without diabetes and vascular disease were recruited. The cannulation type was equal between the two techniques, with six participants experiencing buttonhole and six experiencing rope ladder / area puncture. The characteristics of participants are summarised in Table 7.

Site	Site 1	6 (50%)
	Site 2	6 (50%)
Gender	Male	7 (58.3%)
	Female	5 (41.7%)
Age	Median	71 years
	Range	31-90 years
Ethnicity	Caucasian	8 (66.7%)
	Afro-Caribbean	2 (16.7%)
	South Asian	2 (16.7%)
Haemodialysis Vintage (Months)	Median	40 months
	Range	11-128 months
Vascular Access Type	Radiocephalic fistula	4 (33.3%)
	Brachiocephalic fistula	5 (41.7%)
	Brachiobasilic fistula	1 (8.3%)
	Upper arm graft	2 (16.7%)
Canulation Vintage	Median	33 months
	Range	4-128 months
Cannulation Type	Buttonhole	6 (50%)
	Rope Ladder / Area Puncture	6 (50%)
Cause of CKD	Diabetes	4 (33.3%)
	Acute Kidney Injury (AKI)	1 (8.3%)
	Glomerulonephritis	4 (33.3%)
	Vascular Disease	2 (16.7%)
	Unknown	1 (8.3%)
Presence of Diabetes *	Yes	5 (41.7%)
	No	7 (58.3%)
Presence of Vascular Disease **	Yes	7 (58.3%)
	No	5 (41.7%)

Table 7: Characteristics of Participants completing the Face Validity Test

** Cause of CKD or Co-Morbidity*
***Includes Angina, Myocardial Infarction, Cerebrovascular Disease or Peripheral Vascular Disease*

3.3.2.2 Face Validity Questionnaire (FVQu)

The median score for ease of understanding for all of the four sections of PPN v1 was 7.00, with all inter-quartile ranges (IQR) between 5.00 and 7.00, indicating all sections were easy to understand. The median score of ease of understanding of the introduction was 6.50 (IQR 5.25-7.00). The median scores for the relevance of sections varied from 6.50 to 7.00, again with all IQRs between 5.75 and 7.00, indicating all sections were relevant. The median score for comprehensiveness of the whole PPN was 6.00 (IQR 6.00-7.00), indicating it was comprehensive. To add granularity to categorical data, means were explored alongside medians, although it was accepted these were not an accurate representation of non-normally distributed data. These results are summarised in Table 8.

Measure	**PPN Section**	**n**	**Median (IQR)**	**Mean (95% CI)**
Ease of Understanding	Introduction	12	6.50 (5.25-7.00)	5.92 (4.82-7.02)
	Pain	12	7.00 (5.25-7.00)	6.00 (4.82-7.18)
	Worry	11	7.00 (6.00-7.00)	6.18 (5.06-7.30)
	Problems	11	7.00 (6.00-7.00)	6.27 (5.32-7.23)
	Interaction during Needling	11	7.00 (6.00-7.00)	6.09 (5.12-7.06)
Relevance	Pain	11	7.00 (6.00-7.00)	6.00 (4.80-7.20)
	Worry	10	7.00 (6.00-7.00)	6.20 (5.09-7.31)
	Problems	10	7.00 (6.00-7.00)	6.40 (5.50-7.30)
	Interaction during Needling	10	6.50 (5.75-7.00)	6.10 (5.18-7.02)
Comprehensiveness	Whole PPN	11	6.00 (6.00-7.00)	6.18 (5.59-6.77)

Table 8: Results of the Face Validity Questionnaire

Free text questions determined whether there were any words or questions they did not understand. Positive responses included ‘*Very clear*’ (Participant g) and ‘*No words were too difficult*’ (Participant a). However, one participant highlighted they did not understand the word ‘*Insertion*’ (Participant f). Participants also highlighted questions they did not understand, including ‘*I* *am given information I need about my needling – not sure what this is asking*' (Participant e) and '*Interaction – unsure what this section is about*' (Participant e). Participants felt nothing was irrelevant in the PPN. However, they wanted to '*A question about what pain relief we have and if it works*' (Participant i) and '*Maybe to ask whether the person uses anaesthetic (lidocream / EMLA cream) before needling and what difference this makes to how they feel / worry*' (Participant c). One participant (g) did not feel anything was missing from the PPN, stating '*Not really*' in response to this question. At the end of the FVQu, participants were asked to add any further commented they had about the PPN questionnaire. These comments included '*Very clear and easy to understand'* (Participant g), '*Very quick and easy to complete*' (Participant e) and '*Clear, concise and easy to understand*' (Participant c). Participants also commented on their needling experience within the FVQu, but these comments were included in the thematic analysis in section 3.3.5 Some participants chose to not comment in the free text boxes, but only completed the scoring element of the FVQu.

Following on from the face validity tests, minor changes were made to PPN v1, but the amount did not reach the threshold of 40%. The changes that were made were:

1) The interaction during needling section was removed.
   Whilst scores indicated this section behaved as other sections, free text comments highlighted issues. When this was discussed with patient representatives, it became evident that different patients

interpreted these questions in different ways. Whilst patents felt these questions were important, discussions indicated these concepts were more complex than initially thought and may be more suitable to explore in qualitative interviews or a PREM questionnaire, rather than a PROM questionnaire focussed on symptoms.

2) The word ‘insertion’ was changed to ‘needling’ or ‘having your needles put in’.
3) The question about feeling safe during cannulation was placed at the end of the problems section rather than the beginning. Patient representatives felt this was better suited in this location.

Whilst responses indicated recording local anaesthesia use was important. This was felt to be a characteristic of the sample rather than a question for the PPN. Therefore, this was added to the clinical data collected on participants in the ‘Other Measurement Properties’ phase.

This created PPN version 2.0 (PPN v2), to be used in the next phase of the study.

3.3.3 Other Measurement Properties

Both demographic data and questionnaire answers were found to be non-normally distributed with Shapiro-Wilk test consistently above 0.05. Therefore, medians with inter-quartile ranges were used to describe the distribution of data and non-parametric tests were used throughout the analysis.

3.3.3.1 Participant Characteristics

The questionnaires in this phase (as described in section 3.2.4) were administered to 99 participants at two renal centres. A similar number of participants were recruited across both sites, with 52 participants at one site and 47 at the other. Again there were slightly more males (60.6%) in comparison to females. A wide age range was captured, with the youngest participant being 19 years old and oldest 92 years old. The median age was 69 years old. A range of ethnicities was covered including those from Afro-Caribbean (n=8, 8.1%) and South Asian (n=10, 10.1%) backgrounds. A wide range of haemodialysis and cannulation vintage, vascular access type, cannulation type and those with and without diabetes and vascular disease were recruited. The sample included a mixture of participants with AV fistulas (n=92) and AV grafts (n=5), in a mixture of locations (lower am n=28, upper arm n=67 and AV access in the leg n=2). There were two participants with an AV fistula that contained a grafted section to provide the arterial supply, making this mix of a fistula and graft. A similar mix was obtained of cannulation type, with 48 participants undergoing buttonhole and 50 participants undergoing rope ladder / area puncture. There was one participant who underwent buttonhole on one cannulation site and rope ladder / area puncture on the other. The characteristics of participants are summarised in Table 9, Figure 5 and Figure 6.

Site	Site 1	52 (52.5%)
	Site 2	47 (47.5%)
Gender	Male	60 (60.6%)
	Female	39 (39.4%)
Age	Median	69 years
	Range	19-92 years
Ethnicity	Caucasian	81 (81.8%)
	Afro-Caribbean	8 (8.1%)
	South Asian	10 (10.1%)
Haemodialysis Vintage (Months)	Median	31 months
	Range	1-196 months
Canulation Vintage	Median	26 months
	Range	Less than 1 – 196 months
Cannulation Type	Buttonhole	48 (48.5%)
	Rope Ladder / Area Puncture	50 (50.5%)
	Different each site	1 (1.0%)
Local Anaesthetic Use	Sub-Dermal Lignocaine	5 (5.1%)
	Topical Cream	15 (15.2%)
	Sub-Dermal Lignocaine and Topical Cream	2 (2.0%)
	None	77 (77.8%)
Presence of Diabetes *	Yes	44 (44.4%)
	No	55 (55.6%)
Presence of Vascular Disease **	Yes	26 (26.3%)
	No	73 (73.7%)

Table 9: Characteristics of Participants completing Questionnaires to Assess Other Measurement Properties of the PPN

** Cause of CKD or Co-Morbidity*
***Includes Angina, Myocardial Infarction, Cerebrovascular Disease or Peripheral Vascular Disease*

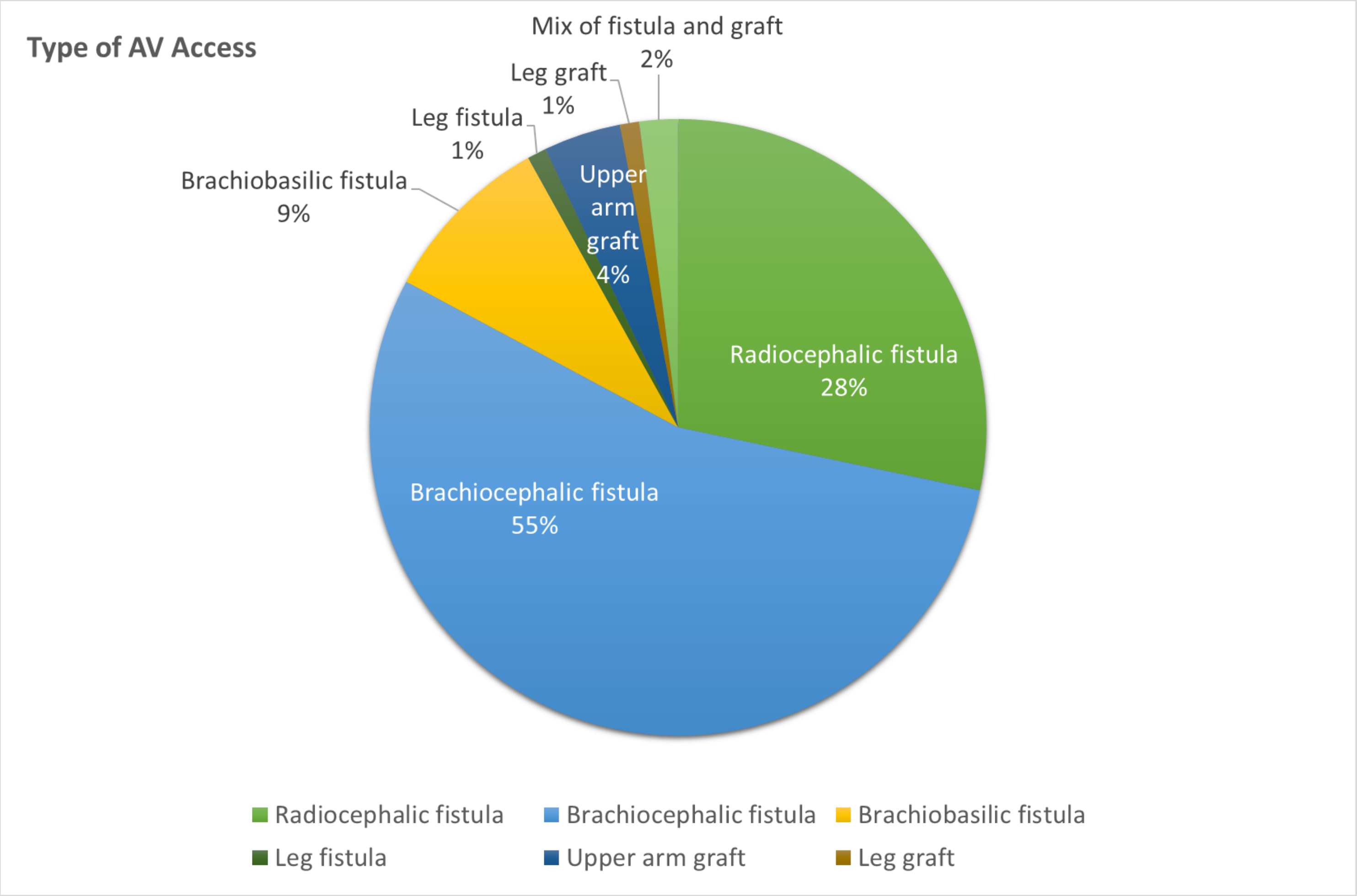


Figure 5: Type of AV Access for Participants completing Questionnaires to Assess Other Measurement Properties of the PPN

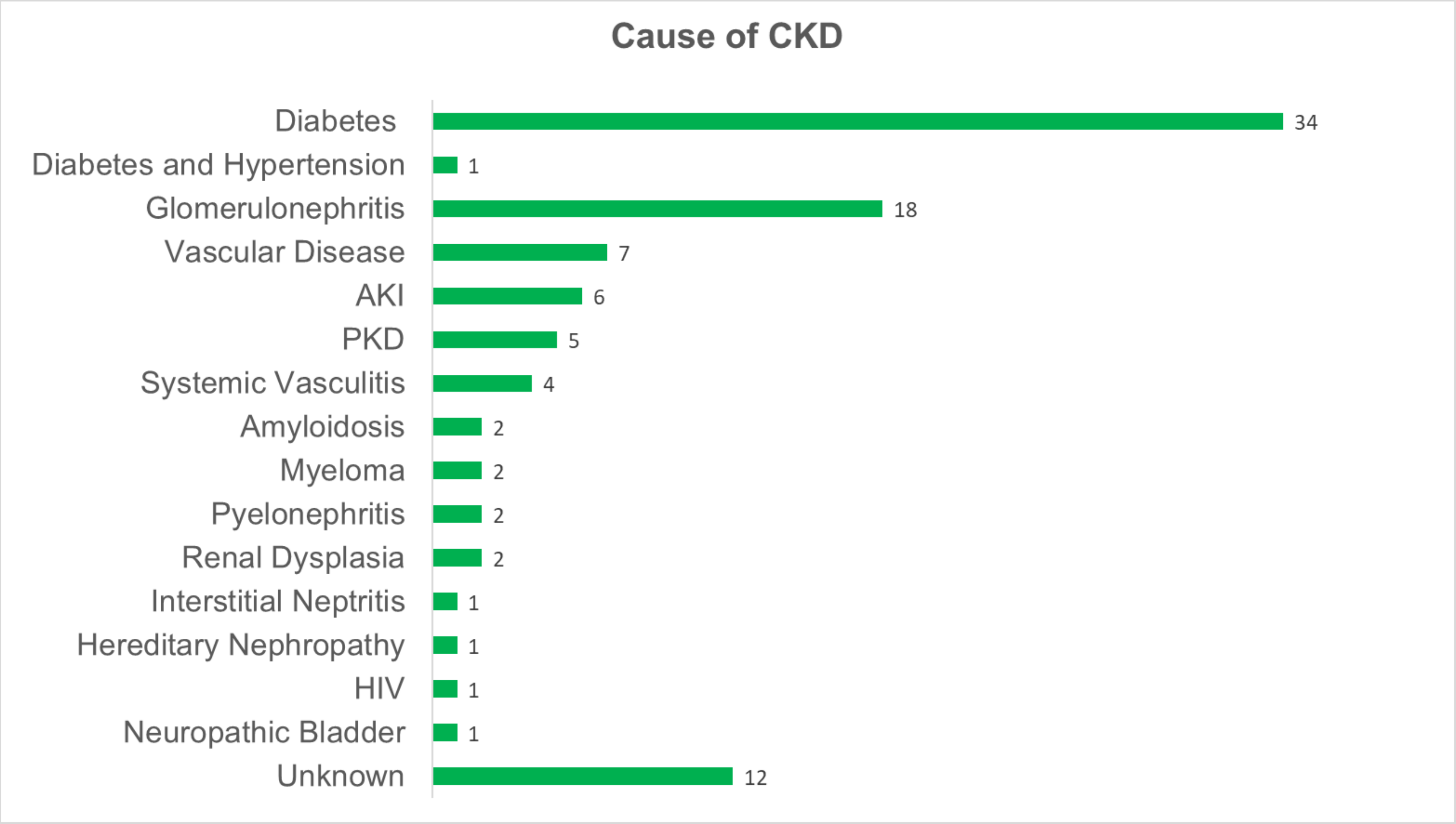


Figure 6: Cause of CKD for Participants completing Questionnaires to Assess Other Measurement Properties of the PPN

3.3.3.2 Missing Data

In total, 98 participants completed at least one questionnaire with only one participant completing no questionnaires. This participant was removed from the study before assessing missing data from questionnaires but is included in the participant characteristics described above. This provided a study sample of 98 participants. Two participants were withdrawn from the study before PPN T2 completions due to ill health, meaning only 96 participants were asked to complete PPN T2. Missing data did not go above the threshold of 20%, with missing data from the PPN similar to that from the SF-VAQ.

Missing data occurred in questionnaires from 29 participants, with only six participants having data missing from more than one questionnaire. However, no participants had missing data from both PPN T1 and PPN T2. For PPN T1, five questionnaires were removed due to missing data from more than two questions and for the PPN T2 and SF-VAQ three questionnaires were removed. As the type of removed questionnaires (i.e. PPN T1, PPN T2 or SF-VAQ) due to missing data varied across participants, rather than missing questionnaires being from the same participant, the sample size for each test varied. Missing data for each questionnaire is described in more detail in Table 10. The remaining questionnaires had missing data replaced as described in section 3.2.4.3. Missing data was explored by question in the PPN, including those questionnaires that were removed, with missing data spread evenly across questions (Figure 7).

		Number of Participants	Remaining Sample (n)
PPN T1	Total	12 (12.1%)	93
	1-2 question answers missing	7 (7.1%)	
	More than two missing questions	5 (5.1%)	
SF-VAQ	Total	12 (12.1%)	95
	1-2 question answers missing	9 (9.1%)	
	More than two missing questions	3 (3.0%)	
PPN T2	Total	11 (11.1%)	95
	1-2 question answers missing	8 (8.1%)	
	More than two missing questions	3 (3.0%)	
Internal Consistency	Number of participants removed, due to missing data	0	98
Convergent Validity	Number of participants removed, due to missing data	8	90
Test-Retest Reliability	Number of participants removed, due to missing data	8	88
	Number of participants withdrawn before PPN T2	2	

Table 10: Missing Data from Questionnaires in Other Measurement Properties Phase

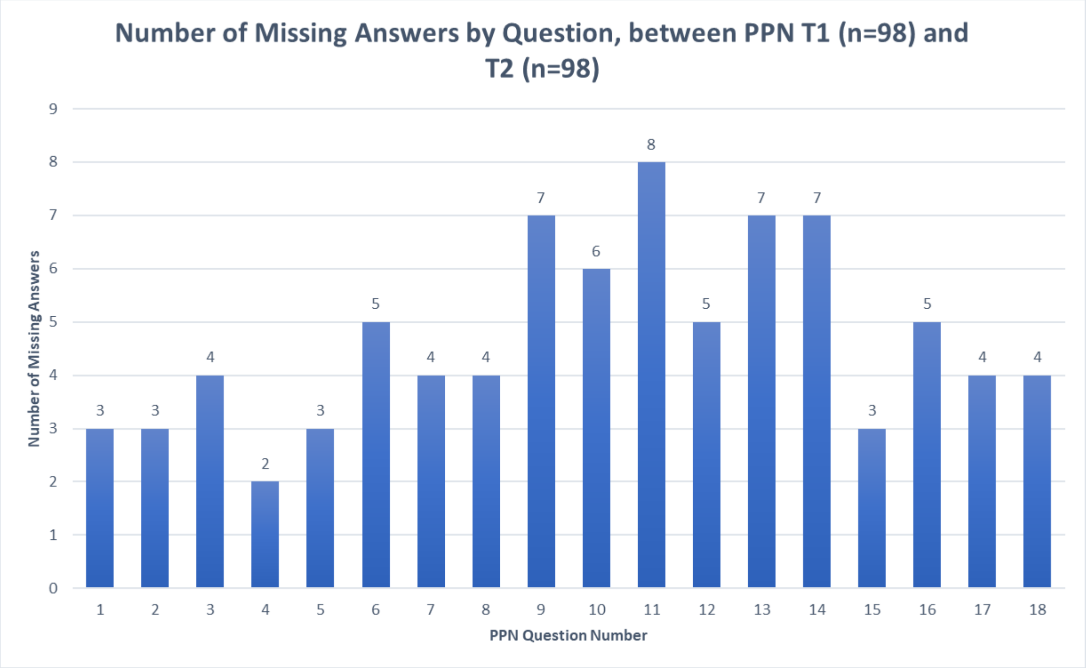


Figure 7: Number of Missing Answers from PPN T1 and T2, by question number

3.3.3.3 Measurement Properties

3.3.3.3.1 Question 18 of the PPN

Following completion of the ‘Other Measurement Properties’ phase, question 18 was removed from the PPN. This question asked how safe patients felt during the needling. This question had been queried during the development of the draft PPN and during the face validity phase. In the Measurement Properties phase, one participant stated in the free text comments box ‘*I do not understand the question ‘feeling safe’ – what do you mean by this?*’ (Participant ay). Sensitivity analyses indicated this question was not behaving as expected, with less reliability and validity than other questions. At this stage, there was concern about this question. This coincided with design of the qualitative interview study described in Chapter 4. Therefore, an appropriate question was included in interviews to explore this concept of feeling safe during cannulation with participants. During these interviews participants did not appear to relate to this question, not understanding what the interviewer meant by safety or answering the question with factors related to personal safety, rather than the aspects related to feeling safe during needling, as described in section 2.5.4.3. Therefore, this question was removed from the PPN and analyses repeated without it. The following results describe the measurement properties of the final PPN, as described in section 3.3.4. However, when tests demonstrate how question 18 behaved with less validity and reliability, test results with the PPN including question 18 have been included alongside those of the final PPN. Removal of question 18 did not change the results of the missing data, reported in the previous section.

3.3.3.3.2 Distribution of PPN Answers

This data analysis uses the ‘Internal Consistency’ dataset, where any participant with an incomplete PPN T1 that was removed from the dataset had this replaced with PPN T2. This provided sample size of 98 participants for all the data represented in this section.

The distribution of PPN scores, section scores and question answers covered the whole spectrum of answers, although the distribution between different answers was not equal. The distribution of PPN and section scores are shown in Figure 8, Figure 9, Figure 10 and Figure 11. Of note, these scores were continuous data that has been categorised by 0.5 score range.

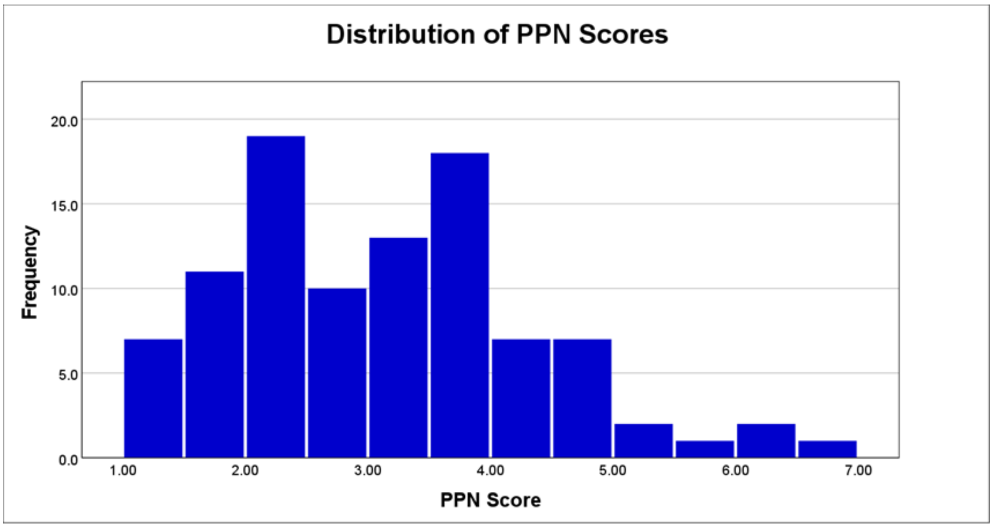


Figure 8: Distribution of PPN Scores

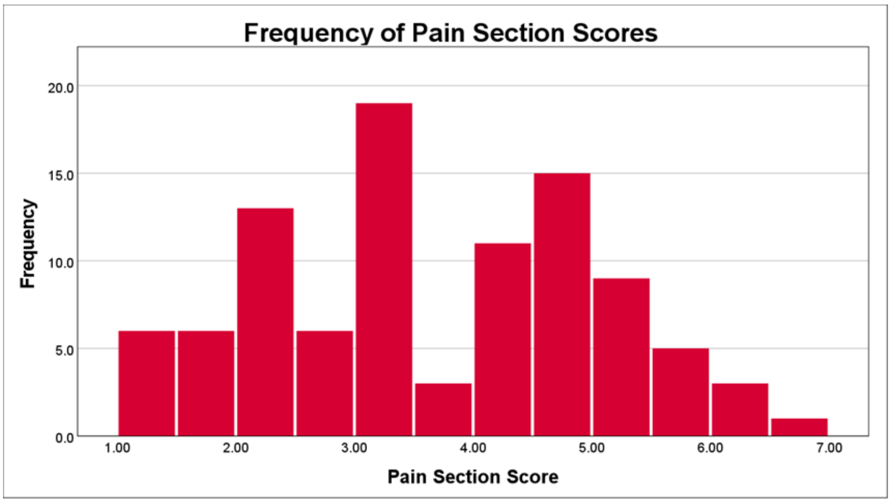


Figure 9: Distribution of Pain Section Scores

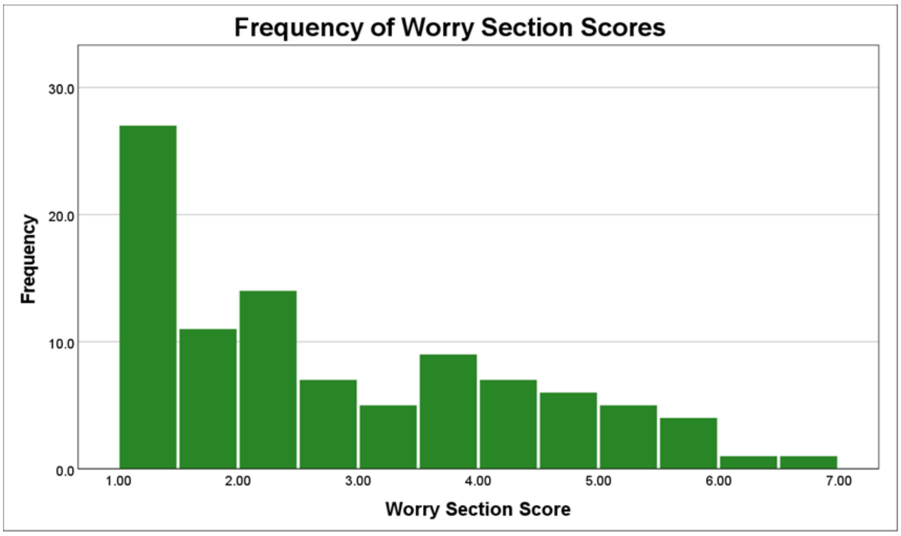


Figure 10: Distribution of Worry Section Scores

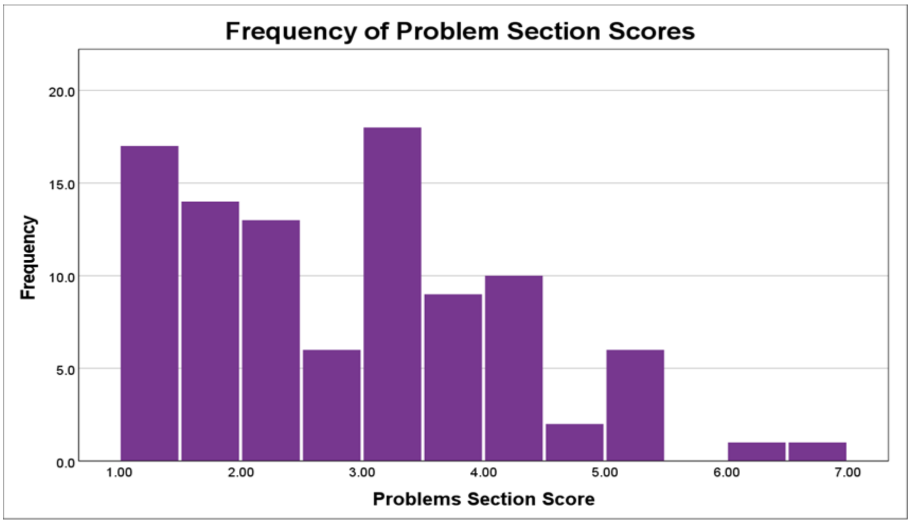


Figure 11: Distribution of Problems Section Score

For individual questions, all categories in each question had at least one participant choose this category except for score 6 for question 13.

3.3.3.3.3 Floor and Ceiling Effects

Mild floor effects were present in individual questions, and in the worry and problems section. However, floor and ceiling effects were absent in the total PPN score and pain section. The results are shown in Table 11. A floor effect in Question 3 was expected, as this asked about the least amount of pain they experienced. Whilst floor effects occurred in Questions 6, 7, 8, 10, 12 and 14, there was also a number of participants who scored 7 in answer to these questions. Both Question 5 and 16 asked about less frequent complications of needling, meaning floor effects could be explained as valid. The floor effects in Questions 9, 11 and 13 could not be explained easily, although there were still participants who scored 7 and patient representatives still felt these questions were important to include.

	No. Participants Scoring 1.0-1.99	**No. Participants Scoring 6.00-7.00**
PPN	18 (18.4%)	3 (3.1%)
Pain	12 (12.2%)	5 (5.1)
Worry	**38 (38.8%)**	3 (3.1%)
Problems	**31 (31.6%)**	3 (3.1%)
	No. Participants Scoring 1	**No. Participants Scoring 7**
Qu 1	8 (8.2%)	8 (8.2%)
Qu 2	4 (4.1%)	21 (21.4%)
Qu 3	**30 (30.6%)**	2 (2.0%)
Qu 4	7 (7.1%)	15 (15.3%)
Qu 5	**36 (36.7%)**	3 (3.1%)
Qu 6	**35 (35.7%)**	18 (18.4%)
Qu 7	**32 (32.7%)**	9 (9.2%)
Qu 8	**31 (31.6%)**	11 (11.2%)
Qu 9	**46 (46.9%)**	6 (6.1%)
Qu 10	**32 (32.7%)**	10 (10.2%)
Qu 11	**45 (45.9%)**	7 (7.1%)
Qu 12	**32 (32.7%)**	8 (8.2%)
Qu 13	**51 (52.0%)**	2 (2.0%)
Qu 14	**38 (38.8%)**	14 (14.3%)
Qu 15	24 (24.5%)	5 (5.1%)
Qu 16	**33 (33.7%)**	2 (2.0%)
Qu 17	21 (21.4%)	3 (3.1%)

Table 11: Floor and Ceiling Effects in the PPN

Floor effects between 30-40% highlighted in orange and floor effects over 40% highlighted in red.

3.3.3.3.4 Measurement Properties

Internal consistency was assessed using 93 PPN T1 questionnaires and five PPN T2 questionnaires, providing a sample total of 98 participants. The internal consistency for the overall PPN was 0.937 (95% CI 0.917-0.954) (p<0.001). The internal consistency for sections are summarised in Table 12. The full PPN score provided the highest internal consistency. Results of Cronbach alpha reached the desired threshold, with all confidence intervals also meeting this threshold, except for the problems section. The lower CI for the problems section was under 0.7. This section contained only three items, which may lead to underestimation of the internal consistency. Therefore, it was judged that this level was adequate. Question 18 made the overall internal consistency of the PPN slightly worse, but the problems section was significantly worse with Question 18, indicating problems with this question.

	Number of Qus	Desired Threshold	Cronbach Alpha	95% CI	p value
Total PPN	17	Above 0.7	0.937	0.917 - 0.954	<0.001
Pain Section	5		0.877	0.833 - 0.911	<0.001
Worry Section	9		0.932	0.910 – 0.950	<0.001
Problems Section	3		0.748	0.648 – 0.824	<0.001
Total PPN with Qu 18	18		0.934	0.913-0.954	<0.001
Problems section with Qu 18	4		0.632	0.497-0.738	<0.001

Table 12: Internal Consistency results for total PPN and sections

Convergent validity was only assessed where there was a PPN T1 questionnaire and SF-VAQ completed on the same occasion. Therefore, 90 participants were included in the convergent validity test. One participant did not complete Question 4-15 in the SF-VAQ but did complete Question 3. This participant had completed PPN T1. Therefore, they were included in the comparison of the PPN to SF-VAQ Qu 3, increasing the sample number to 91 participants for this test.

Convergent validity of the PPN to the SF-VAQ showed a correlation (using Spearman’s rho) to Question 3 of -0.347 (95% CI -0.146 - -0.521) (p<0.001) and to Question 4-15 of 0.613 (95% CI 0.450-0.736) (p<0.001). The convergent validity of sections of the PPN is summarised in Table 13. Convergent validity to Questions 4-15 of the SF-VAQ met the desired threshold. Convergent validity to SF-VAQ Question 3 was below the desired threshold, however the negative correlation was expected. Question 3 in the SF-VAQ is a generic item examining patients' satisfaction with their vascular access, so a weak correlation with this question was judged not to be of concern. Sections varied in their correlation to SF-VAQ 4-15, with the worry section demonstrating the strongest correlation. As convergent validity thresholds for the total PPN were met with Question 4-15 of the SF-VAQ, this was judged as acceptable. The PPN and problems section with Question 18 showed slightly better correlation with the SF-VAQ, but not enough to justify its inclusion.

	Desired Threshold	r	95% CI	p value
Total PPN to SF-VAQ Qu 3	0.4-0.7	0.347	-0.146-0.521	0.001
Total PPN to SF-VAQ Qu 4-15		0.613	0.450-0.736	<0.001
Pain Section to SF-VAQ Qu 4-15		0.494	0.308-0.643	<0.001
Worry Section to SF-VAQ Qu 4-15		0.617	0.455-0.740	<0.001
Problems Section to SF-VAQ Qu 4-15		0.411	0.215-0.575	<0.001
Total PPN with Qu 18 to SF-VAQ Qu 4-15		0.640	0.483-0.757	<0.001
Problems Section with Qu 18 to SF-VAQ Qu 4-15		0.490	0.304-0.640	<0.001

Table 13: Convergent Validity between SF-VAQ sections and PPN and sections

Test-retest reliability was assessed in participants who completed both the PPN T1 and PPN T2. This provided a sample of 88 participants. The median time between PPN completions was 4 days (IQR 2-7 days), with the minimum time at 2 days and the maximum time at 14 days. The test-retest reliability for the total PPN was 0.856 (95% CI 0.788-0.904) (p<0.001), with both the value and 95% CI meeting and exceeding the desired threshold.

The test-retest reliability for sections of the PPN is summarised in Table 14. Again, sections met the desired threshold, with both pain and worry demonstrating good test-retest reliability. The problems section had an adequate rather good correlation for test-retest reliability, but still met the desired threshold. Question 18 made minimal difference test-retest reliability.

	Number of Qus	Desired Threshold	Intra-class Correlation	95% CI	p value
Total PPN	17	Above 0.5	0.856	0.788-0.904	<0.001
Pain Section	5		0.854	0.773-0.906	<0.001
Worry Section	9		0.806	0.718-0.869	<0.001
Problems Section	3		0.688	0.560-0.783	<0.001
Total PPN with Qu 18	18		0.856	0.787-0.903	<0.001
Problems Section with Qu 18	4		0.669	0.536-0.770	<0.001

Table 14: Test-Retest Reliability of PPN and sections

A further test-retest analysis was completed, where participants who stated their cannulation had changed between PPN T1 and PPN T2 were removed from the analysis. Of the total sample of 88 participants, 32 felt their cannulation changed between the two PPN completions. Therefore, this analysis was performed with data from 56 participants where they felt there had been no change in their experience of cannulation. Test-retest reliability improved when participants with a change in their cannulation were removed (Table 15), as would be expected.

	Including all Participants		Only including participants with no change in their cannulation	
	n	Intra-class correlation	n	Intra-class correlation
Total PPN	88	0.856 (0.788-0.904) (p<0.001)	56	0.911 (0.852-0.946) (p<0.001)
Pain Section	88	0.854 (0.772-0.906) (p<0.001)	56	0.846 (0.743-0.909) (p<0.001)
Worry Section	88	0.806 (0.718-0.869) (p<0.001)	56	0.867 (0.784-0.920) (p<0.001)
Problems Section	88	0.688 (0.560-0.783) (p<0.001)	56	0.766 (0.631-0.856) (p<0.001)

Table 15: Comparison of Test-Retest Results when Participants with a change in their needling were removed.

The hypothesis test, a form of construct validity described in section 3.2.4.3.6, was assessed using the ‘Internal Consistency’ dataset, providing a sample size of 98. The hypothesis to be tested was:

Q2 score ≥ Q1 score ≥ Q3 score

All participants met a part of this hypothesis, with 87 participants (88.8%) meeting both parts of the hypothesis and 11 participants meeting one part of the hypothesis (i.e. only met Q2 score ≥ Q1 score or Q1 score ≥ Q3 score, but not both). Of the 11 participants who did not fully meet the hypothesis, seven scored Question 2 lower than Question 1 and four participants scored Question 1 lower than Question 3. The median scores and median differences for Questions 1, 2, and 3 are demonstrated in Table 16. The Wilcoxon signed rank test demonstrated the differences between each pair reach a p-value of <0.001, indicating a statistically significant difference between question answers. The results of the ANOVA Friedman test, where all 3 pairs were tested together, also demonstrated a statistically significant difference (Table 17).

	Median	IQR	Wilcoxon Signed Rank
Qu 1	5	4-6	N/A
Qu 2	4	3-5	N/A
Qu 3	2	1-4	N/A
Difference Qu2-Qu1	1	0-2	p<0.001
Difference Qu1-Qu3	1	0-2	p<0.001
Difference Qu2-Qu3	1	1-3	p<0.001

Table 16: Median and Median Differences for Questions 1, 2, and 3 of the PPN

ANOVA Friedman	Mean	Mean Rank	Chi Squared	df	p
Q2 Mean	4.79	2.62	113.863	2	p<0.001
Q1 Mean	3.91	2.08			
Q3 Mean	2.75	1.31			

Table 17: ANOVA Friedman analysis of differences between Question 1, 2 and 3 in the PPN

3.3.3.3.5 Sensitivity Analysis – Missing Data

Whilst questionnaires with more than two questions missing were removed from analyses, questionnaires with one or two questions missing had missing answers replaced with the mean for the section. A further sensitivity analysis was completed excluding questionnaires with any missing answers. The results of this sensitivity analysis are summarised in Table 18 and Table 19. Overall, the analysis demonstrated that results were similar when missing data was replaced or excluded.

	PPN with Missing Data Replaced (1-2 qus only)		PPN with no missing data	
	n	Median (IQR)	n	Median (IQR)
PPN T1				
Total PPN	93	3.06 (2.09-3.76)	86	2.99 (2.07-3.76)
Pain Section	97	3.40 (2.40-4.80)	86	3.60 (2.40-4.80)
Worry Section	97	2.44 (1.44-4.00)	86	2.28 (1.41-4.00)
Problems Section	97	2.67 (1.67-3.67)	86	2.83 (1.67-3.67)
PPN T2				
Total PPN	93	2.88 (1.98-3.96)	85	2.87 (1.99-3.95)
Pain Section	95	3.20 (2.40-4.60)	85	3.20 (2.40-4.60)
Worry Section	95	2.56 (1.44-4.06)	85	2.56 (1.44-4.00)
Problems Section	95	2.33 (1.67-6.67)	85	2.33 (1.67-3.67)

Table 18: Results of PPN T1 and T2 with and without missing data replaced for 1-2 missing questions

	PPN with Missing Data Replaced (1-2 qus only)		PPN with no missing data	
	n	Test Result	n	Test Result
Internal Consistency	98	0.937 (0.917-0.954) (p<0.001)	86	0.937 (0.915-0.955) (p<0.001)
Convergent Validity with SF-VAQ Qu 3	91	0.347 (0.146-0.521) (p=0.001)	84	0.343 (0.132-0.524) (p=0.001)
Convergent Validity with SF-VAQ Qu 4-15	90	0.613 (0.450-0.736) (p<0.001)	80	0.635 (0.478-0.753) (p<0.001)
Test-Retest Reliability	88	0.856 (0.788-0.904) (p<0.001)	73	0.838 (0.751-0.896) p<0.001)

Table 19: Psychometric Tests of PPN with and without missing data replaced for 1-2 missing questions

3.3.3.3.6 Interpretation of PPN Scores

An item discrimination index was created (Table 20). Questions 1, 4, 7, 8, 10, 14 demonstrated good discrimination between different cannulation experiences. These questions were within the pain and worry sections, specifically about overall pain, the frequency of pain, worry about pain, worry about multiple needles attempts, worry about problems with the AV access and worry about who will insert the needles. No questions demonstrated poor discrimination and no questions had a negative discrimination index. Questions 13 and 16 had the lowest discrimination index.

Item	**Proportion endorsed from H**	**Proportion endorsed from L**	**Item Discrimination Index**
Qu 1	**1.0 (100%)**	**0.04 (4%)**	**0.96**
Qu 7	**0.92 (92%)**	**0**	**0.92**
Qu 8	**0.92 (92%)**	**0.04 (4%)**	**0.88**
Qu 14	**0.84 (84%)**	**0**	**0.84**
Qu 4	**0.96 (96%)**	**0.16 (16%)**	**0.80**
Qu 10	**0.80 (80%)**	**0**	**0.80**
Qu 6	0.76 (76%)	0	0.76
Qu 12	0.76 (76%)	0	0.76
Qu 2	1.0 (100%)	0.36 (36%)	0.64
Qu 5	0.68 (68%)	0.04 (4%)	0.64
Qu 11	0.64 (64%)	0.04 (4%)	0.60
Qu 15	0.68 (68%)	0.08 (8%)	0.60
Qu 3	0.56 (56%)	0	0.56
Qu 17	0.64 (64%)	0.08 (8%)	0.56
Qu 9	0.52 (52%)	0	0.52
Qu 16	**0.48 (48%)**	**0.08 (8%)**	**0.40**
Qu 13	**0.28 (28%)**	**0**	**0.28**

Table 20: Item Discrimination Index

The standard error of measurement was calculated for the total PPN and each section score. Again, the answers to Question 18 raised concerns, with a standard error of measurement higher than one, although the group smallest detectable change at 95% CI did meet the threshold of below 1. Whilst the individual smallest detectable change was larger than expected, between 1.069 to 1.672 dependent on the CI, the group smallest detectable change was low and below the expected threshold.

	SEM*	Individual SDC**			Group SDC**		
		90% CI	95% CI	99% CI	90% CI	95% CI	99% CI
Total PPN	0.458	1.069	1.270	1.672	0.114	0.135	0.178
Pain	0.518	1.208	1.435	1.889	0.129	0.153	0.201
Worry	0.695	1.623	1.923	2.537	0.173	0.205	0.271
Problems	0.727	1.697	2.016	2.654	0.181	0.215	0.283
Qu 18	1.324	3.090	3.671	4.832	0.330	0.391	0.515

Table 21: Standard Error of Measurement and Smallest Detectable Change of PPN, Sections and Question 18

**Standard Error of Measurement ** Smallest Detectable Change*

Of note, as data were not normally distributed, it was recognised that the standard error of measurement and the smallest detectable change were likely over-estimated. However, no alternative equation is available to correct this.

3.3.4 The Final PPN

The final PPN contained 17 items, split into three sections:

1) Pain – 5 items
2) Worry – 9 items
3) Problems – 3 items

In comparison to the PPN v1, the 'Interaction in Needling' section and Question 18 (Question 15 in PPN v1) were removed. Minor changes to wording were made as described in section 3.2.3. The scales and free text box remained unchanged. The scoring system also remained unchanged, but the removal of the 'Interaction in Needling' section and Question 18 meant that all questions scored in the same direction. The final PPN is shown in Appendix 2.

3.3.5 Patients’ Experiences of Cannulation

The data from the PPN also provided further insight into patients’ experiences of cannulation for haemodialysis. The data from the Other Measurement Properties phase was used, examining the results from the ‘Internal Consistency’ dataset. This provided sample size of 98 participants. For clarity, the results have been reported without the inclusion of Question 18, reflecting the final PPN.

The median, with inter-quartile ranges, maximum and minimum scores for the total PPN and each section is shown in Table 22. The pain section scored the highest, indicating this was most problematic for patients, then the problems section and the lowest scoring section was worry. The means were examined beside the medians, to add granularity to the data and provide definition between questions. Questions related to the overall pain from needling, worst pain from needling, frequency of pain and frequency of machine alarms due to the needles all scored the highest, with medians of 3 or above. This was also reflected in their means. Questions that scored highly on the mean, but not on the median, included questions about the frequency of worry about their needling, worry about multiple needle attempts and worry about who will put the needles in. The lowest scoring question was related to worry about bleeding in between haemodialysis sessions, which is rare but traumatic event. The results to individual questions are summarised in Table 23. For interest, the questions with the highest discrimination index are highlighted in green.

	Median	IQR	Minimum	Maximum
Total PPN	3.08	2.07-3.76	1.00	6.56
Pain Section	3.40	2.40-4.80	1.00	7.00
Worry Section	2.39	1.44-4.00	1.00	7.00
Problems Section	2.67	1.67-3.67	1.00	7.00

Table 22: Median, minimum and maximum PPN and section scores

	Median (IQR)	Mean (95% CI)	Rank
Qu 2: Worst pain	5 (3-6)	4.79 (4.42-5.15)	1
Qu 4: Frequency of pain	**4 (2-6)**	**4.24 (3.86-4.63)**	**2**
Qu 1: Overall pain	**4 (3-5)**	**3.91 (3.57-4.25)**	**3**
Qu 17: Frequency of machine alarms due to needles	3 (2-4)	3.09 (2.75-3.43)	4
Qu 6: Frequency of worry	2 (1-5)	3.14 (2.68-3.60)	=5
Qu 14: Worry about who will put the needles in	**2 (1-5)**	**3.14 (2.69-3.60)**	**=5**
Qu 8: Worry about multiple needle attempts	**2 (1-5)**	**3.13 (2.71-3.56)**	**6**
Qu 12: Worry about bleeding at end of haemodialysis	2 (1-5)	2.99 (2.59-3.39)	7
Qu 10: Worry about problems with AV access	**2 (1-4)**	**2.97 (2.57-3.37)**	**8**
Qu 7: Worry about pain	**2 (1.5)**	**2.92 (2.51-3.33)**	**9**
Qu 15: Frequency of multiple needle attempts	2 (1.75-4)	2.89 (2.54-3.24)	10
Qu 3: Best pain	2 (1-4)	2.74 (2.41-3.08)	11
Qu 11: Worry about appearance	2 (1-4)	2.65 (2.26-3.03)	12
Qu 16: Frequency of bruising from needling	2 (1-4)	2.55 (2.23-2.87)	13
Qu 5: Pain during haemodialysis	2 (1-4)	2.54 (2.21-2.86)	14
Qu 9: Worry about whether needles with work for haemodialysis	2 (1-3)	2.39 (2.03-2.75)	15
Qu 13: Worry about bleeding between haemodialysis sessions	1 (1-2)	1.91 (1.65-2.16)	16

Table 23: Median and mean scores for individual questions form the PPN

Participants also provided a number of free text comments related to their experience of cannulation in both the PPN and FVQu. Free text comments from PPNs across all phases were included, as were those relevant comments from FVQu as discussed earlier. In total, there were 66 comments about needling experience from 47 participants, with 31 comments from PPN T1, 29 from PPN T2 and 6 from the questionnaires completed as part of the face validity phase (either the PPN FV or FVQu).

There were three themes and seven sub-themes that were identified from these comments:

- Theme 1: Difficulties with Cannulation

    - Sub-Theme 1: Pain from Cannulation
    - Sub-Theme 2: Anxiety about Cannulation
    - Sub-Theme 3: Problems getting the Needles in
- Theme 2: Cannulation experience Varies
    - Sub-Theme 1: Cannulation varies with the Cannulator
    - Sub-Theme 2: Cannulation experience varies with the Age of the AV access
    - Sub-Theme 3: Cannulation experience varies with Cannulation Technique
- Theme 3: Coping with Cannulation
    - Sub-Theme 1: The cannulation team can inspire trust and improve cannulation
    - Sub-Theme 2: Adapting to Cannulation

These are described further in the sections below, with quotes from participants highlighted in *italics*.

3.3.5.1 Theme 1: Difficulties with Cannulation

Participants used the free text box to expand on problems with their cannulation. These related to pain, anxiety and problems getting the needles in, coinciding with the three sections of the PPN, expanding or explaining their answers to questions.

3.3.5.1.1 Sub-Theme 1: Pain from Cannulation

Participants mentioned how the cannulation was painful, with some indicating that they felt this pain was inevitable: '*In any case you are going to experience pain when needling'* (Participant a, FVQu). This pain was problematic for some, with one participant stating '*I do find it all painful and I have to truly convince myself to accept that I have to go for treatment.*' (Participant au, PPN T1). However, others felt they could tolerate this pain: '*Yes it hurts, but it is always bearable*' (Participant y, PPN T2). For some local anaesthesia was essential to manage this pain: '*I use EMLA cream. So very rare do I feel any pain when putting needles in'* (Participant p, PPN T2). However, some participants also found the local anaesthesia problematic: '*I also have to have lidocaine before inserting as the creams don't seem to work, this is quite painful and makes me anxious*' (Participant aa, PPN T1).

3.3.5.1.2 Sub-Theme 2: Anxiety about Cannulation

Participants felt '*needling is horrid and makes you anxious beforehand*.' (Participant g, FVQu). One participant stated: '*I tend to find it hard to sleep on the evening before dialysis*' (Participant ad, PPN T1). Others talk about their fear of the cannulation: '*I do fear having my needles put in… I feel the worst part about the process is if transport collect early and time is spent waiting in reception and then my apprehension becomes worse*.' (Participant au, PPN T1). However, not all participants worried or found this worry or anxiety problematic: '*The worry about having needles inserted is brief, the time it takes to walk into the unit and actually have the needles inserted.*' (Participant av, PPN T2). Anxiety also seemed to change over time, with participants becoming less anxious, once the procedure is no longer new: '*When I was first on dialysis 10 years ago I was worried about the whole procedure but not at the moment*.' (Participant m, PPN T2). Two participants indicated that anxiety about cannulation is not just experienced by patients, but also by the healthcare staff inserting the needles. Whilst one participant recognised this and reassured the cannulator: '*Sometimes if they can't get the needles in they get frustrated and I tell them it's OK*.' (Participant aq, PPN T2), another found this reduced his confidence in the cannulator: '*Many worry about causing pain and it doesn't install confidence in you or in them.*' (Participant ao, PPN T2)

3.3.5.1.3 Sub-Theme 3: Problems getting the needles in

This sub-theme is about getting the needles into the vein successfully and whether this was problematic or not: *'I always have trouble needling my venous. Arterial is OK. I have had lots of blows!'* (Participant an, PPN T1). Some participants mentioned that more than one attempt to insert the needle leads to searching for the vein: '*It feels like they are treasure hunting or digging for the vein.*' (Participant ao, PPN T2). Two participants linked problems with getting the needles in with a more painful cannulation: '*It depends who puts needles in and how often they have to retry to the pain I get*.' (Participant ab, Q2 questionnaire). Three participants felt their own personal anatomy made it a more difficult cannulation:

> *'My fistula is of a peculiar nature and special.'* (Participant ag, PPN T1)

I feel I have a 'problematic' graft which can cause issues for people who do not needle me regularly’ (Participant i, PPN T2)’

‘I am not sure but (=) [sic] do believe that because of my experience when needling is hard to put the needle in because my skin is so hard. Therefore, they have to push the needle with more force which sometimes makes me worry about hitting the wall of my fistula.’ (Participant as, PPN T1).

Participants also related difficulties with cannulation causing problems during their treatment: ‘*Sometimes have high arterial pressures during treatment which is maybe due to the needling and causes alarms’* (Participant u, Q1 questionnaire).

3.3.5.2 Theme 2: Cannulation Experience Varies

Many comments indicated that cannulation experience varied. Experience could vary with the cannulator, the age of the AV access and the cannulation technique. There is indication across the analysis that difficulties with cannulation vary between sessions, between participants and also over the longer term.

3.3.5.2.1 Sub-Theme 1: Cannulation varies with the Cannulator

Cannulation experience appeared to vary with different cannulators: ‘*Some people hurt when putting needles in by pressing too hard and re-inserting them. Some people I never feel it at all’* (Participant ab, PPN T1). Comments were made that different cannulators were more gentle or more forceful, with gentleness leading to a better cannulation experience: '*Its to who puts needles in. You sometimes hope it is someone who is gentle and some nurses just go for it.*' (Participant z, PPN T2). However, some preferred speed rather than gentleness to minimise pain: '*Worker's experiences differ with how to insert the needle at the initial point, by inserting the needle quickly - less pain. As to inserting the needle slowly - which is more painful*.' (Participant aw, PPN T1). Cannulators were also perceived to vary in confidence and experience: '*Sometimes it depends on who does the needling. I think some nurses are more confident than others …..* ' (Participant y, Q2 questionnaire); *'Instruction must be given and only with experience will they get it right (sometimes they do and sometimes they don't).*' (Participant ag, PPN T1). Some participants felt there were individual cannulators that made their experience better and thus trusted familiar cannulators. This often led to a desire for consistency in the staff that cannulated them:

> *'Its nicer if you have the same one who needles you regularly as you know you can trust them and they know how to get your needles right'* (Participant g, FV questionnaire)

> *'I don't agree with a different nurse each dialysis. The nurse doesn't know what happened last time, where they went or if there were any problems. This leads to scarring as they go for the easiest each time. There is no records of where they've gone. A lot of the time they are asking 'where am I going'. They shouldn't be asking you. They are too busy so they are going to do what is easiest but that is detrimental for the patient.'* (Participant ao, PPN T1).

3.3.5.2.2 Sub-Theme 2: Cannulation experience varies with the age of the AV access

Participants indicated that cannulation experience changed over time, with cannulation experience improving as the AV access became established: '*At the beginning the needles were a problem and machine GOING OFF a lot. After 6 months of being on, the staff have done wonders with everything, and everything as very much improved.*' (Participant at, PPN T1). However, one participant felt that the age of the AV access made it harder to cannulate: '*My fistula is now eleven years old and I need special treatment of the nurse who puts me on most of the nurses know me and are very good at needling.'* (Participant r, PPN T2).

3.3.5.2.3 Sub-Theme 3: Cannulation experience varies with Cannulation Technique

A few participants felt the needling technique used affected their experience, with different participants undergoing different techniques. This highlighted different elements of the cannulation procedure that varied between the two different techniques:

- *'I liked the buttonhole needling which I could do myself.'* (Participant who converted from buttonhole to rope ladder / area puncture) (Participant m, PPN T1)
- *'Probably need to visit the removal of scabs which can be painful as much as the needling.'* (Buttonhole technique) (Participant aj, PPN T2)

- *‘Been on sharps. I do not find problems with taking scabs off so it is much easier.’* (Participant who converted from buttonhole to rope ladder / area puncture) (Participant ad, PPN T2)

3.3.5.3 Theme 3: Coping with Cannulation

Comments from participants also indicated how they coped with the cannulation procedure. Again, the cannulator had a significant impact on this, but comments indicated how the whole team of cannulators could have a positive effect on cannulation experience. Participants also mentioned how they had become ‘used’ to cannulation, accepting it as an inevitable part of their life. A few participants demonstrated how they used humour to cope with cannulation, whilst others discussed how an alternative to AV access was the best way to improve cannulation, by avoiding it.

3.3.5.3.1 Sub-Theme 1: The cannulation team can inspire trust and improve cannulation

Whilst some participants made comments about how some cannulators improved or worsened their experience, some participants praised the whole cannulation team, trusting the whole team to do their cannulation well:

‘*I think some nurses are more confident than others' but this does not bother me and I have complete trust in all of the team.*’ (Participant y, PPN T2)

‘*I have complete trust in the team treating me whatever the future’* (Participant z, PPN T1).

This indicated they felt '*All the nurses do a good job and look after us in a brilliant way*' (Participant x, PPN T2). This made the cannulation easier to get through: '*All staff are positive, patient and friendly which helps to feel calmer'* (Participant c, PPN FV phase). One participant expressed his frustration with the nursing team not listening to him about his cannulation: '*I wish the nurses could listen to my facts as a patient.*' (Participant ae, PPN T1).

3.3.5.3.2 Sub-Theme 2: Adapting to Cannulation

A few participants commented on how they have become 'used' to cannulation and it is an inevitable part of life and receiving haemodialysis:

'Yes it hurts but ….. I have to go through what I have to go through so no point in worrying about it, just get on with it.' (Participant y, PPN T1)

'Having the needle in is now part of my life that I have gotten used to.' (Participant ag, PPN T1).

One participant indicated *'…. it really doesn't bother me, but I just get on with it.'* (Participant ax, PPN T2). Some participants demonstrated how they used humour to help them deal and adapt to the cannulation: *'I try to make joke of it'* (Participant ae, PPN T1). These statements indicated that individual participants had adapted to having cannulation for haemodialysis.

3.4 Discussion

This study developed a new questionnaire, the Patients' Perspective of Needling questionnaire (PPN) to measure patients' experiences of canulation for haemodialysis undertaken by healthcare professionals. This is a PROM type questionnaire that measures the consequences of needling for the patient. It is evaluative, designed to be used within research to measure the impact of interventions on patients' experiences of cannulation. The PPN was developed with patient representatives, underwent validity and reliability tests, and an exploration of how to interpret scores. The results of tests indicate the questionnaire behaves in valid and reliable manner for the tests completed. However, there are mild floor effects within the questionnaire. The smallest detectable change indicate that a change in PPN score above 0.3 is the minimum threshold for a clinically meaningful change.

The results of data from the PPN indicate that pain is the section scoring the worst, with problems with cannulation and worry scoring similarly. The highest scoring questions related to the overall pain from needling, worst pain from needling, frequency of pain, frequency of machine alarms due to the needles, frequency of worry about their needling, worry about multiple needle attempts and worry about who will put the needles in. Free text comments from the PPN expand on participants answers to questions: describing further the pain worry and problems with cannulation they experience; describing how their experience varies with the cannulator, age of the AV access and cannulation technique; and describing how they cope with cannulation explaining how the team of cannulators support them and how they adapt to cannulation.

In line with the aims, research question and objectives of this study, this discussion will explore the measurement properties of the questionnaire further and also what the initial data tells us about patients' experience of cannulation for haemodialysis.

3.4.1 Validity of the PPN

Validity was an important concept assessed in this study, exploring whether the PPN measured what it claimed to measure. Whilst content validity is a concept that can be measured exploring understandability, comprehensiveness and relevance (Mokkink et al., 2010b), how the questionnaire is developed also affects it's content validity (DeVellis, 2012). The approach used to develop the PPN, using patient representatives alongside the findings from the systematic review, potentially guides the content of the questionnaire to be grounded in patients' true experiences of cannulation contributing to its content validity, although it does not guarantee this. Within this study, content validity was also assessed through face validity, using a second questionnaire administered to participants at the same time as the PPN. This provided assurance of ease of understanding, relevance and comprehensiveness, providing a guide on the content of the PPN that needed adjustment. However, there are other methods that can be used to assess content validity, including exploratory qualitative interviews and cognitive interviewing, which can be used to ensure content is truly based in patients' experience and participants interpret questions as intended (Bredart, Marrel, Abetz-Webb, Lasch and Acquadro, 2014). These methods are likely more rigourous that the use of a questionnaire to assess content validity. This decision to use a questionnaire was pragmatic, to enable development of the questionnaire within the timescale allowed. However, it is recognised this method is superficial, providing limited assurance of content validity.

Other assessments of validity have been included in this study, exploring convergent validity and a small element of construct validity. Convergent validity was assessed by correlating the results of the PPN to the SF-VAQ. Whilst the overall PPN demonstrated the expected level of correlation with the SF-VAQ, the different section correlation with the SF-VAQ varied, with not all confidence intervals meeting the desired criteria. However, the two questionnaires measure two slightly different concepts - vascular access experience and cannulation experience – meaning this test similar not the same concepts. The SF-VAQ also appears to have an unrecognised floor effects, which may blunt its ability to detect change or differences in vascular access experiences (see section 3.1.3). This may explain the poorer performance of some of the PPN section correlations to the SF-VAQ.

The hypothesis test to assess structural validity, whilst only assessing a small portion of the questionnaire, does provide some reassurance that participants were interpreting these three questions correctly. The low level of missing data, equivalent to the SF-VAQ, also provides some reassurance of validity. Large volumes of missing data can indicate a problem with the questionnaire, where participants do not find questions easy to understand or relevant (US Department of Health and Human Services Food and Drug Administration, 2009). Missing data was similar across each question, indicating questions were likely missed by mistake rather than due to an issue with specific questions. Whilst this is not a formal measure of validity, it contributes to reassurance of the PPN's validity.

3.4.2 Reliability of the PPN

In this study, the reliability of the PPN was determined by the internal consistency and test-retest reliability. The results of these tests were better than expected, with an excellent internal consistency (0.937 (95% CI 0.917-0.954, p<0.001)) and strong correlation between PPN T1 and PPN T2 for test-retest reliability (0.856 (0.788-0.904, p<0.001). The slight improvement in test-retest reliability when participants were excluded who had experienced a change in their needling between completing PPN T1 and PPN T2, reassures again of the reliability of the questionnaire and suggests (although does not determine) that the PPN is responsive to changes in cannulation experience.

Despite these positive results, these results still need to be interpreted with caution. Both Cronbach alpha and intra-class correlation coefficient are affected by the number of items in the questionnaire, with more items automatically increasing reliability (DeVellis, 2012). Thus, the section internal consistency and test-retest reliability scores are also lower than the overall internal consistency, which may be influenced by the smaller number of items in the sections, in comparison to the complete PPN. However, the improvement of internal consistency in the problems section when Question 18 is removed, despite there being less items in this section, reinforces concerns about Question 18's reliability.

There is also a school of thought that an internal consistency above 0.9 or 0.95 can demonstrate a problem with the questionnaire, where there is too much homogeneity indicating redundant items (Tavalok and Derrick, 2011), although this view is not consistent within the literature. As the PPN achieved an internal consistency above 0.9, this perspective was considered. However, no repetition was identified in items and patient representatives continued to believe all elements were relevant, asking about differing concepts. Therefore, no changes were made to the PPN despite a high internal consistency.

Using absolute agreement for intra-class correlation, which was done in this study, reassures again of the reliability of the PPN, as this examines a strict agreement between the two questionnaire completions (DeVellis, 2012). However, it should be recognised that the time between questionnaire completions was short, increasing the chance participants remembered their answers to the T1 PPN when completing it at T2. This could mean the test-retest reliability was slightly over-estimated, although there was no actual indication this was true. This demonstrates the caution with which reliability results were interpreted, where no single test was viewed in isolation, but each test contributed to a whole picture of the measurement properties of the PPN. Therefore, when one test indicated a change may be required, the impact on other elements of validity and reliability, especially content validity, was considered.

3.4.3 Floor Effects with the PPN

The PPN demonstrated mild floor effects, with twelve questions and two sections having over 30% of participants score one (or between 1.0-1.99 for section scores). However, only three questions demonstrated floor effects of concern, with over 40% of participants scoring one. There was consideration of the causes of these floor effects and whether they were of concern. However, there is an effect noted by Sampson, O’Cathian and Goodacre (2010), where patients were reticent to criticise a service they perceive as saving their life as they were grateful, even though there were elements of the service that could be improved. Within free text comments from the PPN, there was evidence that participants expressed gratitude for the care they received. Despite the PPN not asking about the quality of care, some participants felt they needed to justify that they were well looked after, indicating that they did not want the team that cared for them to be criticised. Whilst these comments could be interpreted in various ways, they do indicate at a reticence to criticise care, which may explain the mild floor effects. This effect was also identified in the later semi-structured interview study.

It was also noted that all questions in the worry section had mild floor effects. Serious consideration was given as to whether the word ‘worry’ needed to change and whether it was too strong, recognising a social context surrounding its interpretation. This was discussed with both patient representatives and collaborators. Alternatives considered included anxiety, apprehension and concerns. However, patient representatives felt these alternatives may not be understood by all patients and that ‘worry’ was a universally known concept. Therefore, it was decided that ‘worry’ was likely the best word to use, and other alternatives could be more problematic.

Finally, some of the questions with floor effects, also had a high discrimination index, indicating that they discriminated well between poor and less poor experience. Therefore, the floor effects may not be as problematic as first thought or the threshold to define floor effects may have been too strict. Due to all these factors, despite mild floor effects in the PPN, these were judged not to be problematic and did not warrant any changes to the PPN.

3.4.4 Interpretation of PPN scores

Two sets of tests facilitated interpretation of the PPN scores. The items discrimination index demonstrated those questions that best discriminated between those with a worse and less worse experience. Whilst the whole questionnaire is the optimal way to determine whether interventions make a difference to patients’ experiences of cannulation, answers to individual questions may provide indication of how the interventions improve their experience. The questions with the highest discrimination index may be the individual questions that add granularity and understanding to data.

The PPN had a narrow ‘Group smallest detectable change’, indicating that a change in score over 0.3 may indicate a clinically meaningful change. Of note, the smallest detectable change is not the same as a clinically meaningful change but does set a threshold that the clinically meaningful change must be above (Mokkink et al., 2010b). This indicates the PPN could pragmatically be used within research, with a large change in groups scores not required to detect differences between interventions. However, the individual smallest detectable change was larger than expected, ranging between 1.069 to 1.672 dependent on the CI. This is unlikely to be a realistic level from a change in score to expect within a seven-point scale. Therefore, whilst the PPN will be useful within research, it is likely to be less useful on an individual level to guide clinical practice.

Of note, the overall PPN demonstrated better validity and reliability than section scores. Therefore, whilst section scores may be useful to add granularity and understanding to data, the overall PPN score is the score of most interest and relevance to research.

3.4.5 Patients' Experiences of Cannulation

Unsurprisingly, pain was the highest scoring section of the PPN, with individual questions relating to the level and frequency of pain scoring highly. Pain is the most frequently researched element of cannulation experience, with many research studies using a 10-point VAS to assess cannulation pain. However, this score hasn't been validated for pain from cannulation, developed to assess a single dimension of pain, its intensity, likely lacking sensitivity to measure this (Fielding et al., 2022a). The PPN adds another level of granularity to pain related to cannulation, not just scoring pain intensity associated with a single cannulation event but collecting data on from multiple questions over a period of time (asking participants to consider the last four weeks). This allows further questions about their best and worst pain, as well as overall pain, considering the frequency of pain and pain during haemodialysis. The free text comments from the PPN also further illuminated participants experiences of pain. These highlighted how pain levels varied between individuals, but also how they coped with this pain varied, either finding it problematic or 'bearable'.

Local anaesthesia was highlighted in free text comments as something that could reduce pain, although this did not appear make cannulation better for all participants. Whilst the effectiveness of local anaesthesia has been evaluated in non-haemodialysis settings (Alobayli, 2019; Bond, Crathorne, Peters, Coelho, Haasova, Cooper, Milner et al., 2016), studies to evaluate this in haemodialysis settings have small samples sizes (Mirzaei, Javadi, Eftekhari, Hatami and Hemayati, 2017), often focussing on paediatric cannulation (Ravanshad, Golsorkhi, Ravanshad, Azarfar, Esmaeeli and Ghodsi, 2021) or comparing different types of local anaesthesia (George, George, Masih, Philip, Shelly, Das and Rajamanickam, 2014). Currently there is no definitive study to demonstrate the effectiveness of local anaesthetic to reduce pain associated with cannulation in the context of haemodialysis, or to consider its effect when used over periods of time for regular or for deep cannulation, characteristics of cannulation for haemodialysis. The PPN highlights the issue of pain related to cannulation for haemodialysis in more detail, with local anaesthesia a possible solution that requires further investigation.

The PPN results also highlight worry associated with cannulation. Whilst worry or anxiety related to cannulation for haemodialysis has been recognised in some research, it is generally poorly recognised and understood. Duncanson, Le Leu, Shanahan, Macauley, Bennett, Weichula, McDonald et al. (2021) completed a scoping review exploring needle fear, identifying five articles on needle fear in CKD. They found the prevalence of needle fear in haemodialysis patients was high, affecting 36-47% of the population. Wilson and Harwood’s (2017) qualitative study highlights that pain from cannulation leads to anxiety. The synthesis of findings from the qualitative systematic review in Chapter 2 highlights that worry is also associated with whether cannulation will be successful. Another study using the VASQoL questionnaire also found that patients worried about the function of their access (Richarz et al., 2021). The PPN similarly asked about worry related to AV access function and the answers to this question were 8th. in ranking of worst experience, scoring in the middle. Whilst this concept ranked lower in the PPN than the VASQoL study, this may be attributed to the different focuses of the studies, with VASQoL measuring how quality of life is affected by vascular access rather than cannulation experience. The PPN results provide further context to understanding worry associated with cannulation for haemodialysis beyond these studies, indicating that patients worry the most about experiencing multiple needle attempts and who will cannulate them. Free text comments again provide further context, indicating that worry varies, being worse when they are new to cannulation. However, the PPN does not provide full understanding of what patients' worry about in relation to cannulation for haemodialysis and further studies need to explore this.

Free text comments from the PPN often coincided with the three sections of the PPN - pain, worry and problems - expanding or explaining their answers to questions. However, despite these being free-text comments, they are likely framed by the questionnaire, rather than freely volunteered due to their importance to the patient. The PPN likely guided patients to comment on these aspects and provide more context. The variability in cannulation experience was also highlighted in free text comments, not just between individual experiences but also within individuals over time and between haemodialysis sessions. This provides insight into how the cannulator affects patients' experiences, affecting how much pain they experience and how cannulators vary in their experience and confidence. Whilst variation in cannulation experience is well recognised in clinical practice, it is something that has never been explored or acknowledged explicitly within current research, indicating this recognition of variation in experience is novel. Further research is needed to explore this variability. Free text comments also highlighted that the whole team of cannulators can support patients through cannulation. Again, this is another novel finding within research, but not well recognised in clinical practice, that requires further exploration in research. This resonates with the ’Feeling Safe’ sub-theme identified in the systematic review in Chapter 2. The sub-theme describing how participants adapt to cannulation as part of their everyday life also enlightens how patients incorporate this into their everyday life by becoming ‘used to it’. Again, this relates to the ‘Learning to Tolerate Cannulation’ sub-theme identified in the systematic review in Chapter 2.

3.4.6 Strengths and Limitations of this Study

A strength of this study is the diverse population that was recruited. Whilst only twelve participants took part in the face validity phase, purposive sampling ensured this was still a diverse population with a wide spectrum of age, vascular access type, haemodialysis vintage and cannulation vintage, and a mix of gender and ethnicity. The sample recruited in the ‘Other Measurement Properties’ phase was similar to the normal haemodialysis population in key characteristics. The UK in-centre haemodialysis population is 62.2% male a with a median age of 66.5 years (UK Renal Registry, 2022). This study recruited a similar proportion of males, and the study population median age was slightly older than the normal UK population. The UK in-centre haemodialysis population is 14.6% Asian and 11.6% black, with a 75% white population (UK Renal Registry, 2022). This study recruited slightly more Caucasian patients (81.1%) than the normal UK populations. Unfortunately, no further national data are available, including no data on the types of AV fistulae or grafts in use. However, the diversity in the sample, not just in characteristics, but also in cannulation technique and administered at two different renal centres, means the results are likely representative of other UK in-centre haemodialysis population.

As with any research, findings are only available from the tests completed, which can limit the strength and applicability of findings. For this study we did not complete assessment of all the measurement properties described by COSMIN (Mokkink et al., 2010b). One test that was missing was the use of confirmatory factor analysis to confirm structural validity. As mentioned previously, the sample size was not adequate to perform this, although an exploratory factor analysis may have been feasible if this had been planned prior to data collection. In the future, there needs to be consideration as to whether a factor analysis would add to the rigour of the PPN development. The PPN was also only assessed in English. Whilst others could assist in completing the PPN, interpreters were not used to assist in completion and all participants spoke English. Cross-cultural validation needs to be considered for both Indian, Pakistani and Eastern European participants. Whilst this study started to explore interpretation of PPN scores, further work needs to be done to identify what is a clinically meaningful change in score, including research that explores this with patients. Finally, no longitudinal data was available to assess responsiveness over time, which requires exploration in the future. The interpretation and analysis of free text comments was also limited due to the nature of this data. As these were written on a questionnaire that was read at a later date and not discussed at the time, there was no opportunity to explore what the content of comments truly meant to participants or ensure the comments were interpreted correctly. Whilst care was taken in the analysis to ensure the content of these comments were not over-interpreted, it is recognised that the analysis was superficial and its trustworthiness limited. Semi-structured interviews alongside the PPN could be used to add further detail to this.

It is also recognised that whilst patients were involved in the development of the PPN, no formal co-design approach was used to structure this phase of the study. Co-design approaches have the advantage of creating research that is more applicable to the end user (Slattery, Saeri and Bragge, 2020), in this case patients, with a similar objective to utilising patient representatives as described in section 1.4.3. However, conducting patient involvement in a structured manner can often ensure that power dynamics between researchers and patients are balanced (Greenhalgh, Hinton, Finlay, MacFarlane, Fahy, Clyde and Chant, 2019). Therefore, the lack of structure to patient involvement beyond adhering to the good practices outlined in section 1.4.3 is a limitation of this study, where patients views and opinions may have been influenced by the power of the researcher. Using a structured approach to patient involvement in the design of the PPN may have led to different results. However, as highlighted previously in section 1.4.3, it is important that patient representatives are not confused with research participants. When interviews, focus groups or other research data collection techniques are used to manage patient representation in research, as described by Slattery et al. (2020), it becomes unclear what is research and what is patient involvement in research. Overall, whilst co-design methods are often referenced in research, definitions of this are unclear, poorly evaluated (Slattery et al., 2020) and often bespoke to individual circumstances of studies (Greenhalgh et al, 2019). Therefore, a pragmatic decision was made to use the current approach to patient representative involvement in development of the PPN to expediate efficiency in its development. However, transparency of the approach is one method to ensure the quality of patient involvement (Greenhalgh et al., 2019), which is described in detail in section 3.2.2. The questionnaire then underwent face validity testing with further research participants, to ensure its relevance and comprehensiveness, further demonstrating content validity, although as mentioned previously this could have been completed in greater depth.

A wider group of stakeholders and patients could also have been used to develop the PPN, using Delphi techniques to ascertain the most relevant items. However, this approach was not taken for two key reasons. Firstly, it was important to maintain the patient’s voice within the development of the PPN and not have this excluded for the sake of others’ opinions, who may not be the patients’ experiencing cannulation. Therefore, it was felt to be important to focus on what patients believed should be in the PPN rather than have others influence this, as per the objectives of the study and the PhD thesis. Secondly, the results of the systematic review in Chapter 2 were used to guide the development of the PPN. Delphi studies are traditionally used when there is a lack of research evidence (Nasa, Jain and Juneja, 2021) rather than to replace this. Therefore, the Delphi technique was not utilised although it is recognised this could be viewed a limitation of the study and may have produced a different questionnaire.

3.5 Conclusions

In conclusion, this study has developed the PPN, to capture patients' experiences of cannulation for haemodialysis, as performed by healthcare professionals. The PPN was developed alongside patient representatives, providing some reassurance of content validity. Face validity tests indicated it was easy to understand, relevant and comprehensive. The PPN demonstrated validity and reliability in the tests completed, although it is recognised there are some limitations to this. However, further testing could add additional robustness to this, including a confirmatory factor analysis, cross-cultural validation and assessment of responsiveness with larger sample sizes. There were mild floor effects within the questionnaire, but these were not of concern. Missing data was at an acceptable level and did not affect the results. The item discrimination index indicates which questions could be useful to explore in more detail when evaluating interventions. The PPN had a small standard error of measurement and smallest detectable change, indicating it is of use when comparing interventions within research studies. However, further work needs to be done to discover what is a clinically meaningful change for patients.

This exploration of the PPN results provides further insight into patients' experiences of cannulation for haemodialysis. Pain appears to the issue that affects patients' the most, being the section that scored with the worst experience. Patients also worry about more than just pain from cannulation, also worrying about multiple cannulation attempts and who will cannulate them. Variation in cannulation experience is evident not just between individuals, but also within individuals over time and in between sessions. This variation may be linked with the cannulator or other factors and requires further exploration. However, the team of cannulators and adapting cannulation as part of everyday life can help patients to cope with canulation.

3.5.1 Summary of Recommendations

3.5.1.1 Clinical Practice

- Consideration needs to be given to how the team of cannulators can better support patients better through cannulation and how to facilitate patients adapting to cannulation as part of their everyday life (discussed Section 3.4.5, paragraph 4)

3.5.1.2 Future Research

- Results indicate the PPN is valid and reliable for use within research studies evaluating cannulation for haemodialysis undertaken by healthcare professionals (discussed Section 3.4, paragraph 1)
- Whilst section and individual question scores can add granularity to data, the overall PPN score should be the main focus of any research. Questions 1, 4, 7, 8, 10, 14 are the ones most likely to distinguish between different experiences (discussed Section 3.4.4, paragraph 3)
- Further studies are also required to:
    - Explore and understand worry about cannulation for haemodialysis (discussed Section 3.4.5, paragraph 3)
    - Understand the variability in patients' experiences of cannulation for haemodialysis (discussed Section 3.4.5, paragraph 4)
- A confirmatory factor analysis with a larger sample size may provide further reassurance of construct validity (discussed Section 3.4.6, paragraph 2)
- Cross-cultural validation work will enable the PPN to be used in non-English speaking patients (discussed Section 3.4.6, Section paragraph 2)
- Collection of longitudinal data over time could provide reassurance of the PPN's responsiveness to change (discussed Section 3.4.6, Section paragraph 2)

This completes the description of the development and evaluation of the PPN. The next chapter starts to describe the final research study in this thesis, a qualitative interview study to explore some of the questions raised by the first two research studies, exploring what influences’ patients’ experiences of cannulation for haemodialysis.

4 Chapter 4: How to Understand more about Patients’ Experiences of Cannulation: ICE-HD, A Semi-Structured Interview Study

4.1 Introduction

Findings from Chapters 2 and 3 raised recommendations for practice, but also further questions about cannulation experience and recommendations for future research. Therefore, the final study in this thesis aims to answer some of these questions and gain more depth to current understanding of patients’ experiences of cannulation, exploring what influences this. This chapter will describe the methodology and methods of the third and final study, providing a description of how this was designed to develop depth to our understanding of what influences patients’ experiences of cannulation. Chapter 5 then completes the study, describing the results with a discussion of these. This study has been named ICE-HD (Investigating Cannulation Experience in Haemodialysis), which will be used to denote this study in the next four chapters.

4.2 Research Aim, Question and Objectives

To provide further focus for this study, the following aims, research question and objectives are outlined below, which link with the rationale for the study described in section 4.3:

Research Aim (same as Objective 3 for thesis)*:* To develop a deeper understanding of patients’ experiences of cannulation for haemodialysis undertaken by healthcare professionals, including an exploration of factors that patients perceive influence their experiences of cannulation to understand how to optimise this, using a qualitative approach

Research Question: What influences patients' experiences of cannulation by healthcare professionals from their perspective?

Research Objectives: Four objectives supported this aim and research question and further defined the study:

1) To gain an in-depth understanding, from the patient's perspective, of whether cannulation varies and what factors influence this, including exploration of how the cannulator, technique and individual factors may influence this
2) To gain further understanding of if, and how, patients' experiences change over-time and what factors may influence this
3) To gain further understanding of if, and how, safety, control and worry influence patients' experiences and what factors may influence this
4) To gain further understanding of if, and how, cannulation can be improved from the patient's perspective

4.3 Rationale

The rationale for ICE-HD is embedded in the conclusions of previous chapters. The systematic review described in Chapter 2 created a description of patients' experiences of cannulation for haemodialysis, that had previously been lacking. However, this created recommendations for future research where gaps had been identified. This included:

- Further exploration as to how cannulation is unpleasant
- An in-depth exploration of pain
- Further exploration of vulnerability, feeling safe and control and how they influence patients' experiences.

Chapter 3 also generated further recommendations for research, including:

- Exploring and understanding worry about cannulation for haemodialysis
- Understanding the variability in patients' experiences of cannulation for haemodialysis

These factors were identified as possible to explore further in a qualitative study, exploring what influences patients' experiences of cannulation and creating the basis for the final study, ICE-HD.

As discussed briefly in section 3.1.4, cannulation by healthcare professionals is a slightly different phenomenon to self or carer cannulation. Therefore, to continue exploration in line with the PPN questionnaire and the focus of the research within this thesis, this study focusses on cannulation provided by healthcare professionals.

4.4 Research Paradigm

Qualitative research was identified as the best research paradigm to fulfil the aim of this study. This paradigm does not aim to prove or disprove a theory but rather to understand and explore individual experiences, views and opinions (Holloway and Galvin, 2017; Pope and Mays, 1995), collating those experiences to increase understanding. Qualitative research is about exploring the ‘emic’ perspective, gaining insights from an individual’s subjective reality (Holloway and Galvin, 2017), providing a thick description of this reality (Pope and Mays, 1995). Care is taken during qualitative research to ensure that *a priori* and potentially unfounded assumptions and preconceptions are not imposed on the research, focussing on exploring participants’ realities (Pope and Mays, 1995). This enables exploration of phenomena that are not well understood, ensuring findings are grounded in reality, not researchers’ or clinicians’ assumptions about reality. Using qualitative research methodology will ensure there is an accurate, full and deep description of the phenomenon being studied, fulfilling the study’s aim.

4.5 Protocol Development

The study design defined in the protocol for ICE-HD, followed the equator network ‘Standards for Reporting Qualitative Research’ (O'Brien, Harris, Beckman, Reed and Cook, 2014). When designing qualitative research, a stepped process can be used to develop the study design, developing the research objectives and then exploring the epistemology, theoretical perspective, methodology and methods in this order to finalise the study design (O'Brien et al., 2014; Wener and Woodgate, 2013; Carter and Little, 2007). These structures have been used to order the design of this protocol. Once finalised, the protocol was registered on the Research Registry (researchregistry7134).

The protocol was also designed in conjunction with patient representatives, (section 1.4.3). Five patient representatives contributed to:

- Choice and refinement of the research aim
- Development of the interview guide, patient information sheet and consent forms
- Reviewing the analysis of semi-structured interviews.

4.6 Epistemological Stance and Theoretical Perspective

Whilst the whole thesis uses pragmatism as the epistemological stance, ICE-HD used constructivism (or social constructivism). Pragmatism, by its very nature of using what works, allows the use of other perspectives and epistemological stances, when required. Beyond this, constructivism is considered complimentary to pragmatism, with many assumption being similar rather than contradictory and some considering constructivism as a descendent of pragmatism (Charmaz, 2017). Whilst this philosophical debate is beyond this thesis, this provides reassurance that using both a constructivist and pragmatist approach is not contradictory.

There are a number of ways in which constructivism is congruent with this study. Firstly, a constructivist perspective assumes that there are multiple, intangible realities (Appleton and King, 2002). Within this study, this enabled appreciation that individual participants may have differing experiences and one person’s experience does not negate another’s. Secondly, constructivism recognises it is difficult to separate cause from effect (Appleton and King, 2002). Whilst this study explored what influences patients’ experiences of cannulation, it did not aim to separate cause and effect. Thus, the focus became the participants’ experiences, providing freedom to explore the phenomenon from the participant’s perspective, rather than enforcing false restrictions and barriers. Thirdly, constructivism states that describing other’s people’s realities is to gain understanding rather generalisability (Appleton and King, 2002). This is an underlying principle within qualitative research, but also congruent with the aim of this study. Finally, constructivism is congruent with qualitative research, reflecting an interpretivist stance, where the researcher aims to understand individual human experiences in their context (Holloway and Galvin, 2017). These points demonstrate the congruence between constructivism and the aims of ICE-HD.

When exploring patients’ experiences of cannulation, it was expected that participant’s experiences did not fully sit within their conscious mind, but some of their experiences of cannulation were sub-conscious. Therefore, the interviewer needed to tease out the participants’ experiences to gain a full picture of these. Constructivism recognises and promotes the researcher and participant co-constructing their experiences (Appleton and King, 2002). This approach was used throughout the interviews to develop depth to understanding. Methods to promote trustworthiness, later described in section 4.12, ensure the interviewer does not influence this inappropriately.

When planning the protocol, no theoretical perspectives were identified to guide the data collection or analysis. As this was relatively unknown area, an inductive approach allowed a full exploration of individual experiences, rather than applying rules from existing theory that may be incorrect or inappropriately restricting.

4.7 Methodology

This qualitative study uses elements of grounded theory (GT), using Charmaz’s social constructivist approach (Charmaz, 1990). GT is a useful qualitative methodology for uncovering phenomena where little is known, ensuring what is constructed is ‘grounded’ in participants’ experiences (Chun Tie, Birks and Francis, 2019; Tan, 2010). The methods deployed in GT are focussed on developing a theory which explains the phenomena in detail, exploring not just ‘what’ the phenomena is, but also expanding into the ‘how and ‘why’ (Charmaz, 1990). This study aims to understand patients’ experiences of cannulation in-depth, progressing beyond ‘what’ their experiences are, to exploring what influences this. GT provided a solid foundation with which to develop this depth of understanding. However, ICE-HD is not a ‘pure’ GT study, but only uses the elements of GT that are appropriate to fulfil the aim.

The main element of GT used is constant comparison analysis (CCA). This analysis concurrently performs data collection and analysis, where analysis of initial data guides the collection of future data in the study (Chun Tie et al., 2019; Foley and Timonen, 2015; Charmaz, 1990). It involves the induction of data from initial interviews, but then as analysis happens concurrently, the researcher can respond to discoveries, following up on leads, exploring new concepts and adapting interviews as the study progresses (Hunter, Murphy, Grealish, Casey and Keady, 2011a; Charmaz, 1990). During ICE-HD, this process aided exploration of participants' experiences that were not directly in their consciousness, adding depth to findings. As well as adding depth to the interviews, CCA added depth to the analysis. CCA facilitates responding to discoveries in interviews throughout the interview process, but also involves comparison of different parts of the dataset, including comparison within an individual participant interview and comparison between interviews from different participants (Timonen, Foley and Conlon, 2018; Boeije, 2002; Charmaz, 1990). This enables an exploration of diversity within the data, looking for similarities, but also differences, exploring multiple possible explanations for the data (Timonen et al., 2018; Foley and Timonen, 2015; Hunter et al., 2011a). In CCA, coding explores not just what is in the data, but relationships between codes and categories, again adding a further dimension to the analysis (Chun Tie et al., 2019; Memon, Umrani and Pathan., 2017; Foley and Timonen, 2015; Tan, 2010). Both these elements brought depth to the analysis.

Theoretical sampling and intensive interviewing are parts of GT and facilitate CCA. They enable to researcher to follow up on discoveries, exploring these in more detail in future interviews (Charmaz, 2014). These elements are discussed in more detail in sections 4.8.2 and 4.10.2.

CCA, theoretical sampling and intensive interviewing were used to guide the design of ICE-HD. However, other elements of GT were not used to design the study. For clarity, the elements of GT not used to design ICE-HD were:

- The outcome was not tied to a theory and did not focus on developing a core concept. Many believe a study which does not have this focus is not GT (Chun Tie et al., 2019; Lauridsen and Higginbottom, 2014; Hunter et al., 2011a and 2011b; Tan, 2010; Charmaz, 1990). When designing this study, the focus was on responding to findings and presenting these in a manner that best fits findings, rather than adhering to a rule that may restrict this.
- This study used prior research findings to focus the research aim, building knowledge. Some believe GT does not allow *a priori* research to influence the development of the research question as this introduces bias, although this is currently debated (Timonen et al., 2018; Holloway and Galvin, 2017; Charmaz, 2014 and 1990; Dunne, 2011). Within this study, the influence of prior knowledge was accepted, but there was awareness that there may be discoveries that were contrary to this (Timonen et al., 2018; Dunne, 2011).

These two elements mean ICE-HD is not ‘pure’ GT but uses the elements of GT appropriate to answer the research aim. Whilst methodological purists may argue this is not a valid approach, this use of what is needed is congruent with the pragmatic approach to this thesis.

4.8 Sample

This section describes how the sample for ICE-HD was determined. The sample was recruited from two renal centres, one of which also recruited participants from a satellite unit. The cannulation technique used at each centre varied, with one using predominately buttonhole and one using predominately rope ladder. This ensured participants were recruited with varying and different experiences.

4.8.1 Eligibility Criteria

Participants with the following characteristics were eligible to be included in ICE-HD:

- Adults 18 years old and above
- Patients on regular in-centre haemodialysis, including haemodiafiltration, who meet the following criteria:
    - Currently undergoing cannulation of AV access for haemodialysis
    - Undergoing cannulation by healthcare professionals
- Able to consent to involvement in the study and complete a semi-structured interview either via telephone or video call

Both English and non-English speaking patients were included in the study. Medical interpreters and translated documents were used when required.

To maintain focus on the aim of the study, participants with the following characteristics were excluded:

- Haemodialysis for acute kidney injury or non-haemodialysis treatments
- Self- cannulation or cannulation by non-healthcare professionals
- Cannulation not using standard AV access
- Currently solely undergoing ultrasound guided cannulation, with no blind cannulation in the week prior to consent

These types of participants were likely to have a different experience of cannulation and detract from the phenomenon under investigation.

4.8.2 Theoretical Sampling

Theoretical sampling involves identifying where there may be gaps or ‘thinness’ in developing categories and recruiting participants that may enlighten those gaps (Chun Tie et al., 2019; Timonen et al., 2018; Charmaz, 2014). Whilst new codes or categories found during theoretical sampling are never ignored, the main focus of theoretical sampling is to expand understanding and gain depth in pre-existing categories (Timonen et al., 2018; Charmaz, 2014). Therefore, purposive sampling is used to identify participants for initial interviews to generate categories, which then progresses on to theoretical sampling to explore these emerging categories (Chun Tie et al., 2019; Timonen et al., 2018; Charmaz, 2014).

In ICE-HD, there were two phases to the sampling of participants:

1) Purposive sampling was used for first 16 initial interviews. This ensured that participants with differing characteristics were interviewed, to gain a breadth of experiences. This directed recruitment to ensure inclusion of participants from different haemodialysis sites with a mix of genders, ethnicities, ages, dialysis and cannulation vintages, and those with diabetes
2) Theoretical sampling was used for the final 14 interviews. Participants were selected to include patients that would illuminate emerging categories, targeting patients who have:
    - Differing levels of problems with their cannulation, especially those considered to have less problems with cannulation
    - Haemodialysis in differing environments, including those dialysing in a room on their own and in a satellite unit
    - Haemodialysis initiation with differing types of vascular access
    - A sensory deficit or communication difficulty.

There was also some natural variation in these characteristics within the study sample. The decision to move from purposive to theoretical sampling was made when there were no new concepts emerging in interviews, although it was recognised that the breadth of experience within concepts may not have reached saturation.

4.8.3 Sample Size

Determining sample size during qualitative research can be difficult, as without full understanding of the phenomenon. For ICE-HD to determine the sample size, guidance was sought from three sources:

1) Examination of sample sizes of 13 identified qualitative studies from the systematic review in Chapter 2, exploring pain, cannulation and vascular access experiences of patients on haemodialysis.
    a. Samples sizes varied from 6 to 30 with majority of studies claiming to have achieved saturation
2) Exploration of information power likely to be produced by the study, as outlined by Malterud, Siersma and Guassora (2016). The assessment of information power for ICE-HD provided the following guidance:
    a. The study aim was narrow, requiring a smaller sample size
    b. The specificity of the sample was dense, complimented by use of purposive sampling, requiring a smaller sample size
    c. There was minimal application of theory related to the phenomenon, requiring a larger sample size
    d. The quality of dialogue was moderately weak, with a novice researcher attempting to explore concepts that may not be immediately in the consciousness of participants, requiring a larger sample size
    e. The analysis technique involved some cross-case analysis, but was not phenomenology, so required a moderate sample size

3) Consideration of the variation in characteristics required in the purposive sampling phase, with consideration of the additional theoretical sampling phase, dictated the minimum size of the sample

Following this assessment, it was determined that a maximum sample size of 30 participants was required for this study.

4.9 Ethical Considerations

ICE-HD received approval from the HRA which authorises research conducted within the NHS in the UK (IRAS No:300898).

.

4.9.1 Recruitment and Informed Consent

Potential participants were identified by the clinical care team with reference to the inclusion and exclusion criteria. Eligible patients were approached by a member of the clinical team and asked if they are willing to discuss participation in ICE-HD whilst attending for their regular haemodialysis treatment. Patient representatives identified that this was the optimal time to discuss this, without adding any burden to the current treatment regime. If participants were deemed to lack capacity to provide consent, they were not approached as they were deemed unable to complete the interview. If they agreed, patients were provided with a participant information sheet and an opportunity to discuss participation in the study. Patients were given verbal information on the study, the opportunity to ask questions and time to consider the information provided, before deciding whether to participate in this study. A time was arranged to return to the participant to determine whether they were willing to take part in ICE-HD, when they were asked if they are willing to consent to the study.

During discussions about the study during the consent process, the following aspects were discussed:

- Involvement in ICE-HD was voluntary and they could withdraw consent at any point. Whether they chose to take part in the study would not affect their normal care in anyway
- Participation in ICE-HD involved completing a semi-structured interview either via telephone or video call, away from the dialysis unit
- They were informed that after the interview, they would be asked if they were willing to discuss the interview in a short conversation a few weeks later, but that they could still be part of the study if they did not wish to do this
- Information would be collected from their medical records
- All information used in the study would be anonymised
- If they withdrew consent after completing the interview, then the information they had provided so far would be retained in the study, but no further information would be collected.

Consent was obtained using a written consent form.

Once informed consent had been obtained, the participant’s contact details were passed onto to me to arrange the interview. Prior to starting the interview, I re-checked participants were still happy to proceed, repeated information about the study and checked if the participant had any queries, before starting the recording of the interview.

4.9.2 Anonymity of Participant Information and Data Security

All data were handled in line with the UK GDPR (Information Commissioner's Office, 2018) and adhered to the local hospital policies for data protection and information governance.

On consent each participant was assigned an individual participant ID, to enable anonymisation of research documents and files. At each site, a separate enrolment log was kept containing the participant's name, date of birth and participant ID, to permit identification of all participants enrolled in the study. For the purposes of reporting the results, each participant was allocated a pseudonym.

Paper documents containing participant data were treated as confidential documents, stored onsite securely with restricted access in line with the local hospital policy. The data were transcribed to electronic databases and thus not removed from each hospital site. Computer held data, including the study database, interview recordings and transcripts, were held on a secure computer drive at the University of Nottingham, which is subject to regular back up procedures and password protected. Anonymised data transported outside the University of Nottingham were stored using only encrypted data storage.

Prior to the interview, participants were asked not to mention others' names during the interview to protect their identity. However, on occasion this still happened and participants also mentioned the name of their renal unit. When reviewing the transcript, these names were removed and replaced with the role (e.g. Nurse 1, Dialysis unit 1). Interviews were recorded on an encrypted digital recorder and only sound was recorded during video calls. To protect confidentiality, the interviewer was always in a room alone when conducting the interview. Following the interview, the recording was transferred to a professional transcription company via an encrypted link. Once all transcriptions of interviews had been checked, the verbal recording was deleted and only the written transcription stored as part the archived research records.

4.10 Data Collection

4.10.1 Participant Characteristics

To describe the study population, data were collected on participant characteristics. This included demographic characteristics, treatment type, vascular access, the cause of their CKD and co-morbidities. Once theoretical sampling started, further information was gathered on the type of vascular access they started haemodialysis with and whether they dialysed in a room on their own, with some data collected in retrospect from those who had already completed an interview in the initial interview stage.

4.10.2 Semi-Structured Interviews

Semi-structured interviews were used to collect data for the main analysis. Interviews are the most common way to collect data for GT, which can be semi-structured or unstructured (Holloway and Galvin, 2017; Foley and Timonen, 2015). An unstructured or lightly structured interview guide is often recommended for GT, to ensure the researchers preconceptions do not influence the interview (Timonen et al., 2018; Charmaz, 2014). However, planned questions also give the interviewer the foundation and flexibility to improvise during the interview (Charmaz, 2014). Therefore, interviews were semi-structured using a flexible interview guide to support myself, as a novice researcher. This was designed to tease out experiences and clarify the influence of elements not initially volunteered. Questions were balanced to ensure they never led the participants to answer in one direction, either to confirm or refute whether something existed. The initial interview guide is provided in Appendix 3.

Interviewing as part of CCA is a flexible and creative process. Interviews change and develop through the study as the researcher responds to emerging concepts (Timonen et al., 2018; Foley and Timonen, 2015; Charmaz, 2014; Hunter et al., 2011a). The interviewer can diverge from the interview guide if required, following unanticipated areas of inquiry, hints, implicit views and accounts of actions (Timonen et al., 2018; Foley and Timonen, 2015; Charmaz, 2014; Hunter et al., 2011a). ‘Intensive interviewing’, as described by Charmaz (2014), was used to facilitate this approach, where the initial interviews explore participants’ experiences and later interviews adapt to explore emerging concepts. The interview guide was changed on two occasions, after 16 interviews and then a further question added after 21 interviews. These changes are summarised in Appendix 4.

All interviews were conducted remotely, due to restrictions in place for the COVID-19 global pandemic. Participants were given a choice whether to complete interviews via telephone or video call, with the process for each discussed with them at the consent interview. Once the participant had agreed to take part in the study, I contacted them to arrange the interview at a time convenient for them. If the interview was via telephone, I then contacted the participant at the agreed time. For interviews via video call, the participant was emailed a video link for the interview. To reduce anxiety in participants, they were reassured if they could not complete the interview via video call, the interview could convert to telephone easily. All participants were given my work telephone number in case they had problems connecting or attending the interview. On some occasions, I contacted the participant at the pre-arranged time and they could not complete the interview as they were busy, unwell or had forgotten. In these circumstances the interview was re-arranged for another time. All interviews were recorded using a digital encrypted dictaphone, with devices placed on speaker to enable the recording. Participants chose whether to have the camera on for video calls, but only their voice was recorded. The recording of the interview was then transcribed verbatim, in preparation for analysis.

4.10.2.1 Using a Medical Interpreter for a Semi-Structured Interview

One participant completed an interview using a medical interpreter. She was able to have a basic conversation in English but could not explain complex emotional concepts. I wanted to be as inclusive as possible in this study, to gather a breadth of experience, and she was very keen to be involved in the research. Therefore, despite the difficult in conducting a qualitative interview with an interpreter, this was accommodated in the study. The participant information sheet and consent form were translated into her language to facilitate informed consent. In the interview, it was agreed the participant would describe what she could in English, as she was comfortable with this, but there was an interpreter present and available to use them when needed. This made her feel less anxious about the interview.

It was recognised that using an interpreter may interrupt the flow of the interview and the interpreter may not relay information accurately. Advice about conducting the interview was sought from NHS staff with expertise in breaking bad news via an interpreter. The following aspects were implemented in response to their advice:

- Prior to the interview, it was highlighted to the participant that this may make the interview a little harder and that there may be times in the interview where it is suspended to solve problems or have a discussion with the interpreter. The participant reiterated she was comfortable with this

- A professional medical interpreter was used, who was used to translating conversations during medical consultations, including breaking bad news
- Prior to starting the interview, the interpreter was briefed about the content of the interview, with a copy of the interview schedule provided
- The interpreter was asked to allow the participant to speak as much as she wanted to and to provide translation as close to verbatim as possible
- The interpreter was informed the interview would be recorded and reassured her identity would be anonymised
- The interpreter was reassured that she could also ask questions through the interview
- When the participant joined the call, she was introduced to the interpreter. All three members of the call, then discussed and agreed how the interview would work.

Of note, to protect the identity of the participant, the use of an interpreter is not identified in the analysis. It was recognised that this participant’s words were paraphrased by the interpreter on occasion. Whilst this may compromise the integrity of the data, it was more important to protect the anonymity of the participant.

4.10.3 Field Notes

Field notes were taken immediately after each interview. This is common practice in qualitative research and can highlight points of interest, events, actions, interactions and provide essential context for interviews (Phillipi and Lauderdale, 2018; Holloway and Galvin, 2017). The content of field notes prompted reflection on the interview, including noting any interruptions, how the participant responded to questions, the initial thoughts about concepts and how I felt I had performed. This included comments about anything that could guide future interviews, with theoretical sampling and intensive interviewing in mind. The interviewer kept field notes on the general context of the study, when there were events that affected multiple participants.

4.11 Analysis of Semi-Structured Interviews

Once the verbatim transcription of the interview was complete, this was checked thoroughly for accuracy, listening to each interview whilst checking the transcript. The transcript was corrected as required and once the transcript was correct, the recording of the interview was deleted. This process also re-familiarised myself with the content of the interview prior to starting coding. The transcript was uploaded to NVivo 12, which was used to categorise verbatim quotes from interviews into codes, sub-categories and categories. After initial coding of all transcripts, a comparison both within and between interviews was used to further develop codes and understanding. Memos were referred throughout to develop and refine codes, as well as identify relationships between codes. Coding, the comparison and memo-ing are described in more detail below.

4.11.1 Coding

Coding is the base unit of thematic qualitative analysis and CCA, reducing interview transcripts into small chunks to facilitate extraction of meaning from them (Maguire and Delahunt, 2017; Leech and Onwuengbuzie, 2007). Constructivist GT uses initial coding, focussed coding and theoretical coding to interpret interviews beyond a description of experiences, extending this to an exploration of the relationships between codes (Chun Tie et al., 2019; Charmaz, 2014). These are not three separate phases of coding that occur in a linear manner over time, but an iterative analysis that progresses backwards and forwards through these different levels of coding as required (Chun Tie et al., 2019; Charmaz, 2014). In line with CCA, analysis occurred concurrently alongside semi-structured interviews. Therefore, gaps in coding guided future interviews and the coding itself developed and changed as new information was discovered in interviews (Charmaz, 2014).

Initial coding was the start of the analysis, fragmenting transcripts into manageable chunks of text and categorising them into codes (Chun Tie et al., 2019). Coding at this stage can happen word-by-word, line-by-line or incident-by-incident (Charmaz, 2014). For this study, there was concern the word-by-word analysis may fragment the participant’s words too much, losing the true meaning. Therefore, it was not utilised. However, the detail of line-by-line coding enabled discovery of concepts that initially are not obvious when reading the transcript, with incident-by-incident coding recognising the overall concept conveyed in a section of text (Charmaz, 2014). Both line-by-line coding and incident-by-incident coding were used in this study.

The structure for initial coding was guided by Charmaz (2014) and included:

1) Familiarisation of the data by reading completely through the transcript of the interview in detail (Maguire and Delahunt, 2017). As well as the transcript for the interview, other documents were also read to refresh the research of the whole context of the interview (e.g. field notes, interview summary)
2) Initial line-by-line coding and incident-by-incident coding
3) Review and refinement of the codes alongside re-familiarisation with the data
4) Identification of the gaps within the codes to guide future interviews.

Whilst it was initially planned that interviews would be coded directly after the interview, in reality initial coding of interviews happened in two waves – one after the initial 16 interviews and one after all interviews had been completed. This was due to time constraints to complete interviews to both PhD and HRA deadlines. However, memos as described in section 4.11.3, were used to note and explore emerging concepts. Initial coding was inductive, guided by the content and interpretation of the interview.

Focussed coding involves sorting through codes, refining and merging these and developing categories to start to summarise large portions of data (Charmaz, 2014). This helps to identify the pertinent aspects of findings, making decisions about the data and creating more structure to the analysis, with relationships emerging from this process (Charmaz, 2014). This appears similar to the stage in thematic analysis where themes are developed (Braun and Clarke, 2020), but goes beyond this to start to explore links between categories. During this analysis, focussed coding did merge into initial coding, as the analysis naturally developed. However, once all transcripts were coded, the main focus became focussed coding to develop the categories whilst refining codes. Focussed coding considered the what, when, where, why, how and consequences to deepen this coding process (Charmaz, 2014; Wilson Scott and Howell, 2008). Whilst this process refers to codes and categories, this analysis also developed sub-categories, equivalent to sub-themes in thematic analysis.

Theoretical coding further refines the relationships between categories and codes to develop a complete story of the phenomenon, making the analysis coherent and comprehensible, bringing it all together (Charmaz, 2014). For this, diagrams and memos were used to explore relationships between categories, sub-categories and codes.

4.11.2 Comparison

Comparison is a core part of CCA, promoting a deeper and richer analysis. Whilst the comparison does not need to be structured (Charmaz, 2014), Boeije (2002) describes a more structured process of comparison that helped facilitate this process. This approach was replicated to highlight specific planned comparisons, as shown in Table 24. Whilst this comparison process happened throughout the analysis, this was also reviewed after initial coding was complete, adding to focussed and theoretical coding. However, this was not described as a separate analysis, but was part of the analysis process to produce the codes, sub-categories and categories. Inconsistencies and discrepancies in these comparisons were not viewed as problematic or used to exclude codes, but rather explore the diversity in the data and why this might happen.

Comparison	Aim	Important Questions
Within Interview	To explore the diversity and consistency of experience within the interview	What is the overall experience within the interview?
		How does this overall experience reflect in codes?
		Are codes throughout the interview complimentary or contradictory?
		What leads to differences throughout the interview?
Between Interviews	To explore the diversity and consistency of experience between participants	What is similar and different between participants' experiences? What drives similarity? What drives differences?
		What is different in the context of the participants?
Between Codes and Categories	To explore the connections between codes and categories. Where connections are not obvious, explore the diversity	What connections are there between codes and categories?
		How do these connections demonstrate congruity and incongruity?
		Are any codes or categories isolated with no connection to others and if so, why?

Table 24: Comparisons used in the Analysis of Semi-Structured interviews to explore what Influences Cannulation for Haemodialysis

4.11.3 Memo-ing

A core part of CCA and GT is memos (Chun Tie et al., 2019; Timonen et al., 2018; Charmaz, 2014 and 1990). It enables the researcher to record their thoughts which will ultimately develops the analysis (Timonen et al., 2018; Hunter et al., 2011a), expanding it beyond the codes (Charmaz, 2014;

Hunter et al., 2011a). Memos aid the researcher’s thought processes and are (Charmaz, 2014):

- Part of the data analysis, so separate to field notes
- Informal
- Unstructured
- Spontaneous
- Personal to the researcher
- Methodological or analytic

They create initial thoughts, ideas about codes, ideas about how codes and categories link together and incisive insights into the analysis (Timonen et al., 2018; Charmaz, 2014). During ICE-HD, memos were kept throughout the interview and analysis process and were unstructured, responding to what facilitated the analysis. Memos were reviewed throughout the analysis, to facilitate the process.

4.12 Methods to ensure Trustworthiness

There are many perspectives and debates surrounding how rigour or trustworthiness are viewed and assessed within qualitative research (Creswell and Poth, 2018). For the purposes of ICE-HD, trustworthiness is used, as it is congruent with constructivist qualitative research (Appleton and King, 2002). Part of trustworthiness and authenticity lies in appropriate design and reporting of the study. CCA itself develops trustworthiness, as findings from initial interviews are explored and checked with future participants as part of the process (Cooney, 2011). Routine parts of qualitative research also develop trustworthiness, including producing a thick description of findings with use of participant's voices to demonstrate this (Creswell and Poth, 2018; Holloway and Galvin, 2017). This is used throughout the results section to describe the findings. To promote reflexivity the reflexive diary (described in section 1.4.2) was maintained. However, beyond this, other elements were added to increase the trustworthiness of findings, which are outlined in the sections below.

4.12.1 Peer Review

Peer review is a method for each individual's analysis to be checked. This normally involves collaborators re-analysing the data, with peer reviewers seen as 'keeping the researcher honest' (Creswell and Poth, 2018; Holloway and Galvin, 2017). ICE-HD did not strictly implement peer review but used a pragmatic approach. Interview extracts and analysis were shared with collaborators in one-to-one meetings. This provided the opportunity to check the interpretation of interviews and codes, but also expand and broaden the analysis. Peer review was also used with patient representatives. They were sent anonymised extracts to review from interviews and codes, focussing on codes that were complex and novel. Definitions were also provided of technical words and jargon. The patient representative's views on the codes and extracts were then discussed in one-to-one meetings. It was recognised that the patient representatives were not experts in qualitative research and thus may not manage their assumptions and biases in the same manner as a researcher. To manage this, patients were asked for their opinions and perspectives, but also reminded that findings would be grounded in participants' experiences rather than their own. I used my own reflexivity to guide this process, judging the opinions of patient representatives against what was represented in participants' voices. Patient representatives were asked to be away from the haemodialysis unit during discussions, as they may dialyse with participants in the study, with a risk the discussion of participants' words would be over-heard.

4.12.2 Member Checking following Interviews

Member checking is often viewed as participants checking the researcher's interpretation of the interview or the final analysis of the study (Creswell and Poth, 2018; Holloway and Galvin, 2017). However, the final analysis is not just one participant's views, opinions or experiences, but an amalgamation of many participants. Therefore, individual participants may not recognise their individual story in the final analysis (Morse, 2015). Additionally, in ICE-HD there was a long period between some participants' interviews and the final analysis, introducing recall bias. Therefore, there was no member checking of the final analysis. However, following the interview, I provided participants with a summary of the interview, from my perspective. Participants were able to assess my interpretation of the interview and correct or confirm this in a further virtual one-to-one meeting, completed within four weeks of the interview. This was not a semi-structured interview and was not recorded or analysed. However, following this discussion with each participant, I created a memo to summarise the discussion.

This section has described the methods used to complete and analyse semi-structured interviews, outlining the methods of ICE-HD study to explore what influences patients' experiences of cannulation for haemodialysis. These methods aim to explore this in depth, using CCA, intensive interviewing and theoretical sampling from GT. The next chapter will describe the results from ICE-HD.

5 Chapter 5: A Deeper Exploration of Patients’ Experiences of Cannulation: What Influences This?

The previous chapter described the methods for ICE-HD, demonstrating how a semi-structured interview studied was designed to gain understanding of what influences patients’ experiences of cannulation for haemodialysis. This next chapter describes the results this study. This includes a description of participant characteristics and the analysis of semi-structured interviews. The results of study will then be discussed, also exploring the strengths and limitations of the study

5.1 Results

In total, 30 participants were recruited to ICE-HD and all 30 completed a semi-structured interview. The interview was split into two sections for two participants, one due to fatigue and the other due to an unexpected interruption. Of the interviews, 27 were conducted via telephone and three via video call. The median interview time was 61 minutes, with the shortest interview 30 minutes and the longest 79 minutes. All participants were willing to check their interview summary and arranged a time to do this, but four participants did not do this either because they were too busy, unwell or uncontactable at the time arranged. All participants agreed with their interview summary, with only a few asking for minor changes. This aided the interpretation of their interview and were thus reflected in the analysis. Of note, 60 analysis memos were recorded, excluding memos to record the discussion of the participant’s interview summary. Process memos recorded detail and changes in analysis procedures, generating a total of six throughout the analysis.

5.1.1 Participant Characteristics

A similar number of participants were recruited from each renal centre, 17 from one and 13 from the other. Of the 13 participants from the second renal centre, five dialysed in a satellite unit. The median age of participants was 56 years old, with the youngest 26 years old and the oldest 86 years old. A proportion of participants were 70 years old or older (7/30, 23%). A similar distribution of males (16, 53%) and females (14, 47%) were interviewed. The majority of participants were Caucasian (22, 73%), with a few from Afro-Caribbean (4, 13%) or Indian or Pakistani (3, 10%) backgrounds. One participant was mixed race Caucasian and Afro-Caribbean.

The majority of participants dialysed for 4 hours, three times week using haemodialysis, but a few either dialysed for less time, more frequently or using HDF. There was a mix of lower (10, 33%) and upper arm AV access (20, 67%), but no leg AV access. There were two participants using an AV graft for haemodialysis. The median cannulation time of the AV access was 25 months (range 2 – 118 months). The canulation technique used varied, with 17 participants using buttonhole technique (57%), 10 using area puncture (33%) and three using rope ladder (10%). Whilst the cannulation technique was often dictated by the renal centre they dialysed at, there was one participant who did rope ladder at the predominately buttonhole site and one participant who did buttonhole at the predominately rope ladder site. Local anaesthesia was used by nine participants, using either sub-dermal lignocaine (5, 17%) and topical anaesthetic cream (4, 13%), with two of these participants only using topical anaesthetic cream occasionally. The participant characteristics are summarised in Table 25.

Renal Centre	Renal Centre 1	17 (57%)
	Renal Centre 2	13 (43%)
	Main Unit	25 (83%)
	Satellite unit	5 (17%)
	In a room on their own	4 (13%)
	In a room with other patients	26 (87%)
Gender	Male	16 (53%)
	Female	14 (47%)
Age	Median Age (Range)	55.5 (26-86) years
	Under 50 years old	11 (37%)
	50-69 years old	12 (40%)
	70 years or older	7 (23%)
Ethnicity	Caucasian	22 (73%)
	Afro-Caribbean	4 (13%)
	Indian or Pakistani	3 (10%)
	Mixed Ethnicity	1 (3%)
Dialysis Modality	Haemodialysis	28 (93%)
	HDF	2 (7%)
Dialysis Length	3 hours	1 (3%)
	3 hour 30 mins	1 (3%)
	4 hours	27 (90%)
	4 hours 15 mins	1 (3%)
Dialysis Frequency	3 x week	29 (97%)
	4 x week	1 (3%)
Median RRT vintage		50 (5 – 360) months
Median haemodialysis vintage (this episode, without interruption)		27 (5 – 247 months)
AV access type	Radiocephalic fistula	10 (33%)
	Brachiocephalic fistula	17 (57%)
	Brachiobasilic fistula	1 (3%)
	Upper arm grafts	2 (7%)
	Upper arm	20 (67%)
	Lower arm	10 (33%)
AV Access age	Median (Range)	35 (3 – 120) months
	Less than 1 year	2 (7%)
	1-2 years	8 (27%)
	3-5 years	16 (53%)
	More than 5 years	4 (13%)
Number of previous AV Access	0	22 (73%)
	1	7 (23%)
	2	0
	3	1 (3%)

Number of previous AV access used for haemodialysis	0	28 (93%)
	1	1 (3%)
	2	1 (3%)
Used a CVC previously for haemodialysis	Yes	19 (63%)
	No	11 (37%)
Type of access at start of haemodialysis	AV access	13 (43%)
	CVC	16 (53%)
	Unknown	1 (3%)
Cannulation Technique	Buttonhole	17 (57%)
	Rope Ladder	3 (10%)
	Area Puncture	10 (33%)
Previous Cannulation Techniques	Buttonhole	2 (7%)
	Rope Ladder	1 (3%)
	Area Puncture	1 (3%)
	None other	26 (87%)
Cannulation vintage for this AV access	Median (Range)	25 (0-39 months)
	Less than 1 year	4 (13%)
	1-2 years	10 (33%)
	3-5 years	12 (41%)
	More than 5 years	4 (13%)
Age of AV Access at First Cannulation	Median (Range)	25 (2-118) months
	Less than 2 months	8 (27%)
	2-6 months	15 (50%)
	More than 6 months	7 (23%)
Local Anaesthesia use	None	21 (70%)
	Sub-Dermal Lignocaine	5 (17%)
	Topical anaesthetic cream - always	2 (7%)
	Topical anaesthetic cream - occasionally	2 (7%)
Cause of CKD	Diabetes	10 (33%)
	Glomerulonephritis	4 (13%)
	Ischaemic Nephropathy	3 (10%)
	AKI	2 (7%)
	Polycystic Kidney Disease	1 (3%)
	Interstitial nephritis	1 (3%)
	Vasculitis	1 (3%)
	Pyelonephritis	1 (3%)
	Primary renal tubular disorder	1 (3%)
	Primary reflux disorder	1 (3%)
	Congenital Neuropathic Bladder	1 (3%)
	Enteric Hyperolaxuria	1 (3%)
	Unknown	3 %10%)
Diabetes	No	16 (53%)
	Yes	14 (47%)
Vascular disease	No	22 (73%)
	Yes	8 (27%)

Table 25: Characteristics of Participants undertaking Semi-Structured Interviews

5.1.2 Analysis of Interviews

Throughout the analysis, the terms ‘category’ and ‘sub-category’ have been used to denote what is often known as themes and sub-themes, to maintain consistent terminology for CCA. In total the analysis generated 35 codes which were formed into three categories and nine sub-categories:

- Category 1: Trying to make cannulation more comfortable
    - Sub-Category 1: Familiarity makes cannulation less alien
    - Sub-Category 2: Avoiding or minimising pain from cannulation
    - Sub-Category 3: Making cannulation more predictable: Getting the needles in easily
    - Sub-Category 4: Reducing anxiety about cannulation
- Category 2: Preserving humanity and individuality during cannulation
    - Sub-Category 1: Empathy: Being understood and not being alone through cannulation
    - Sub-Category 2: Trusting the cannulator
- Category 3: The necessity of cannulation for haemodialysis forces coping
    - Sub-Category 1: Stoicism gets me through unpleasant but necessary cannulation
    - Sub-Category 2: Acceptance of an unpleasant and unpredictable, but necessary procedure
    - Sub-Category 3: Being able to contribute to cannulation helps me cope

A complete list of categories, sub-categories and codes is provided in Appendix 5.

Within this chapter, each category and sub-category are described in a section, with anonymised quotes from participants used to illustrate these (highlighted in *italics*). As described in section 4.11.1, the analysis did not just focus on what was present within codes, but the relationship between categories. The chapter ends with a description of how these three categories influence patients' experiences of cannulation, describing what makes it easier or harder.

5.1.2.1 Category 1: Trying to Make Cannulation More Comfortable

Participants describe how needling will never be a nice or pleasant procedure. They describe it as '*something hard to do'* (Emma) and '*it's not something that, like, you're happy to have.'* (Nicholas). Some describe how difficult they find the cannulation due to the unpleasantness, describing it as '*awful! In a word I've never liked it … I think it's very hard to feel good about it in general because it's just not a pleasant thing.'* (Clare). Some describe the cannulation as '*the worst bit, it's hands down the worst bit*' (Molly) of haemodialysis. Molly continues to describe how '*if you could eradicate that bit, dialysis wouldn't be half as stressful'.* Whilst others do not feel their cannulation is bad, they still find it an unpleasant procedure: *'I mean, don't get me wrong, it's never been bad … I've never had the urge to scream or shout! ([Laughs] … but it was never the top of my list of favourite things to* *do.'* (Joseph). Some describe how their cannulation has improved, but even though it is better than it was 'i*ts still not nice but .. yeah, it's still not nice'* (Deborah). The unpleasantness sometimes seems inevitable, as '*I don't think you can really improve it because .. it's always going to hurt and it's always not going to be pleasant … it's always going to be shit!'* (Clare).

Participants describe things that can make needling more comfortable, making it easier to tolerate. As George states, *'I didn't want to suffer. A patient doesn't want to suffer … it should do the job it's doing without producing anguish and pain'*, indicating that canulation should be made as comfortable as possible. Participants are *'trying to do everything I can to make sure that it goes right .. like as well as possible.'* (Nicholas), often indicating a desperation to make it more comfortable. Things that address the unpleasantness and unpredictability of cannulation, as well as the anxiety this produces, make cannulation easier:

> *'Normally they just say 'OK, we're going to – are you ready for this' and I'll say 'yes' and the needle will go straight in. Then it's not painful and it makes me feel less anxious and I feel quite calm about the fact that it's gone in and I say to them 'well thank you, that was lovely'! You know, because it's not hurt me and I'm not tensed up or anything and I feel quite good about the fact that they've gone in straightaway and there's no pain.'* (Charlotte)

> *'It's more calmness and, what's the word, calmness and – because you know they're going to do it quick with less pain … I'm just more calm. I*

don’t worry about it. I have no anxiety about it … it’s been so easy and quick and obviously less pain. That is a relief then.’ (Jessica)

However, whilst making cannulation more comfortable improves cannulation, some continue to talk about how they would like to avoid cannulation completely: *‘Um…it would be nice if we didn’t have to have it done at all but that’s about the only thing really, it’s not a problem, there’s no issues with it.’* (Joseph). Most appeared to fantasise about having something different for haemodialysis that avoided cannulation:

‘Yeah, some sort of a magic needle…um… It would just slide under the skin without any pain whatsoever.’ (Sarah).

‘*It would be great if they found a way to clean your blood without actually taking it out your body, but that’s a tomorrow’s world job I think to call it’* (Steven)

Molly summarises how many participants truly felt about cannulation: *‘I’d like to not need to be needled, that would be a massive bonus, just if there was another way to do it … I suppose with all the technology we've got, I mean, it’s fantastic, you know, we've got these machines, but you just think surely is there another way? … I don't know what that other way would be, but you just ideally you wouldn't need needles at all’.*

5.1.2.1.1 Sub-Category 1: Familiarity makes cannulation less alien

Part of the unpleasantness is that cannulation is an alien procedure that is '*quite strange. It's strange'* (Emma); '*well I know it's not everyday*' (Bridget); *'It's just a funny experience'* (Charlotte). Molly describes how the cannulation and having needles in her arm still feels unreal, despite feeling used to the cannulation: *'You're thinking, 'But obviously I'm used to it now' but when I explain to people what I have to do, they're like 'what, you just sit there with needles hanging out your arm' and you're sort of, like, 'well, yeah, I do really'*. *And it seems almost unreal*'. Participants also find the cannulation is '*invasive'* (George), heightening the alien nature of the procedure as *'it's unanatomical … I am lying in a chair and someone is putting a great big needle into me'* (George). The invasiveness of cannulation is difficult to deal with:

> *It's a bit of intrusion into your body isn't it all the time …. Physical thing that normally you wouldn't let your body go through … Yeah, it's very invasive isn't it. I think that has an emotional effect on you'* (Sarah).
>
> '*Just that you're having a foreign body in your body, you know, put in your body … when somebody's putting a foreign body into your body, its not that easy is it?'* (Michael).

Participants often describe how *'just familiarity really'* (Toby) with cannulation makes it easier for them. They describe how *'the more you do it, the easier it gets … just regular, doing it regular … same with anything, the more you do it the better you get, yeah.'* (Adrian). Participants often mention how they've become *'used to it, I feel OK now.'* (Tessa) and '*settled into the process'* (Charlotte). This familiarity with cannulation makes the procedure more normal and less alien: *'I've been coming a good few years now and it's just like an everyday thing now.'* (Bridget). Developing familiarity was also about *'understanding a bit more about the process of the needles going in and my dialysis.'* (Charlotte). For some, they wanted to know and understand the cannulation: *'Yeah, I'd rather know everything … rather know everything that's going on, you know .. I'm always asking questions, 'what's that for? What does that do? Why are you doing this? Why are you doing that?' '* (Michael).

Participants describe how they *'relax into the routine'* (Daniel) of cannulation, making it easier: *'It's just everyday, I know what my routine is … familiarity, yeah. It becomes almost routine … So if it's routine you just accept that that's what you do and that's it, so you stop thinking about how bad it could be, how bad it is, because you just think well it's got to happen, I'll deal with it then and there.'* (Molly). For some, they become more familiar with the pain from cannulation making it easier to deal with: 'A*nd you get used to where the point the pain's going to be … Um…just being prepared for what it's going to be like … I'm used to where that's going to be, so I know what's going to happen.'* (Sarah). Others describe becoming more familiar with the cannulation process, but also everything that goes on around it, including the environment and people:

‘Yeah, because now I'm used to everything, I'm used to everything, everything what they do. I'm used to the people that do it right for me … because when you first get your fistula in it’s just not knowing where to go isn't it, so it like takes some time to get into it, so it was a bit scary because of knowing what was going to happen, you know … just getting to know the procedure, it is, yeah.’ (Joanna).

‘Yeah, so now I'm quite used to, I know what I'm going to get … I came to know the staff, I got used to the environment, our treatment base … so I know how the system – I won't say I know everything about it – but I know how the system goes on now .. needling and taking off the needles, yeah.’ (Graham).

Consequently, unfamiliarity makes cannulation much harder to deal with, which was particularly evident as the start of cannulation: *‘At first I was very, very nervous … it’s not knowing … it’s the unknowing, not knowing.’* (David). Participants often then progress on to describe that they do not feel prepared for needling at the start, seeming like they were stepping into the unknown, exaggerating the unfamiliarity and alien nature of the procedure:

‘Because it was new and I didn’t know what was going on – nobody had explained it to me or anything that had happened, or what was happening or how to deal with it – it was scary.’ (Ben)

‘It’s when you first go into dialysis you have no idea, you have no expectancy of what level of pain or what exactly is going to happen, and it makes that difference.’ (Daniel)

Participants often felt at the start, they are not provided information about the cannulation before it happens, making it harder: *'I don't think I got any information about the needling when I first went on to fistula dialysis. So a lot of information would have been quite acceptable, better. I think it would have eased the apprehension as well.'* (David). As Charlotte describes, the provided at the start information focusses on dialysis, not cannulation *'They tend to talk about the dialysis as it's, you know, like - a lot of the people that was there were doing it at home, which is completely different to the haemodialysis that you're doing on the unit. And I don't think there's enough spoken about how traumatic the needling can be'.* This lack of information on cannulation often continues once they are being cannulated, with participants not understanding why changes are made to their cannulation: *'I don't know why I came off buttonholing ... well I just wondered why it had happened. Nobody seemed to be able to tell me.'* (Adam). Some find this lack of information about cannulation frustrating: *'I don't really feel I'm give information, unless I force it. I sometimes feel like the opinion is I can't cope with that information or it's not useful to give me any information. Makes me a bit frustrated, to be fair. Because I'd like to think I was…hmm…interested enough in my – what's going on with me - and intelligent enough to take information on-board. But I don't think that's always taken into account.'* (Sarah). Whilst some *'don't want to know too many things'* (Emma) as '*I was frightened'* (Jessica), this leads to them feeling later like they *'missed out because I was just too frightened. Really too frightened.'* (Jessica). As Daniel describes, as the start '*when people don't go to watch the dialysis side, it's because that person's in denial'.* Thus, whilst some patients may not want to talk about cannulation, this may be a sign they need support to face the future procedure, rather than just ignoring this, which leads to a culture of not talking about cannulation for haemodialysis.

5.1.2.1.2 Sub-Category 2: Avoiding or Minimising Pain from Cannulation

Participants describe how cannulation is painful: '*But jabbing needles into people, [laughs], hurts basically!'* (Georgina). All participants mention pain from cannulation, although some found it less problematic than others. Some describe how the pain is minimal, although it's still not painless: *'Well there's obvious pain when it goes in but I wouldn't say it's anything ..,When I say pain, I've got to put it in perspective, because it's not pain, I can feel it going in but it's not pain as such.'* (Toby). Others found the pain much harder to bear: *'Needling like, its like a pain … Yes, it's just like a pain. Because every time we go we get a pain with the needling … It's so painful.'* (Tessa). Some also find the scab removal during buttonhole cannulation painful: *'They take the scab off and that hurts. … it was really hard to get the scabs off my arm and it was all hurting before they'd put the needle in.'* (Michael).

Most find the pain from cannulation easier to cope with because '*it was just that moment in time'* (Michael) which *'once you'd got over that initial pain when they put the needle in, it was OK then.'* (Michael). As David describes *'it only lasts for a couple of seconds when they're sticking the needle in and once it's in there's no problem'*. Again, this doesn't mean the cannulation is painless, but that it is easier to cope with because it is brief: '*The needle,* *when the needle goes in, yes it does hurt a bit, but it's less than a minute maybe usually that it actually hurts. Once the needle has pierced the skin, it's alright … it doesn't bother me, it's only like a minute, it's a very short'* (Avril). However, for some the pain goes on for longer than the needle insertion and thus, is harder to deal with: '*And then you have to sit there for 3 to 4 hours in pain, you know, and you shouldn't need to do that.'* (Ben). Penny describes on one occasion how the pain from the needle was so bad and upsetting during her haemodialysis that she had to come off early: '*The pain that I get when they first put the needle in was there the whole three hours and it was getting worse and worse and worse … in the end I was absolutely sobbing at three hours and I said 'please just…', I begged them 'take it out'.* For some, the pain does not just endure whilst the needles are in, but continues once the needles are out, they are off haemodialysis and at home: '*And sometimes .. I used to get home after dialysis and I couldn't bear to move my whole arm. It was so sore that I had to just lay it on a pillow or a cushion and it hurt all the time and it'd be like that for the following day.'* (Georgina).

Different participants describe the pain from needling in different ways. Some describe it as '*it's sharp…very sharp…um…yeah it's just like a sharp pain.'* (Sarah). Others describe it as having a large object inserted into their arm, like a metal tube or pen:

‘*It is very painful .. it’s like putting a steel tube in your arm, it’s not putting a needle in your arm, it’s like putting a steel tube in your arm. So it does hurt, it does hurt, it does hurt as I say.’* (Daniel)

‘*It’s like having a ballpoint pen stuff in your vein … Well it’s not like giving birth I know … As I said, it’s like having a biro stuck in your arm – well it feels like it, like when you have something in your eye and there’s nothing there but it feels like a brick.’* (Matthew).

Others describe it as ‘*a shooting pain.’* (Simon), ‘*like a burn.’* (Emma)’, ‘*it stings.’* (David) or ‘*a bit of pressure and a bit of a stabby pain’* (Adrian). Only a few participants describe it as’ *just like a little scratch, that’s about it … it’s just like a little scratch.’* (Martin).

Participants often mention how the pain from cannulation varies. For some the pain varies between different haemodialysis sessions where ‘*some experiences can be completely pain free and others can be really hurtful.’* (Matthew). Some also mention how the pain from cannulation varies over time, going through periods where it is more painful which makes cannulation more difficult to get through: ‘*Yes I withstood it. I can take quite a lot of pain but in my particular case, if that’s any use to you, it’s been going on for quite a few months. There was a whole process and I was getting a little bit sensitive towards needling.’* (George). For the majority of participants, the pain is worse when they first start needling and becomes less and easier to cope with over-time: *‘You know I used to struggle when I start in the beginning. It was so painful that time … But now its OK, better now, much* *better.'* (Tessa). However, for some participants the pain is worse now than at the start: *'When I first started dialysis I didn't have a problem with the needling at all, it didn't hurt, it was fine. But in the last few months I've found it extremely painful.'* (Sarah). For some, the pain varied with different needle sites:

'Yeah, that one that goes in first, that is very near my bone and there's a lot of nerves in there and that does hurt a little bit and then the back one, that just goes in straightaway no worries … Yeah, minimum little pinprick, that's it, nothing at all.' (Matthew).

'*Quite often I found the bottom one anyway, I never really felt much, it was always the top one that was problematic.'* (Steven).

However, Martin feels the cannulation '*always feels the same, there's no difference in it'.*

Participants attribute this variation in cannulation to different characteristics of the cannulation. Most participants mention that cannulation in the same or similar place can be less painful than cannulation somewhere different: '*Yeah, it does, it hurts more when they go in different places, yeah.* (Joanna). Participants describe how they '*get used to where the point the pain's going to be … just being prepared for what it's going to be like. Where the pain might vary if it was going in different places*' (James). Some *'prefer the buttonholes because they don't hurt as much.'* (Ben), where cannulation is always in exactly the same place, as *'once the scab is off, it's just, there's no pain, you just slide it in … because the pain is that breaking through the* *skin.'* (Avril). However, for some, individual sites can become very painful, thus moving the needling site made it less painful: '*Because they've moved it, it's changed … Yeah, well, until they moved it, every time they did it … it was always painful coming in.'* (Georgina). Participants also mention how the size and type of the needle makes a difference to the pain from cannulation. The larger needle '*was more painful*' (Jessica) and *'I've had someone trying to use a bigger needle before and it hurt, more than what the normal needle would.'* (Deborah). However, for one participant, he feels the larger needles are less painful, although he cannot explain why: *'It's weird but like the thicker the needles the less it hurts … the little green needles, they used to sting like beestings, and then these white ones they're like crochet needles and I barely feel a thing.'* (Adrian). Participants who have experienced both blunt and sharp needles describe about how there is a different type of pain with each type of needle: *'I start stressing about sharp needles because it's a different pain to the blunt needles … when you're being needled with the sharps it is .. more of a 'ouchy' pain … sharp is an 'ouchy' pain, a blunt is more of a 'ooh'! [Laughs] Like a 'ooh you bugger'!'* (Deborah). Some find the blunt needles less painful: *'If I don't pay attention and she's not paying attention she'll stick the sharp needles in and I'll be like 'argh, that hurts really bad'.'* (Ben). However, others feel the sharp needles are less painful: *'Well sharps is quite easy actually .. the needle's in in no time and it's very rare I get pain from it. … the blunt needles would be a little bit painful.'* (Adam).

Participants identify that the pain is individual for each patient, where '*pain depends on the threshold of the patient'* (George) and '*everybody's different, you know, one person, I mean, would just be very stoical can think oh yeah, 'Ow, it hurts', you know, and just deal it, but other people won't, you know, we're all different, you know.' (*Georgina).

Whilst how problematic the pain from cannulation varies for individuals, all participants describe how it is important to avoid the pain from cannulation:

> *'No-one wants to feel pain'* (Nicholas)
>
> *'If there's a way of making it painless please just do it.'* (Simon)
>
> *'Clearly I'd prefer it to be painless'* (Avril);

However, as Georgina recognises *'I mean, it would be lovely in an ideal world you'd have it pain free but I don't know if that's possible! … I just want them make it as painless as possible!'*. Therefore, whilst participants recognise pain free cannulation may not be possible, focussing on minimising the pain from cannulation is important.

Participants mention various ways that the pain from cannulation can be minimised. The most frequently mentioned option was local anaesthesia, which can either be an injection of lignocaine just under the skin surface at the needle site (sub-dermal) or a topical cream with local anaesthetic in it that numbs the skin. For some, the subdermal lignocaine reduced the pain from cannulation, making it much easier: *'Lignocaine was a godsend! … At* *the very beginning, I was wanting Lignocaine all the time, because I knew it numbed some of that pain.'* (Deborah). Others used the local anaesthetic cream and found that reduced the pain for them: *'And the .. erm .. I've got this cream now what you put on and it sort of numbs it … And that's made it a lot easier.'* (Michael). This made some participants fearful of cannulation without local anaesthesia: *'I do worry that they'll say one day that I can't have it anymore … that the pain would be so outrageous I would find it very difficult to be needled.'* (Sarah).

However, participants also mention problems with using local anaesthesia, with some avoiding or reducing its usage for these reasons. Sometimes the sub-dermal lignocaine doesn't work as it can take time to work and *'if it doesn't settle in straightaway I can still feel it so it obviously defeats the object.'* (James). Also, some describe how *'lignocaine only deals with surface pain, so as my needle goes in further it just doesn't work really.'* (Sarah). For others, having sub-dermal lignocaine involves an extra injection or needle, so they avoid it: *'Then you're still needled for the Lignocaine so you still feel it anyway … to have the lignocaine you have to have an injection and my preference is not to have needles full stop.'* (Simon). Some found the lignocaine injection painful as *'when they put that first in that feels the same like burning. Yeah, like a nettle sting sort of.'* (Adrian), and thus avoided it. Others worried about damage to their skin or veins from sub-dermal lignocaine, as '*one of the problems is that Lignocaine makes it* [the vein] *narrower'* (Georgina) or '*hardens the area and it's more difficult to needle me'* (Sarah). Local anaesthetic creams also didn't work for some: *'The first* *couple of times I had the numbing cream and I can't really say that did anything.'* (Molly). Some worried about the local anaesthetic cream as *'I gather they're not good for the skin, they're not good for infection control'* (Avril) with Jessica discovering *'I'm allergic to the cream. They had to stop using it'*. Participants also found it difficult as '*you've got to guess where the nurse is going to put the needle in, to put the cream on and you've got to do that an hour beforehand, so that comes with its own anxieties as well you see.'* (Avril).

Other things that reduced the pain of cannulation included:

- Ice spray: *'an ice spray they do it, and then I think it puts things right … Yes it makes difference with pain, minimise it.'* (Graham).
- Getting the needles in quickly, which helps minimise the length of the pain: *'And of course if you do it very quickly it's in, done, you know, and that's it sort of thing, you know. The quicker it's done the less pain you're going to feel, isn't it.'* (Georgina).
- Having a cannulator that causes less pain: *'One of your best needlers that causes no pain for some reason that day … It's like if you have someone that's going to hurt you and someone that isn't, it's like sometimes you get the person that is going to hurt you, whereas as a patient side you think well that's unfair because that person is sat on the chair and I can see them and they cannot hurt me and you're going to hurt me whilst they're watching me.'* (Nicholas).

A few also mention that they believe plastic cannula would be a less painful alternative to cannulation with metal dialysis needles: *'I mean, I don't know if you can in some way do like with a cannula where if you've got the plastic and wire going in at the same time as the needle and pulling the needle out … some way they could get the needle in and get it out straightaway but…a little bit of plastic in your arm or something'* (Steven).

5.1.2.1.3 Sub-Category 3: Making Cannulation more Predictable: Getting the needles in easily

Participants regularly describe how '*you have to expect that the needling will change.'* (Daniel). Some describe how the cannulation tends to vary:

> *'I mean I've had like two or three weeks while they just came and took like one minute to needle both of them and sometimes it takes like 10 minutes … And then it's like 'why?'. Why? … Sometimes good, sometimes not so good.'* (Emma)

> '*Well nothing against them, it's just the fact that, you know, sometimes you think that they're going to get it in and they don't.'* (Toby).

This makes some consider what would happen if the cannulation goes wrong as '*you can make a mess and you can, you know, get it right or get it wrong.'* (Joseph). However, this is more than variation, with how and when it varies being unpredictable. This leads to a constantly unpredictable and precarious procedure, where *'the experience is different every time'* (Sarah) and '*sometimes it happened .. sometimes its not*' (Tessa), so they never know what the cannulation is going to be like: *'Sometimes they put it in at a slight* *angle or apparently your fistula can move slightly each day. So it is a bit of a guessing game … Well, yeah, I say guesswork!*' (Molly). This makes the cannulation harder for some participants: *'It was more of the mental side of it … like, it's like a thin line, like, it could be right, could be wrong.'* (Nicholas). This unpredictability gives participants good and bad days with cannulation, where unpredictability is inevitable: *'I think you either have a good day or you have a bad day … Um, yes I think it does vary sometimes … if it's a good day I'm really happy, if it's a bad day then I don't feel so happy, but it's…yeah, it's how life goes. I mean, you can't expect to be right every time can you.'* (Charlotte).

Cannulation seems to be less predictable when they first start needling, often due to a new fistula that had not fully developed and has not been used to having needles inserted:

'Yes, when I started on my haemodialysis, I had quite a traumatic time, because every time they tried to get needles in my arm they blew, the veins blew in my arm.' (Bridget)

'Yeah, I mean, again, at the beginning I did feel vulnerable and I didn't know if it was going to work or was I going to need another nurse. So I always felt vulnerable because there was potential issues' (Steven). Demonstrating congruence with this, others describe how their cannulation has become more consistent over time, making it easier: *'I'd say it's smoother now, yeah. People get to know you and it goes in a lot easier and, yeah, on the whole it's a lot easier, it's a lot more straightforward.'* (Toby).

However, Avril describes how cannulation often starts in a context that is unpredictable, which makes it harder, where it '*coincides with some form of trauma. So like the first time I went on haemodialysis, it was after a transplant failed so there's all the trauma of that and it's a whole new system that you've got to get used to - so it's a new place, a new system and you just don't know what's going to happen .. So it's never one thing in itself. It's always the trauma that surrounds it as well.'*

Overall, participants seem to feel cannulation is precarious, which leads to some participants considering themselves lucky when they don't have problems: *'So really, luckily, I've been pretty lucky ever since, you know'* (Bridget) and using luck to prevent problems *'Touch wood it never does!'* (David). Whilst unproblematic or successful cannulation is seen as lucky, participants often held themselves responsible for problems:

'I think it's just me being awkward. … So I'm just awkward!' (Rose)

'I feel as if I'm letting the side down when it doesn't go straight in. That it's somehow my fault, I know it's not, but that's just how it makes you feel.' (Sarah).

Participants also describe times when cannulation goes smoothly: *'Sometimes they go straight in, I can feel them popping into my vein and I think oh great that's gone in first time, lovely, you know, and no problem.'* (Charlotte)*.* This made the cannulation easier: *'if it is just straightaway it's in and it's done, then that's much more manageable'* (Clare). As Nicholas describes he wants them to *'set a good example on the first try, so they don't* *have to try again the second time'*. As problems getting the needles in can make cannulation more painful, when the cannulation goes smoothly, participants describe how it is less painful and the pain is brief as it takes less time:

'It just slips in, you don't feel it has gone in … no, there is no pain, there is no pain when the needle slips in.' (Graham)

'I just go in, sit down, the person comes in and we just do it and it's done and I'm on in five minutes normally, it's fine, yeah … the guy came in, he did it on a regular basis and straight in and five seconds and I was on.' (Toby).

The majority of participants describe what it's like when the cannulator '*was having trouble getting the needles in'* (Bridget) and *'… how they manoeuvred it sometimes if they hadn't quite got the vein.'* (Bridget). Avril describes how they are '*trying to find the best place for the needle to go in. So once they've gone in, then sometimes they have to .. well usually they have to adjust it a bit to try and get the good flow. So they have to sort of bring it in about a bit or just adjust the angle fractionally, very small movements and that's what they're doing to get the best angle to get the flow. The blood doesn't always flow straight away. They have to find a good place for it'*. This manoeuvring the needle once it is in the vein can be painful: *'If they can't get in first time they start fiddling about, but it hurts … they're trying to put this needle in and they start wiggling it about and fiddling about … and I think that's trying to fiddle about isn't nice, you know.'* (Georgina).

This is not just about manoeuvring the needle once it is in, but multiple cannulation attempts where *‘they’ve got to put multiple holes in my arm to actually find the right way … so it’s numerous injections.’* (Toby). This makes cannulation harder: *‘It became a little bit depressing because it got to the point where literally every time I was going in I was having three or four needles. So I mean in terms of mental wellbeing it became, it did become a little bit of an issue, because .. I was just dreading going in because I was dreading how many needles I was going to have.’* (Steven). Unsurprisingly, having the cannulation procedure more than once makes it more painful: *‘The needles, I mean they hurt on the first attempt. The second attempt is bearable but when it keeps being pushed in, I tell them to stop because I can’t bear it.’* (Jessica). It also makes the cannulation process longer: ‘*They tried half an hour and they did struggle. It couldn’t work. Three, four nurses tried and then it worked, you know.’* (Tessa). This means participants worry that problems with needling will delay their treatment, meaning they go home later. Clare describes how problems with cannulation extend how long she is on the haemodialysis unit: *‘One time I was there til 2am when I should have left at 10 o'clock, just because they just couldn’t get it in over and over and over, it just kept – it’s incredibly frustrating … I just think, you know, is it – it’s just going to keep happening and, again, like the times where they'd have to leave it then for half an hour or so and then come back and try again and I think well how long now am I going to stay here, you know, if I've got things that I need to do the next day I can't be here all night’.* Some participants describe how some needle sites are easier to cannulate and less problematic than others: *‘Sometimes what happens .. she has inserted needle in the artery and when she comes to inserting the upper arm, in the upper outlet, the venous one, so it doesn’t.’* (Graham).

One problem with getting needles in the right place is blows, where *‘ you go in, you can go straight through it, but they’ll blow it’* (Matthew) or *‘it’s just where … it just seeps* [blood] *underneath the skin and then all of a sudden instead of the blood going down through the needle it bursts and goes under the skin and it blocks off the needle and then it clots and then your arm just swells.’* (Martin). Blows are often ‘*horrible and scary’* (Deborah) and as David describes*, ‘it doesn't make you very happy, put it that way.’* Blows are often ‘*extremely painful’* (Penny) or ‘*it’s unimaginable pain, I can’t even describe what it feels like to you. It’s really not nice*.’ (Ben). The pain is ‘*a different pain. It feels like there’s something blowing up in your arm, obviously it’s the blood…um…what can I…how can I say it…it’s the blood building up that’s making your arm swell, you know like that, you feel it.’* (David). Participants also describe experiencing extensive bruising from blows: *‘It looked so badly bruised, because it was a mess, I mean, it was pure purple-y black.’* (Penny). Sometimes, participants cannot be cannulated after blows. Therefore, they require alternative forms of access for haemodialysis. For some, they are able to use a CVC they already had in place: *‘If you do have your blow out for the first time you automatically go back to the line for the couple of extra sessions until it eases down and then they start using the fistula again.’* (Martin). For others, *‘they’ll take one needle out and leave one needle in and do a one needle dialysis.’* (David). However, for others it is more traumatic, requiring an additional CVC to be inserted, which is frustrating and disruptive: *'Because the first time I went in it blew. Yeah, so I ended up being in hospital for about a week having a line put in my groin … I was annoyed because I'd just had that done for dialysis and then they couldn't use it, so I had to go in and have something else done like. At the time it felt a bit pointless but now I see why it had to be done.'* (Adrian). For others they require additional surgical procedures to correct the blow, which are also unpleasant: *'I did have an issue a few years back where somebody new needled my arm but they put the needle straight through the vein. And I had, it was like a golf ball situation happened in my arm where they had to operate and remove it.'* (Michael).

As well as describing how problems with cannulation and blows make the cannulation unpredictable, participants also suggest why they believe these things happen. Participants describe how the *'fistula is a piece of anatomy. It can vary from patient to patient.'* (George). This affects the ease of cannulation as 's*ometimes the fistulas are opening up and you could drive a double decker bus through it and other times the fistulas are deep down and not so easy to anticipate'* (George). Some describe individual traits to their AV access that make it easier or harder to cannulate, like:

- Small veins: *'My veins are not really good .. I know that my veins, are like very small, like a baby's veins, you know. So they sometimes have a problem. So they try but they can't do it.'* (Tessa) as *'it's just* *like trying to put a needle into a straw instead of a needle into a wider, bigger straw'* (Matthew).

- The route of the AV access vessel: *'With mine it's twisted, like, it goes like a zig zag … I'd want it straight like my other one so it would be easier access.'* (Nicholas).
- The depth of the AV access makes it harder to cannulate: *'In the beginning and then I was told that my fistula was quite deep and difficult to reach.'* (Simon).

Some participants describe how *'the fistula bits do move around occasionally I think - I think they do it on purpose!'* (Joseph) where the vessel can be '*all over the place'* (Rose). This can make the cannulation unpredictable: *'When you're needle into somebody's vein, veins don't always stay in the same place. I know I used to be able to say to them it is to the left or it is to the right, but because they move – some of them do move more than others, it's not always 100% that you can needle straight into that vein in a complete and proper way.'* (Daniel). A few participants also discuss how their skin or veins are '*very tough'* (Penny), making the cannulation harder as *'I know they've got to give it a push … I'm telling them to push harder, because normally you don't have to push that hard, do you, to get them in'* (Penny).

Most participants describe how the cannulation varies with different cannulators: *'Like I say, some nurses are better at doing it than others; it's a bit of a lottery with me really.'* (Ben). As Matthew describes *'they've all got their different techniques … Everybody's got it down to their own style, their* *own different way of doing stuff'*. Cannulation often *'depends on the nurse doing it'* (David). However, not all participants feel cannulation varies with the person doing it: *'I don't feel any different when I get needled by different people – it all feels the same every day, yeah.'* (Adrian).

The cannulator can affect how painful the cannulation is: *'Sometimes it hurts and other times it don't, it all depends who's doing it really, what persons are doing it.'* (David), or how easily the needles go in: *'Certain nurses get it in the right track first time, other nurses, because they're not used to my fistula - no complaints on their needling, it's just getting used to it - there's a lot of wrong tracks and once they've realised after four or five attempts they're in the wrong track they'll pull it out and start again and they usually do then get in the right track.'* (Penny). It's not necessarily the procedure of cannulation that varies, but how the cannulator inserts the needle:

'So I have had some needlers before where I feel like – most needlers – they do all the stages the same, like, remove the scabs and then they're straight up. It's more or less pretty much the same, but the way people needle … they will go down and it's like one swift movement like it's going to be straight, but then like as they go down, like, they kind of feel like it's not right or I'll scream because I'm in pain. Whereas the needlers that I'm used to, they will literally do it like bit by bit and it's like, I feel like as they do it they have more of a, like, understanding of how my arm works' (Nicholas).

‘Some people can do it slow and guide it in, which is brilliant, because then it doesn’t hurt as much. Others are very, as I’d call it, stabby-stabby, and they just try and ram the needle in’ (Deborah)*.*

Whilst Nicholas attributes the difference to the cannulator knowing his AV access, Simon attributes it to experience: *‘Certain people can do it well and certain people don't … I'm thinking when somebody’s more experienced it’s like being – obviously they just go straight in and it’s not so…um…they don't seem to have so much trouble. Where somebody that’s less experienced it differs. The pushing in doesn’t seem to be as seamless, if you see what I mean, you can actually feel it more’*.

However, as *‘it’s never always the same person every time that puts you on.’* (Martin), this increases the unpredictability of the cannulation as *‘I think who’s going to be doing it today, you know, is it going to be someone I know has hurt me before, you know, or it could be someone completely different’* (Georgina)*.* As Toby describes, *‘I mean, I do have thoughts of like it’s a little bit like – I don't know if you know the TV show Stars in your Eyes, who’s going to come through the door to do the needling for you’*.

As unpredictability makes cannulation harder, reducing this can make the cannulation easier. Thus, participants often describe what helps to increase the predictability of cannulation. This includes developing a strategy to cannulate them successfully, working out the best way to do this: *‘Mainly I think they had a strategy of how to needle me because I kept on blowing in* *the beginning and there was a way that somebody did it that it worked and then I think that that was communicated amongst them and then they all tried it that way.'* (Simon). The cannulators get to know how is best to cannulate individual AV accesses as *'once they know your fistula, they know which position to go in, they know how deep to go in, they know how hard to push.'* (Penny). Often, they use the direction on a clockface to guide the direction of cannulation: *'They started talking about it like it was a time on the clock, which way you approach it, from the side or, you know, wherever,'* (Simon), allowing them to identify the exact way to cannulate someone: *'The motto for that one is strictly 'twelve o'clock shallow'. If the nurses stick to strictly twelve o'clock shallow, that's fine.'* (Sarah). Those on rope ladder also believe the scarring from previous cannulation, whilst is also unsightly, guides cannulation: *'They all just look at my fistula, they look where the line's gone, they look from where the needles went in last and just go above.'* (Martin).

As Simon eluded to earlier, participants often describe how communication between the cannulators about the strategy to cannulate them is essential, to increase predictability. Sometimes the cannulators do this by learning from each other: *'When they needle there is only one or two nurses that come. Like sometimes they came all of them because I was like new, they had to explain how it should go inside.'* (Emma). This approach is challenging as cannulators need to remember how to cannulate different AV accesses: *'I think nurses doing 15, 23, 40 different fistulas a day, obviously it is going to get a bit puzzled because, yeah, you've got to remember who's…like sometimes I can't even remember my cousins' names, you know what I* *mean. So they've got to remember everybody else's fistula, like.'* (Nicholas). Therefore, participants describe how cannulators use documentation to communicate the best way to cannulate someone, which increases predictability and success of the procedure: *'Whoever's doing it, it's written in the notes that it's either shallow or deep or whatever'* (Charlotte). However, a few participants feel frustration that these records are not used by the cannulators to assist successful cannulation: *'It's supposed to be written down in front of them. All they have to do is read it, you know, it's the instruction, they have to read the instructions and do it … I have to make sure, I tell them to write things down on my prescription. I'll say to them .. can you make sure that you put down that I am a buttonholer, that you've crossed off that I have sharps, that I have to have size 15 buttonholes' – they don't!'* (Ben). Participants also describe how they learn the best way to needle their fistula, so they can guide the cannulators: *'My graft is very shallow and sometimes when I say to a nurse who hasn't done it before .. I'll say to them look it's very shallow and it jumps. You have to keep a firm hold of it, it is very shallow … I always explain that so that they understand, well hopefully they will understand that before they start.'* (Avril). Participants find this *'gives me the reassurance that I've told them the best way to do it.'* (Deborah) to make the cannulation easier: *'I direct them nowadays what to do. Yes, to make things easy'* (Graham). Unfortunately, participants describe situations where they are not listened to: *'then [audible sigh] I mean it's inevitable, it's human nature but if it's the first time, they've gone 'oh oh it is shallow isn't it?' I think yeah, I told you that. But yeah so it's nicer if they, if* *they take your advice and sort of say thank you for that advice, so that's helpful.'* (Avril).

Participants describe specific interventions that make their cannulation more predictable and successful. For some, '*what is it – tourniquet?'* (Graham) helps make cannulation easier as *'it helps to us or the nurses to find the slot, yeah.'* (Graham). The tourniquet makes *'the veins so much more pronounced .. it just makes it a lot easier to get it in'* (Clare) and *'it seems to bring it more to the surface, so it doesn't need as much pushing.'* (Penny). It also keeps the vein still, so *'they have to use the tourniquet to hold my fistula still and then they put their hand on there to hold it still as well and then it will go in eventually.'* (Ben). This seems to be unique to participants on buttonhole cannulation, possibly as it assists inserting blunt needles into the track and vein. Another technique to promote predictable cannulation is use of the ultrasound scanner to find the vein and assist with cannulation: *'And so they got that ultrasound thing out and they scanned my arm, found the vein and then went in like that and it worked.'* (Adrian). Some participants feel the ultrasound scanner is not always used enough to prevent problems: *'But when I had that needler and that gave me the first blow, they didn't have the scanner. So they didn't learn how to initially do mine perfect first time because it didn't have the scanner. It's just things like that where maybe it would have prevented.'* (Nicholas). Some note that using the US scanner could lead to delay to their cannulation as *'having to wait for the scanner and you've got to wait for the nurse who does that, who is qualified to do that'* (Penny), which is frustrating. However, once the cannulators become familiar with the position of the vein, the US scanner was no longer needed: *‘I had to have it scanned to actually .. for them to find it again, you know ..then they found it and then they just did it from that you know.’* (Toby).

They also describe how they minimise unpredictability by wanting no changes to their needling when it was going well, to maintain the status quo and avoid problems. Participants describe trying to keep the cannulation as consistent as they could: *‘No changes, it should be as it is, now.’* (Graham). They describe it as *‘absolutely fine at the moment and I'm hoping that it stays that way,’* (Penny), so they avoid any changes that may disrupt and cause problems with their cannulation as *‘I can't afford anything go wrong.’* (Matthew). As multiple cannulators adds to the unpredictability of cannulation, increasing predictability is also about having the same people cannulate them, who are familiar with their fistula and able to get the needles in easily: ‘A*t one stage that was the only person I wanted to do them … It’s because they became that used to doing my needles … I had many members of staff couldn't do it, I’d be then getting anxious just saying ‘I want this person to do it'. ’* (Deborah). Participants often describe how they would like the same cannulator: *‘If you could pick your nurse when you went in who you want to needle you, you'd have the same nurse every time.’* (David). They describe how continuity in the cannulator allows the cannulator to become familiar with how to cannulate their AV access: *‘Rapport with the fistula so you know it inside and out, so yeah … initially it’s practise makes perfect, so I just feel like the more they practise on a specific fistula the better they're going to be.’* (Nicholas). However, this was more than just knowing the AV access, but also about the cannulator knowing them as a person and how to support them through the cannulation: *‘So new people come with new difficulties – does that make sense? … It’s that continuity … Because it’s not the first time that you're communicating with them and it’s not the first time that they're delivering or, or, um, do you know what I mean, it’s not the first time that they're doing your fistula’* (Simon). However, Clare highlights that whilst having the same cannulator would makes cannulation easier for her, *‘I don't know if that’s counterproductive in that you don't trust other people to do it for a while! So yeah, I don't know, it’s a tough’.*

For those on buttonhole cannulation, they also describe that having consistent needling sites helps promote consistent cannulation: *‘It’s not always that they move the site that they’re using … just basically because they know where they’re going, you know, it’s not a point of them using the scanner to find out where the vein is, you know, prodding about to see where the vein is. They know where it is.’* (Michael). The blunt needles are also advantageous as they can prevent a blow: *‘I think it’s the fact that it’s very hard to blow the vein with a blunt needle. Like, they'd have to kind of try to do it, for it to happen. So that was kind of almost more comforting to me .. it doesn’t so much matter now that my vein’s not huge, because if they can get it in then there’s not really that chance of it blowing and because it now can go in consistently, that’s kind of not an issue that I think about, too much.’* (Clare). However, this was not the case for everyone, as *‘I like the sharp needles … Because they tend to be more successful going in.’* (Sarah). Whilst those on buttonhole feel it creates predictability, those on rope ladder or area puncture feel the same as they know what to expect: *'It's all consistent, because they do it like on a ladder run, so they're always working up above the needles that they've done prior to that, so they're just making ladders … It's one of them things that they've been doing and you just get used to it.'* (Martin).

5.1.2.1.4 Sub-Category 4: Reducing anxiety about cannulation

The majority of participants experienced anxiety about their cannulation. They used different words to describe this, using *'anxiety'* (Deborah, Emma), *'fear'* (Adrian), being *'scared'* (Emma, James), *'apprehensive'* (George, Jessica, Bridget), *'panic'* (Charlotte, Clare), *'worried'* (Georgina), *'anticipation'* (Michael, Clare, Avril), *'being uneasy'* (Graham), *'on edge'* (Sarah) or *'tense'* (Steven, Clare). For some *'this is the disturbance in the mind.'* (George) or '*psychological*' *(Steven).* For others they experience physical symptoms from their anxiety, as described by Penny: *'I get, I would say, almost like quite sweaty and it's quite strange to explain because I feel very anxious with it, which you would think makes my blood pressure go up, but actually my blood pressure drops down and I go quite light-headed … I sort of hold my breath while they're doing it … on occasions my arm's been tense'*. Whilst Penny's symptoms are quite severe in comparison to most participants, they summarise the range of symptoms individuals can feel. Regardless of whether it was physical or psychological, for some participants, they find their anxiety about cannulation difficult to deal with:

‘I have this thing when I get, like, when I'm anticipating the needling, I get really tense and I get quiet, but that’s my way of dealing with it … I'm focusing so much on trying to not .. I guess panic ... it’s that thing, I appreciate when people try and talk to me but, at the same point, they shouldn't expect a response, if that makes sense!’ (Clare)

‘But before you even get there you're sort of worried about it and you're remembering it and it just adds up and adds up … you just want to pull your hand away and go ‘no, no, don't come near me’, you know, it’s very hard to describe.’ (Georgina)

‘I do panic and then I just want to tear everything out, you know, and stop it, you know. It’s not a good feeling.’ (Charlotte)

‘I’m so uneasy with myself and I don’t like that feeling to be fair and I don’t think I should be feeling like that, you know … The major part is the needling and the picking of the scab bit.’ (Ben)

‘Yeah, it’s like a fear factor thing, innit … Oh yeah, yeah, it’s the scariest thing in the world if you're worried or scared about it. It’s the scariest thing in the world to have two great big needles stuck in your arm’ (Adrian)

However, a few participants do not experience any anxiety:

‘Yeah, I don't get het up about it or worried about it.’ (Joseph)

‘*I've not been worried – I don't worry about anything.’* (Matthew).

For those participants that report anxiety, the time it starts varies. For some it starts just before the cannulation:

'When I sit in the chair then it starts. When I see them coming with the needles' (Emma)

'When I first go into the ward you've got that period you're waiting for the machine to work, prime and get ready, so you've got like 10 minutes or something like that where you're sitting down and you're waiting. I think the anticipation of .. erm … someone putting needles in your arm, or somebody putting needles anywhere, is a bit daunting.' (Michael).

For others it Is when they leave to attend hospital for haemodialysis: *'Yes, it was just when I knew I'd got to go to the hospital and have my haemodialysis, you know what I mean. You know, oh I've got to have the needles in again and that was when I was winding myself up, if you like.'* (Bridget). For others, their anxiety Is more severe, starting the night before: *'Yeah. I can't sleep most of the time because I'm thinking about it. From 11 o'clock the night before – that's my bedtime, 11 o'clock – till I walk through the door and I see who my nurse is, the anxiety's there all the way through.'* (Ben).

The majority of participants have anxiety when they are first being cannulated: *'That's right. I mean, I had trepidation the first time we really used the fistula.'* (Toby). However, they often describe this got better over time. For some their anxiety disappeared completely: *'I was scared at the very beginning, because of the needling, I was scared. But then I just – but then after a bit I was alright.'* (Joanna). For others their anxiety becomes easier, but does not go away completely: *'I think it would probably be fair to* *say I used to be quite anxious about it, whereas now I'm just like conscientious that it can be problematic still.'* (Steven). However, for others their anxiety lessens over time, but was remains at a level that is still unpleasant*:*

'I'm not as scared as I was. I was so frightened to start off with, I wouldn't be able to bear it .. But now I feel differently about it, I'm not really frightened, just anxious sometimes.' (Jessica)

'*Mentally I think when it came to the needles … even now, like, my heart starts racing before I go in for, I'm needled, even now. Not as much as it used to be, I'm coping with it a hell of a lot more now'* (Deborah)

For others their anxiety actually becomes worse over time as they experience problems with cannulation: *'I'm more apprehensive now when they needle than what I was in the beginning, but I think that is purely again because the bottom one is so painful and the top one they have got to really push it. So I would say I'm a lot more apprehensive now with needling than what I was in the beginning, because it wasn't painful in the beginning at all.'* (Penny).

Whilst the anxiety is problematic before and during the cannulation, participants calm down once the needles are in successfully. They talk about being relieved it is over:

'I knew once they needles were in, we're all right then for the next four hours.' (Adam)

‘Once she’s adjusted it and reassured me and taped it alright, I'm alright … Yeah. And then when they’ve done it I go ‘oh thank god for that, what time do I come off’ [Laughs]’ (Rose).

As Michael highlights, once the needles are in, he wonders what he was anxious about: *‘As soon as they put the needles in, that’s when it’s gone, that’s when it’s gone. I don’t feel it then because the needles are actually in my arm … And then as soon as the needle’s in you’re thinking what was I worried about in the first place?’*.

The anxiety that participants experience about cannulation is exacerbated by the unpleasantness and unpredictability of cannulation:

‘I just feel like I don't know, is it going to hurt, is there going to be an issue, am I going to have to be re-needled.’ (Steven)

‘Thinking what have I got to face tomorrow and I don't know what’s going to come.’ (Molly).

Participants worry about the pain from cannulation:

‘It really plays on my mind and I think this is going to hurt me, it is, yeah.’ (Joanna).

‘It makes it harder because I know every single time, like, literally in two hours from this phone call I'm going to be in pain with that first needle … I don't really want to go but I'm just dreading that first needle, like’ (Nicholas).

Concern about whether the cannulation is going to be successful also creates anxiety: *‘Yeah, just complete sort of fear of the needle either blowing* *or just having to go out and have another needle put in, because like I said it did happen quite a lot at the beginning … well it's not just the problems. I'm always, like I say, slightly anxious before whatever needle's going in, but normally I'm pretty quick to, you know, I remain calm, but then if there is a problem then I will become a bit more anxious on it'* (Steven). Often repetitive problems increase anxiety, and as Bridget describes, preventing problems may have reduced her initial anxiety: *'They was having trouble getting the needles in at the first, you know, first instance sort of thing and that was what was worrying me more than anything … I used to think 'oh crikey I've got about 400 holes in my arm', you know, and that, sort of, I think if they'd given up a little bit earlier, put me back on the permacath and then tried again I'd have been alright, but it was sort of bringing me out in a cold sweat when I knew I'd got to go and have these needles put in my arm, I knew what was going to happen'*. Congruent with this, Matthew believes he does not worry or become anxious as his cannulation was successful at the start: '*I mean, if I'd have had a blow on the first day that would have put me in fear of everything every time I think, but everything went well'.*

When the cannulation goes wrong participants start to worry about the consequence of problems, as *'if it doesn't go well you start thinking why it went wrong, yeah.'* (Graham). Some worry about damage to their AV access: *'Each time they were poking, they were going to a different tissue plane … I was worrying that the line was poking around in the fistula area was going to cause anatomical damage and I was worried about that because I knew that at the outset, my vascular anatomy of my arm was .. err degenerate … I* *could anticipate a damage happening'* (George). They also worry about whether they will be able to have their haemodialysis: '*I have panicked on quite a few occasions, 'Oh my gosh, if it's clotted all the way up I'm not going to be able to have a dialysis' '* (Molly). As Molly describes, *'The fistula is a lifeline, it's the lifeline'* and participants show awareness of how their life and health is reliant on a precarious procedure, cannulation:

> *'I know it's their job, like, obviously they're professionals but, like I said, that's your job, but this is my life. It's way more important'* (Nicholas)

> '*They're sticking a needle in you aren't they so they don't…it can be quite dangerous … so obviously there are some reservations'* (Simon).

Participants also worry about who will cannulate them, becoming a source of stress: *'And I think because I don't know and I don't know who I'm going to be in with and what nurses are there, that unsettles me a bit as well.'* (Charlotte). Staff they do not know often cause anxiety as they do not know what they will be like: *'If you get a different one to the one that you're used to then yeah, there's a bit of apprehension … Kind of like 'oh no, what's it going to feel like? I hope it doesn't hurt that much'. A little bit of apprehension. I mean they'll be good at doing it, they know what they're doing, but I just think oh no, is it going to be painful or is it going to be a quick thing?'* (Jessica).

As David summarises, he worries about the unpredictability of cannulation, which includes the cannulator: *'I'm thinking have they got it in right and is the fistula going to blow, because when it blows that is painful … Well thinking* *about is it going to blow, is the nurse needling me right, all those sort of things like that'.*

Participants also describe how their anxiety about needling is problematic, as it also makes the cannulation more difficult and painful: *'The more tense you are, the harder it is for them to needle you and then the more painful it's going to be.'* (Daniel). Participants recognise that if they are anxious this makes them more sensitive to the pain:

'If you're mentally uncomfortable, the physical side of it also tends to magnify proportionately.' (George).

'If you get yourself tight and whittly about it, that's when they start to hurt a bit' (Bridget).

'It's the anticipation. Anticipation heightens the sensation … I think that anxiety for needles exaggerates or exacerbates the feeling.' (Simon).

The expectation of the pain sensitised them to it:

'I think because you're always expecting it to hurt, so therefore I think that when it does start hurting it aggravates it. You know, all your fears, if you like, are then magnified because it's what you're expecting so therefore, you know, it's self-fulfilling isn't it … I think it makes it more painful.' (Georgina)

Participants also recognise that their anxiety makes it harder to get the needles in the correct place in the vein: *'I just think it would make it, or could make it more difficult, harder for them to get the needles in if you're tensed* *and tightened up, you know … I think a bit of both. More difficult to find the vein and difficult to, sort of, to go through to the vein.'* (Joseph)

Some participants recognise it *'a never-ending cycle'* (Georgina) where the anxiety makes the cannulation more painful and harder to get the needles in the right place, which then makes them more anxious:

> *'And I think your actual pain threshold goes down a bit because you're anxious and because you're anxious, you know, then you feel pain then it makes it worse and you get more anxious, you know'* (Georgina)

> *'I know my veins will shrink or tighten up and make me more anxious, which then causes the needles not to go in as easy … and then it becomes more painful to needle you … and then if you can't do it and I'm getting more anxious. So a bit of both ways. I'd get anxious they'd try to get it in, they can't get it in so it's making me more anxious'* (Deborah).

Thus, as anxiety can make cannulation experience worse, participants describe how important it is to stay relaxed through needling and not become tense, as they feel this makes the needling better: *'I think the more relaxed you can be obviously the easier it goes in, if you know what I mean … I think the more relaxed you are the better off you'll be … I just think the main thing is to just relax.'* (Toby). Participants highlight that *'when you feel more relaxed you're not as more on edge* [sic] *wondering what's going off and because the more that you're flinching your body about and moving your arm the more then you're causing the machine to keep bleeping … where if you* *just stay there relaxed .. you go for a perfect session … you have a lovely session, the needles go in fine, you have no problem.’* (Martin).

However, participants also highlight that it’s not easy to relax during cannulation:

‘They usually say ‘relax your arm, relax your arm’ but when somebody’s putting a foreign body into your body, it’s .. erm . . not that easy is it?’ (Michael)

‘The objective is to trying not to tense up so that they can go through, but that’s also quite difficult with the fear of needles.’ (Simon)

‘People kind of say ‘oh just go to your happy place’ and it’s like I'm in my happy place while the needles go in and then it’s painful in my happy place! You know, it’s not that easy.’ (Clare).

Some describe how *‘I've learned how to – I can calm myself down a bit more now when I'm being needled … So it’s a lot easier.’* (Deborah). They recognise that relaxing does make the cannulation easier: *‘Eventually when I’d got relaxed and they could get the needles in easier, if you like, because I wasn’t so tense with it and that’s when the pain stopped … once I got used to the fact they'd get the needle in, the pain goes, relax, you know, and I sort of kept putting that through my head.’* (Bridget). However, *‘it took me a long time to try and calm myself.’* (Steven). Sarah highlights that she does not believe that relaxing made the cannulation better, but that she copes with it better: *‘I think if I'm relaxed it helps me deal with it better … I don't think the pain is any different. I think it’s just how I approach the situation’*.

Participants often describe relaxing during cannulation as active process, using different techniques to try to relax. For some, it was controlling how they think about the cannulation:

> *'Just spoke to myself a bit mentally before I get there.'* (James)
>
> *'I had to talk myself down, because it's all in my head.'* (Rose).

Tessa describes how thinking differently helps her relax, which then helps her with cannulation: *'Be relaxed, because if not - it's just a mind, just mind-set you know … If you think pain, pain, pain, then it's pain .. if that I said that I'm happy I think that 'Oh I'm happy' .. If I'm sad and I'm thinking sadder things and if my life is upset as well'*. For others, they use deep breathing to help them relax during cannulation: *'She told me to, she gave me some like breathing techniques to try, like deep breaths or slow, shallow breaths.'* (Steven). Others used music as *'I don't get anxious because I listen to my music.'* (Ben). For some, they had unique ways to relax: *'I do have a little soft toy that my partner bought and I squeeze it when they're putting the needles in, so that kind of helps a bit … I've given it to some other people when they have been having troubles and they're kind of getting frustrated, I'll offer my soft toy services to them to help kind of relieve some of that stress!'* (Clare). However, others they did not need to actively relax as its *'just the way I am. I'm relaxed with most things! … I don't have to do anything. I think it's just a natural reaction*.' (Joseph).

Chatting to the cannulator was the most frequent intervention to help participants relax, frequently describing it as putting them at ease and making the cannulation easier:

> *'Most of them talk to you while they're needling you. You know, they're concentrating on what they're doing, but they're also talking to the patient to keep the patient at ease.'* (David).

> *'I think just general chit chat really, if you know what I mean, you know. You start talking about something, you can have a bit of a laugh and a joke about it and you're easy before they put the needles in and then they put your needles in and it's OK … if you relax and you've got a nurse that's chatty with you and on about silly things, you can have a little chat, you're sort of a lot easier in yourself'*. (Bridget).

Humour and having a joke with the cannulator also help participants relax: *'A laugh and a joke before you have the needles in and it sort of calms you down a bit.'* (Adrian). For some it appears that chat and humour builds a relationship that makes cannulation easier and more normal:

> *'I think the camaraderie, the way you approach people, the way if you're not too clinical, if you approach us .. somebody as a friend or somebody friendly that makes all the difference, if you start to make it clinical I think that's when people start to get apprehensive.'* (Daniel)

> *'It's just the banter we have, you know, we all talk. We sort of try to make quite a .. it's not a – it don't feel like a clinical situation half the time because you see these people often, you see them more than your family sometimes.'* (Molly)

This relationship is explored further in Category 5.

Participants also describe how they use distraction during cannulation to make it easier and not focus on the unpleasantness: *‘If somebody’s distracting me from something that I don't want or I know it’s going to hurt or I don't like, then it helps me and it’s helped me practically all my life if somebody distracts me from something nasty.’* (Charlotte). As Avril describes *‘It doesn’t make any difference to the pain but it reduces the anxiety. You put your mind somewhere else’.* Again, various techniques are described to achieve this, including:

- Avoiding watching the cannulation, taking their focus away from this: *‘I deliberately look away … Not looking at the needle! I’ll be perfectly relaxed if that’s the case … But I just put my mind somewhere else .. I just switch my mind off.’* (Simon).
- Thinking of something more pleasant to distract themselves from the unpleasantness:
    - *‘Think of something nice, as you don’t want to be here.’* (Rose)
    - *‘I just pretend I'm on an island with some sun somewhere and just look away … I just look away and just pretend I'm somewhere else! [Laughs] Until it’s all over and then obviously you get the pain back and you're back in the hospital! [Laughs] … Yeah, pretend I'm on a different island somewhere.’* (James).

- Listening to music: *‘I will do my best to tune into the music and try and sing the music in my head. So the music is taking my mind off what they're doing, so I'm not 100 % concentrating on what they're doing, I'm trying to think of something else.’* (Penny)
- Counting sheep: *‘Another one was literally like a counting sheep. She told me to try counting sheep and things to just take my mind off what was happening’* (Steven)
- Reading or watching something: *‘It’s just a matter of just keeping your mind occupied. I just normally sit there with my phone and just go on the internet and just read my papers and that.’* (Martin)

Opposingly, Clare uses her focus on learning about cannulation to distract herself: *‘Because I'm trying to watch it kind of go in now as well, I'm more kind of focused on that, which is hard, because I still go to like flinch away, instinct as they’re about to put it in! But even that is then I try and just focus on ‘oh OK so that’s how they do it’ and they do it like at this angle and, you know, so because I think I'm focusing on that’*. Whilst many describe specific actions to distract themselves, it’s not always about the specific action but *‘it’s just having that other option where you can probably, you know, think about or do something else rather than wait for the pain to come’* (Toby). A few participants describe how they use not just mental distraction but also physical distraction to distract from the pain of cannulation: *‘I tend to pinch the inside of my thigh to confuse my nerves! … And it does sort of distract … there are tracks where you're feeling the pain receptors … it’s not concentrating on your arm and you're thinking about oh my leg – you* *sometimes forget that you're even being needled because you're thinking oh my leg hurts! It’s all very basic but it works for me.’* (Molly).

Whilst chatting to cannulator is referred to as relaxing, chatting in general is also a distraction, indicating it has a dual purpose: *‘Well they talk to you while they're needling you, they try to distract the needle going in - no not that, that’s not right is it - they distract me by talking to me so I don't think about it – that’s what I'm trying to say.’* (David). Chatting not just to the cannulator but also other patients also distracts from cannulation: *‘When you’re having a conversation with somebody across the way in another chair you’re not thinking about what they’re doing to your arm at that point in time; your mind’s elsewhere … So you’re not focusing on ‘this is going to hurt, this is going to hurt’, waiting for it, waiting for it, waiting for it, you know, your mind’s elsewhere, you’re having a conversation, you’re talking about something else other than that … It just takes your mind off the whole entire situation, which is good.’* (Daniel).

5.1.2.2 Category 2: Preserving humanity and individuality during cannulation

Throughout interviews, participants would regularly indicate how their cannulation was not just a physical process, but also a mental and emotional one too:

‘Yeah, it’s not just a physical process, it’s an emotional one as well I think.’ (Sarah).

'The mental aspect of a patient is most important, patients are not all uniform … To ignore that is .. is bad. It's counter-productive … The main problem is that human beings as a corporate person, mind, physical bit and er.. they all go together' (George).

Cannulation is more than just a physical process, as *'we're all human'* (Joseph). Graham explains how the human interaction with the cannulator is important: *'I mean any machine can't needle us .. rather than human hands are needling. I think human hands will be there .. are required to needle … I'm not able to explain to the machine, what do I tell the machine? I can switch it off and switch it on, isn't it, but I'm not able to speak to them'*. Without an interaction that preserves their humanity, *'it makes you feel a bit worthless really … I feel out of control. I feel very upset and I feel angry'* (Sarah).

Participants also describe how *'everybody's different'* (Rose), *'because people, everybody's different aren't they.'* (Joanna). This means the experience of cannulation, *'it's different with everybody'* (Jessica) as *'they've all got different needs and wants and feelings, you know, and pain receptors'* (Georgina) or *'some people have different thoughts and different ways … …see it depends on different people doesn't it.'* (Daniel). As Tessa describes *'if there is 1,000 patients, every single person would have a different vein, a different body, a different you know kind of pain through their body system.'* This means that being treated as individual is important: *'Obviously mine's a unique situation so that's why I think looking at…um…personalised treatment* *and looking at my…er…my situation, my unique situation’* (Simon) as *‘I guess it’s a personal thing … It’s just a personal thing.’* (Simon). For some, they describe situations where individualised care helps make cannulation easier for them: *‘That makes me a bit more reassured that they're going to try their very best, its like .. like, I'm not their hundredth patient of the day, I'm their first … I think that is the best thing, is not to treat your hundredth patient, just to treat them like your first.’* (Nicholas). For others, the lack of individualised treatment makes cannulation harder for them, which highlights how important it is to recognise and respect their individuality and humanity:

> *‘They don’t discern that any individual A may be different from individual B, I feel … Yes I think more sort of human communication, which seems to be lacking .. lacking.’* (George)
>
> *‘I said, you know, I says ‘just be careful with what you do and be right about what you say’. I said ‘I know you’re under pressure but, you know, I’m not a piece of meat, I’m a human being’ ’* (Michael).

George’s quote (above) also starts to highlight how important the interaction with the cannulator is in preserving the participants’ individuality and humanity. As a minimum, participants need *‘an interaction with that person, which just makes you feel a bit better*.’ (Michael). However, this is more than just a single interaction, building a relationship with the team of cannulators that becomes the vehicle where their humanity and individuality is maintained: *‘Yeah because then you're able to build a rapport aren't you and they know you as an individual so it becomes a little bit more interpersonal* *doesn’t it … with not one but a number of individuals that are constantly working with you.’* (Simon), as *‘personalised medicine is the way to go isn't it’* (Simon). Adam describes how he gets to know the nurses, and when he has a new nurse who had never cannulated him before, he makes the effort to get to know them and start to build this relationship: *‘We get on all right with every nurse … They all know me now, the nurses. They know what me foibles are … if there’s new ones come in, I like to introduce myself and get them to tell me their name and try and remember them. Just lately we’ve had quite a few new Filipinos and they’re all lovely, they’re all lovely, and I like to have a chat to them. Sometimes I ask which part of the Philippines they’ve come from, you know, to get to know them a bit better’*.

5.1.2.2.1 Sub-Category 1: Empathy: Being understood and not being alone through cannulation

Participants often talk about how empathy from others makes needling easier:

‘Well it would placate a disturbed mind … reassuring and I think the other word for that, empathy.’ (George)

‘It’s nice to know that you’ve got somebody looking out for you.’ (Bridget)

Empathy from the cannulator is particularly important: *‘They just made me feel like they was there for me and that was the main thing, which they always do’* (James). Participants recognise the cannulation is going to be unpleasant and painful, but that knowing that the cannulator understand helps: *'You know you're going to get hurt, but never mind. They're there for you, so that's a good thing.'* (Matthew). It's not necessarily that it changes its unpleasantness but works as a balance for the unpleasantness as '*they were so kind. They knew, they understood what it's going to feel like to stick the needle in me and they knew I was frightened.'* (Jessica). Sometimes, participants feel the only people who understand what they were going through are the cannulators: 'O*f course the nurses know. It's quite difficult to talk to people because they don't really understand. So obviously nurses see it day in/day out, so they know.'* (Molly). Some also feel empathy from the cannulator means they are more gentle and thus the cannulation is less painful: *'I think they have the idea that it's not very nice and they verbalise that they don't like hurting people. So they go out of their way to try and not hurt, where I'm not saying the others try to hurt you, I'm saying they just, you know, don't perhaps give it as much thought.* (Sarah). Participants find *'it's reassuring that they're not trying to hurt you'* (Avril) and *'you feel more comfortable and you know that they're not going to intentionally hurt you because they want to hurt you, but because it's part of their job to do that'* (Daniel).

However, empathy is important as it preserves participants' individuality and humanity: *'There's got to be that personal element in it and 'how are you? How are you doing? How are you feeling?' … maybe that would be a bit of a reassurance on the person that they do care, you're not on a conveyor belt … I think that, you know, we've got to be a bit more personable … just five* *minutes or something like that, just to make that person think that you're actually in their corner, that you're actually thinking about them, which sounds a bit daft but I think it goes a long way.'* (Michael). Consequently, absence of empathy denies the participant's humanity and individuality: *'I find it very impersonal – I didn't like the people there – I seemed to be, like, I felt like you were like cattle being put in and it wasn't nice at all'*. (Toby).

George describes how he feels empathy is not always present in cannulation and needs to be included in training: *'For some operatives, it was a matter of their honour that they were able to cannulate a vessel or not, so they kept on poking until they did, or not. I didn't get the feeling they were conscious of it or they were sympathetic or empathetic. It made me feel distressed … Yes the humanity of it. It's not always there. It's not always there because perhaps the operator hasn't got an insight into humanity. They are taught to do a physical procedure but they aren't taught that this is causing somebody mental and physical anguish … conversation .. empathetic conversation would have helped'*. As Sarah describes *'I think the only thing that can improve it for me is that nurses being perhaps a bit more aware of what it's like from my point of view from where I am .. Yeah, so I just think a bit more understanding perhaps, yeah'.*

Whilst empathy from the cannulator is important, empathy from others also helps. Family members can provide support through cannulation, making it easier, as they know and understand them as an individual: *'I had my partner with me every time I was needled, which kind of gave me a bit of* *reassurance … He was able to calm me down when my anxiety started rising. He was reassuring, he held my hand, he distracted me while I was being needled and he didn’t, like, belittle me like I felt some of the staff did .. It was because he knew me’* (Deborah). However, the absence of family support through cannulation during COVID made it much harder for some participants:

‘When Covid hit and my partner wasn’t allowed to be with me I was traumatised. I actually walked out and said ‘I'm not doing dialysis without him’. The next day I felt ill from not having dialysis so I came in. Still very upset I couldn't have my partner with me … So that was only three months then I think working that out. Yeah. So I wasn’t ready for being left on my own for it at all.’ (Deborah)

‘Because of Covid he wasn't allowed to stay there. So then it was very much like I felt I was alone and I was in this place where it’s just pain and it’s very scary’ (Clare).

This starts to demonstrate that empathy is not just about being understood, but also how this makes participants feel not alone, providing social support through cannulation.

Other patients also provide comfort through cannulation: *‘I think it’s nice, it makes you feel nice when you’ve got people round you and they're nice, yeah, it’s brilliant, yeah. You get on with everybody, you know.’* (Joanna). This comfort came from other patients understanding what they were going through, with mutual empathy:

‘Obviously it’s five chairs in a bay and we’re all talking about our own experiences what’s on dialysis when they're needling and all that sort of stuff and when you hear other people’s stories, what they have to say about it, it makes you, I think it makes me a little bit easier to accept what’s going off.’ (David).

‘Everyone’s alright, it’s like a little family, but like we're all in the same boat. We’ve all got to go through the same thing …The same thing, the same everything basically .. obviously it’s like a kidney community isn't it.’ (James).

Sometimes this mutual empathy leads to practical sharing of advice and information: *‘And it’s like we’re all a mixed age group but we all understand what the problems are and we all talk to each other about certain problems that we've been having in dialysis and it’s like one of us are bound to have had the same problem somewhere along the line. And we can always share out information and it just like helps them on their way.’* (Martin). This again stops participants feeling alone: *‘Everyone’s there, everyone needs advice sometimes and that’s what everyone’s there for.’* (James).

However, not all participants appreciate support from other patients. Some did not feel they have the capacity to support others, so isolate themselves: *‘A lot of people do like to talk, whereas I don't. I just like to zone out and do my own thing … It’s awful to say out loud, but I don't really have any interest in how other people have got there, do you know what I mean. I just feel like my bucket is full with what I'm dealing with.’* (Molly). They feel like they need to *‘mentally focused on myself, I don't really want to get into other people’s* *stuff because I'll start, like, I don't know, just diverting from myself .. it's very important to make sure that your mental state is obviously happy before everybody else's is.'* (Nicholas). Others do not find support from other patients helpful: *'And I think sometimes as well the other patients don't help. As I say, I think it was even my first or second session, I was across from someone who was like 'oh don't worry it only gets worse' and it's like obviously that was a joke to them but when you're not feeling good about it regardless, it just makes you feel so much worse. And in the early days because I was so anxious and I was having so many problems and I was upset, people trying to talk to me just annoyed me more than anything. I'd almost rather be by myself and have that kind of quiet time.'* (Clare). Some struggled with the lack of privacy when being cannulated, as others could see them in distress: *'Sometimes I'm aware that people might be thinking 'oh god she's making a right fuss about being in pain' and I'm a bit embarrassed about the pain I feel. Yeah, I try not to say 'ow' or whatever but sometimes you can't help a response and I just sometimes feel that I'd rather that was in private sort of thing.'* (Sarah).

Participants also demonstrate that they understand that cannulation is difficult for the cannulators too, demonstrating empathy towards the cannulator. Some describe how they recognise the cannulator can be distressed by causing them pain: *'And I feel bad for the nurses because they know it's hurting but it's not their fault so I'm sort of saying to them 'don't worry, don't worry, I'm just pulling a face, don't worry, it's not you, it's always like it'. And I feel bad for them because they're there to help you and do the* *best for you and they're hurting you … I think I feel more uncomfortable for them than I do me, because it can't be nice for them.'.* (Penny). Others recognise that having problems with cannulation is difficult for the cannulators too: *'It's not always easy. You've got to .. you've got to look at it from their side. They can hit the vein, but they go through it go to the side of it or, you know … to be honest, I'd hate to be on the other side and try and needle some of those.'* (Daniel). This empathy with the cannulators causes participants to consciously not blame the cannulator when the needling goes wrong as *'its not their fault.'* (Tessa). They often clarify they are not complaining: *'Yeah, that doesn't mean I'm, you know, complaining about nursing or anything … It's not a criticism – that's the word I was looking for.'* (Sarah). This empathy with the cannulator enables participants to let new nurses cannulate them even though they know it may be more unpleasant: *'Oh yeah, it was a lot longer and a lot slower and a bit painful but she got it in the end … They've got to learn, so just get on with it, let them have it.'* (Matthew). They recognise that new cannulators need to learn as *'the only way they're going to be just as good .. is by letting them needle me.'* (Jessica). Some find it rewarding to support new nurses, as they know it beneficial for them to learn cannulation: *'If anybody is trained or being trained even, I don't mind … I don't mind, you know ... most of that staff, they came and learned on my arm … It makes me feel good that I have helped people.'* (Graham). This balances out the extra discomfort from the cannulation, as they recognise it is necessary for cannulators to learn: *'So that little bit of discomfort is worth it in the end because they're all learning … Well they have to, otherwise wouldn't have dialysis people would we.'* (Rose).

5.1.2.2.2 Sub-Category 2: Trusting the cannulator

As already discussed, the humanity and individuality of the participant is expressed through a relationship with the cannulator. Being able to trust the cannulator through this relationship is important:

‘I mentioned to one of the staff, when I'm in your hands, I feel I’m safe … When I come there, I say nurses, they are there, I'm in your hands.’ (Graham)

‘I’m in good hands … I’m feeling OK, I know nothing bad will happen.’ (Emma)

‘So you’ve just got to face up to it and put your faith in the person that’s doing it haven't you.’ (Joseph)

‘I fully trust them what they do.’ (Matthew)

This trust often helps them feel relaxed about the cannulation: *‘As I say, if it’s someone that I kind of trust and I know will do a good job, I think from the get-go I'm more relaxed about it’* (Clare). Participants describe trusting in the cannulators’ expertise and training:

‘I tend to let them get on with it because they know what’s best for me in the long run … I know they’re going to do their job and I know they do it as well to their capability … I always go by their judgement because in my eyes, as a patient .. well they know the complete ins and outs of how my veins could collapse … They won’t let anything bad happen.’ (Rose)

‘I don't feel scared because these guys …um…this is what they're trained to do, yeah?’ (Simon)

As all the participants were cannulated by healthcare professionals, this trust is important, as they often described how they did not have the expertise to cannulate themselves: *‘I’d rather leave the needling to the experts … What’s the point of me telling you about the needling when I don’t know how to do it myself? … It makes me feel better because I know that somebody with the knowledge is doing it.’* (Michael). This trust is also important because cannulation is a precarious procedure that can go wrong, where they often describe putting their life in the cannulators hands: *‘Well it means everything, like, to me, I see it as like the biggest bond, like, their hand .. like, my life is in their hands at that moment in time … So in your head it kind of, like, it just plays, like .. trust plays on your mind a lot and fear of anything going wrong.’* (Nicholas).

Participants often describe how a relationship of trust builds over time: *‘I think it’s just a matter of time because .. They're all very friendly, you know, and they all try and chat to you and things like that, so it’s not like people care cold or whatever, I think it is just having that trust build up over time.’* (Clare). Often success and competence with cannulation can help build trust*: ‘And some nurses, some needlers, they have the technique where they can do my fistula and we've created a bond where I fully have trust in this person where I can fully relax in that seat, I don't have to worry about anything and that’s kind of, like, how I like it ... just know that, like, I'm totally in good hands with this person because they’ve worked on my fistula numerous times and that just takes a whole lot of weight off my shoulders and off my mind.’* (Nicholas). Displaying confidence in cannulation can also build trust: *‘It’s just* *their whole aura. I don't know if it's because they've got .. Yeah, they just give off an air of confidence … if I can sense they've got confidence then it makes you feel more confident.'* (Molly). As it's about developing a relationship of trust, some trust individual cannulators, where *'sometimes you just have to like pick your people really.'* (Nicholas) as *'it's about having trust in the individual that's treating you.'* (Simon). For others they describe trusting the whole team of cannulators:

> *'I get on the chair and I let them get on with it … I leave it to them, what they're doing … because the nurses know what they're doing … They're all lovely.'* (Adam)

> *'I feel safe that I've got that team of people around me who I obviously trust'* (Steven)

Participants also describe situations that have made them lose confidence in the cannulator or team of cannulators, impacting this relationship of trust. Some participants tell emotive stories, where their cannulation has gone wrong which makes them feel like *'I didn't really want to come back into the hospital'* (Michael) as they are worried about '*getting injured again'* (Michael) as *'if they have problems, you don't want them to touch you again.'* (Michael). Whilst they trust in the expertise of the cannulators, when things go wrong they lose confidence, meaning they can't trust the cannulator during cannulation:

‘*Well I wondered whether they were sort of, like, competent or not! Sorry! … I know that sounds terrible but, you know, I thought oh, you know, obviously what are they doing if they can't find the right fistula’.* (Charlotte)

‘It didn’t give me confidence in the nurse that was needling me, put it that way, until the sister came and she sorted it out and she got it straight in without no problem, yeah.’ (David)

‘Then of course you’ve lost all your faith in that nurse .. Then if they can, they will ask someone else to do.’ (Avril)

Loss of confidence can also be generated by the way the cannulator behaves: *‘I think if somebody had got an attitude and they're sort of rushing their side of the job I’d probably think about it then’* (Bridget). This wasn’t just about what the cannulator did during cannulation, but also how they performed in other parts of their job: *‘I've only ever had one situation which was a bit awkward where one nurse who was a very nice person but not good at what they did! And that was the only occasion I've actually said ‘can you get somebody else to put the needles in for me’, because I wasn’t confident of their abilities … Just the way they were on the ward, they did everything – as much as they could to avoid doing things and were bumbling about and making excuses so they sat the other end wandering off and coming back.’* (Joseph). A few also mention that if the dialysis unit is busy, this *‘makes you think what’s gone wrong today’* (Graham). As Molly describes, this is *‘a bit unnerving … it does make an effect, if they're stressed and understaffed or whatever and running round trying to sort everything out’* and she becomes *‘nervous that it might be a bit of a rush job when they needle me’.*

5.1.2.3 Category 3: The necessity of cannulation for haemodialysis forces coping

Participants acknowledge that needling is an inevitable part of haemodialysis, as without it they wouldn't be able to have their treatment: *‘Obviously there’s a process to having dialysis. You must have an access and haemo is one of the ways where you have to have a way of needling’* (Nicholas). They recognise that *‘the dialysis to me is saving my life. It’s cleaning all the toxins out of my body. I know it’s got to be done. If I don't have it done I could just, you know, pass away.’* (David). As having the cannulation is an essential part of haemodialysis, this also means the cannulation has to be completed regardless of how they feel about it: *‘the be-all and end-all is that I have to have dialysis so by hook or by crook .. I’ve got to get the needling done.’* (Michael). This doesn’t just mean that the cannulation needs to be done, but also that it needs to be successful, as *‘if the needles don't go in you can't get the haemodialysis can you.’* (Charlotte).

Some find it difficult to go for their haemodialysis, as they know this will involve the cannulation. This leads to a dilemma of whether to go through cannulation, a procedure they do not want, versus avoiding it, which means they cannot have life-saving haemodialysis: ‘*So I’ll literally make a conscious decision, which is probably the bad one, and just to go home because that* *pain or that blow or having that IV in my neck is horrifying, like. I can't think of anything worse, other than death of course … So now that I'm home, like … I just think oh I just hope I don't die til the next sesh is what I basically do, but when I wake up from the sleep I kind of think OK, like, I should be OK. Like, that's how I kind of feel … I worry about dying rather than being in pain.'* (Nicholas). Due to this dilemma, participants often describe being forced to have cannulation:

> *'Yeah. It's like I feel forced … So, it's like force of circumstances … Even if I need it. I know that I need it and I'm forced to do it.'* (Emma)

> *'It's like it's been forced upon you to accept it because if you don't you don't get your treatment, you don't get your treatment, you can become really poorly.'* (Deborah).

However, it is difficult it to force yourself to have cannulation as *'you have to force yourself three times a week to go to somewhere where you know you're going to get hurt, it's essentially like a form of torture.'* (Clare). As James describes, *'it's like it can't be escaped … it's just something that you got to have, so… inevitable isn't it so … . it's the needle isn't it. You can't escape it, it's there'.* Others describe the inevitability of cannulation more positively: *'There is no choice, there is no choice but you get comfortable with it.'* (Graham). Some also describe how the necessity of cannulation motivates them get through the procedure:

> *'So it's that sort of necessity that's kind of getting you through it … I think you have to make the best of a bad job. It's something that has to be done as part of a process to save my life'* (Sarah*)*

> *‘I’ve got to get through - all I’ve got to get through the needling … if you haven’t got kidney failure, they’ll be ‘oh, I can’t do it, I won’t be able to do it’ but if you have to do it … you can do it.’* (Jessica)

> *‘Because it’s saving my life innit…. So just get on with it basically … So you take it on the chin … Because you know what’s coming. You can't change it. It’s got to be done.’* (Matthew).

Some participants use analogies that reiterate the necessity and inevitability of cannulation as part of their life:

> *‘It’s almost like breathing, isn't it … It’s like this is what I've got to do now so it’s got to be done … all I did was tell myself it had to be done, yeah.’* (Adrian)

> *‘Well it’s rather like entering an aircraft which you know could drop down and once the door has shut, somehow your mind settles down to the inevitable and what has happened, you consent to it … It is at the present moment it’s not very pleasant but I have to go through it to have my dialysis.’* (George).

As haemodialysis happens over long periods of times and cannulation is necessary for haemodialysis, cannulation also goes on for a long period of time, often for years: *‘Yes, I've been coming, I came in 2014, now we are in 2021, that is about seven years … Yes, yes, because, you know, I have been risking my arm for the last seven years’* (Graham). For some, the regularity of the cannulation over a long period of time makes it harder to manage: *‘I thought to myself ‘oh crikey I've got to go through this three times* *a week for the rest of my life' and that was when the apprehension came in'* (Bridget). However, for others *'the crucial is repetition, three times a week.'* (George), as it helps them become used to it. For some, the regularity seems to provide a mixed response, with both the advantage of becoming used to it, but also dread of regular cannulation: *'just regular, doing it regular. You get more chance to get in with it, if you do it every other day … You're facing it three days a week … you think 'bloody hell I've got to do this again on Wednesday and Friday''* (Adrian). Of interest, a few participants stated that whilst cannulation did not bother them and was not a problem, when asked if they could cope with cannulation more regularly many responded as Joanna did: *'No, I don't think I could do it, I think three times is enough … it's like just going through it, isn't it. It's like going through it and just, you know, and I think god I wouldn't be able to do any more, you know'.*

When considering how long they had been having cannulation, participants also reflect on the future, highlighting that they had not just had cannulation for a long time, but they would also need it for an unpredictable amount of time going forwards: *'It's going to be something that's happening for obviously we don't know how long. It could be a year, it could be thirty years.'* (James). Ben discusses his tortuous journey, where even though he may have breaks from cannulation with different types of renal replacement therapy, it will always remain part of his life: *'Down the line I'm looking at doing APD from here when I'm in bed at night time, so I won't be doing the sharps then or any kind of needles because it will be in my stomach. So hopefully this will be a bit of a distant memory, but I'm also told that you can* *only have that for a certain period of time and then you have problems with your pancreas, so it will be back to this again if I don't get a kidney … So regardless of whether that comes out and anything else comes off it, if I get a kidney or not, it's always going to be that, you know. It's always going to be needles and fistulas somewhere down the line … I've got to have this for all my life, for the rest of the days that I'm on this planet'.* As Georgina summarises, *'it's OK having say done once, if you have it done three times a week, like, you know, if you like, forever and ever, you know, to an unknown specified date, you know, it's a bit different isn't it'.*

5.1.2.3.1 Sub-Category 1: Stoicism gets me through unpleasant but necessary cannulation

As cannulation is a necessary procedure for haemodialysis, participants display stoicism to get through unpleasant cannulation: '*I was accommodating the distress as one would accommodate pain … well it depended on one's stoicism.'* (George). Participants often use euphonisms to describe stoicism, using terms like *'grin and bear it*' (Penny, Jessica, Rose, Nicholas), *'grit your teeth*' (Michael, Rose, James, Charlotte, Jessica) or *'white-knuckling it'* (Ben) as they *'just try and get that … get myself through it … you've just got to brace yourself in the process, that's all.'* (James). They also describe having to *'face up to it'* (Joseph) or *'man up'* (Michael) as they have to *'learn to try and be like a .. grownup with needles'* (Deborah). A few describe that they '*could stand the pain'* (Adam, George), they '*just got to try and ignore it'* (Adrian) or '*suck it and see'* (Matthew), so that *'I don't let it upset me.'* (Adam). As Joanna describes, *'yeah, it used to hurt, really hurt* *and then I just got used to it .. I mean, obviously it does sometimes but I just get on with it, you know, yeah … now I just don't bother, I just get on with it*'. Some also describe how they feel distress from the cannulation, but feel like they need to hide this: *'My arm was so painful that I could have cried, but I tried to keep it back sort of thing, you know what I mean.'* (Charlotte). As Jessica describes *'you can't complain about everything'* but *'it would be easier if we didn't have to hide it'* (Avril).

Using stoicism to get through cannulation often takes energy and thus, they often cannot cope with the cannulation as well *'when I'm feeling a bit off kilter'* (Sarah) as *'if I'm tired or feeling a bit off it perhaps and I don't deal with things as well.'* (Sarah). Molly describes how she is more sensitive to the pain making it harder to bear if she is not in the right mood: *'I find the pain is very much dependent on my mood – so if I'm a bit down or a little upset or something then I'm more sensitive and the pain is quite noticeable … so any sort of pinching or needling just seems to be more emphasised … being in a bad mood or a low mood it just makes it harder'*. Participants also describe how they need time before the cannulation to *'to build myself up for it before I get there, kind of, just, you know, big myself up for it eventually! Maybe not as much physically but mentally I would say.'* (James). Penny describes how if she knows when the cannulation is coming she can brace for the pain of cannulation, whereas when its unexpected she does not have the time to do this: *'I think it doesn't take 2 seconds to say 'are you ready' and then whether I'm ready or not I'm going to say yes because I know it's got to be done, but I'm prepared. I can – especially with the bottom one I can hold – I hold my* *breath and I clench my fist – I can put myself in a position where I'm able to deal with that pain. Whereas if they haven't said they're going to stick it in, it's like 'bloody hell that is painful', you know, and I've not psyched myself up to it, if you like, so I'm not prepared for it … As I say, I do think time has a big part to play in it and those few seconds of just saying 'right, I'm going to put the needle in now, are you ready' is hugely important rather than just stabbing you basically'*.

As participants use stoicism to get through cannulation, for a few this can also make them feel brave or strong that they have got through the cannulation: *'Err … just facing one of my worst fears … it makes me feel safe. That means I'm alive, you know … I'm going through it and I feel brave that I can do it, to be honest … I'm feeling brave for myself.'* (Emma).

5.1.2.3.2 Sub-Category 2: Acceptance of an unpleasant and unpredictable but necessary procedure

Participants talk about accepting cannulation into their everyday life, where it becomes *'part of me life … It's part and parcel of me life now so yeah, I just take it as it comes.'* (Adam). They describe becoming used to cannulation:

'Putting needle is, I've got used to it, I'm used to it, I don't know about other patients, I'm used to it,' (Graham)

'Um…it's the norm now, isn't it, I've got used to it.' (Joanna).

Some describe how they've had to learn to accept cannulation: *'And it's just one of them ones where I've just kind of trained myself just to kind of, like, just get on with it'* (Nicholas). For others they *'just take it as it comes.'* (Joseph). However, the necessity of cannulation drives this acceptance: *'You have to accept it* [cannulation], *don't you, because it's part of the process, you can't exactly miss them out … accepting really is the word.'* (Sarah). It's important to note that this is not about cannulation getting better, but that *'I've got used to it.'* (Avril) and *'that's another thing you just tolerate, or I just tolerate.'* (Jessica). Participants adapt to coping with cannulation rather than cannulation becoming better: *'I don't think it will ever not bother me – it's just kind of trying to cope with it as best as you can.'* (Clare). However, for Ben he feels he will never get used to cannulation: *'I can't even say I've got used to it because you never, ever get used to it, never. Yes, you always know the feeling, it always feels the same, but you never get used to it'.*

As acceptance is about getting used to coping with and adapting to cannulation, participants describe how accepting cannulation is about accepting it will be unpleasant and unpredictable:

'It means accepting that I'm going to feel pain three times a week, but knowing that it won't last long … I'm a bit more blasé now, I just think oh I'm going to be in pain and that's the end of it!' (Sarah)

'Because they change it every so often, it becomes an acceptance I think that they change. Your body accepts that, your arm accepts that and I think you get used to it.' (Daniel)

‘You know, take it how it comes … What’ll happen will happen and invariably it happens alright … You're going to get a bit of pain. You're going to get one or two really, really bad experiences .. just say take it as it comes.’ (Matthew)

However, many also recognise that as they accept this unpleasantness and pain, then cannulation becomes easier:

‘And I think once you learn and you get that in your head … then you're prepared, mentally and physically you are in – it will hurt but not as bad.… You accept it, your body accepts it, your mind accepts it … it’s a matter of course now, it’s par for the course.’ (Daniel)

‘Acceptance is the big thing really … It just has to become part of your new routine, part of your life, until the day when it doesn’t have to be … [be] *honest with yourself then it’s easier to deal with. Being in denial and trying to think that you don't need it .., in fact makes it worse because being in a bad mood or a low mood it just makes it harder.’* (Molly)

As Adrian describes, *‘You can either sit and worry and panic about it or just do it!’.*

However, participants also describe how it takes time to get used to cannulation, as they come to terms with needing cannulation and accepting it: *‘I've always known it’s something I have to have, there’s no doubt about that, but it’s me just getting used to it and I've been in that routine now for so long, there’s not much I can change about it, so I've come to accept it.’* (Deborah). For most, *‘there was a massive transitional period before that that* *was, that I had to work through'* (Molly) and they come to terms with cannulation over time: *'I think just the fact that I've been doing it so long now I know it's just another day at the office, so to speak.'* (Steven).

Participants describe how they feel positively about needling as it allows them to have their haemodialysis, understanding the *'treatment is doing you good.'* (Daniel). As Toby explains *'I dialyse three times a week for four hours and that's basically keeping me alive so I haven't got a problem with it at all, you know'.* Graham describes *'needling as far as I'm concerned is a lifeline for me'* as it enables his haemodialysis. Understanding the benefits of haemodialysis helps them get through the cannulation:

> *'The fact that its doing a job but you see the .. you've got to be grateful that it's doing a job, and a good job … It helps me get through the needling.'* (Jessica)

> *'Knowing that it's part of a positive process because it's helping keeping me alive … I think the fact that it was a useful part of the process probably helped in a way, yeah .. It's something that has to be done as part of a process to save my life.'* (Sarah)

Many describe how the advantage of haemodialysis is not just that it keeps them alive, but that they feel healthier and are able to do the things they want to in life:

> *'No, once that needle's in, it's absolutely fine and I always feel relieved that my dialysis has been done. I feel better for it and once the needle's out I could hop and skip down the corridor! So, yeah, no, I am*

always glad that it's been done and I do feel the benefits of having the haemo. 100 % feel the benefits of it.' (Penny)

'So, it has to be done and when I do have my dialysis I do feel much better.' (Tessa)

'I'm not a sickly person dialysis, I am quite well and fit, so where I can I will still - we have weekends away skiing and things like that, so I still try to do the things I enjoy, that's what living's for … So positivity is key.' (Molly)

'So now I know I'm on borrowed time but, you know, that's why you get it done. I want to see next year, I want to see my grandkids so … They're in a very privileged position, because people in other countries are dying through lack of dialysis.' (Matthew)

James describes how the advantages of enabling haemodialysis balances out the unpleasantness of cannulation: *'It's for my health, it's benefiting me so … You've got to look at the good things from it I suppose, you've got to look at the advantages and the advantages outweigh the disadvantages, so yeah … it makes my body better ... the only disadvantage is having to deal with the needle going in and the sharp pain for, what, all of a split second, where obviously the advantages, it helps me detoxify my body'.*

This positive mindset also extends to gratitude to the cannulators for being able to provide their haemodialysis and cannulation. This was demonstrated through simple praise for cannulators:

‘They’re a brilliant bunch, all of them … The nurses or the technicians that can needle, they’re brilliant as well … Oh yeah, I’d recommend the nurses to anyone. They really are brilliant.’ (Adam)

‘They were ever so good, ever so good … Yeah, oh they're brilliant, absolutely brilliant, they are.’ (Rose)

‘Really it’s just that and, like I say, the nursing staff are just are all .. are all great, you know … I do think the staff make a massive difference to people in there … I think they all do a pretty good job.’ (Steven)

Matthew takes this further as *‘if you think about it, they are saving your life, aren't they. So you don't have to moan every time … apart from the odd one or two renegades out there they all seem to be brilliant!’*. Towards the end of her interview, whilst Penny found cannulation difficult, she wanted to express her gratitude to the cannulators: *‘Thank you, because I think they do a lovely job. I can't do my own and I'm always extremely grateful that they’ve done it and managed to get it in and put up with me really, because I can be a pain in the backside sometimes, so no, I think a thank you is what I’d like to say more than anything’.*

5.1.2.3.3 Sub-Category 3: Being able to contribute to cannulation helps me cope

Participants describe how being part of the cannulation process helps them cope with cannulation. For some this was about having an element of control over the process: *‘Um…I think at the very beginning I wanted full control of everything. Looking at it now, I suppose I wanted to be partly in control, but*

I'm more than happy for the staff just to do it.' (Deborah). However, participants recognise *'there's no way you can control your needling is there'* (Matthew). For the majority of participants, it was about being involved rather than in control, feeling *'part of the process, that it's something you're doing together and that they're trying to help you in a good way … makes me feel more of an integral part of the process that I'm doing something positive and I'm taking control of my experience and my body.'* (Sarah). This was rewarding for participants as *'it makes me happy that I have done something, I have contributed something … like to say part of the team.'* (Graham). Most feel *'thankful, yeah, thankful that they do include you'* (Steven) and being able to contribute is rewarding: *'It made me feel like I was helping somebody and you feel like you're speeding up the process and obviously if you help somebody rather than just sitting there doing nothing and then saying 'please help me', that's no good, that's not the way that I do things, so yeah.'* (Simon). Some describe how they did not want to feel dependent, and thus being able to contribute to cannulation made them feel more independent: *'It's very easy when you go in there to feel like things are just being done to you, if that makes sense, and I don't like feeling sort of weak and feeble and, like, you know, like I've got no say in the matter almost, so it's kind of nice to have a bit of that independence … I don't want to feel like a victim or like I'm weak. I'd rather have that bit of control so it's less like it's just happening to me and it's more I'm agreeing to it being done!'* (Clare). Daniel describes, how getting everything ready for cannulation, doesn't just make him feel like he is contributing, but also helps prepare him for cannulation: *'You are then part – you own part of that .. part of the operation – that bit is yours. So you* *know when you're prepared, you know you’ve got everything set out and you know when you’re prepared to have the needle will be put in’.*

Not all participants wanted to contribute to their cannulation: *‘I mean, the person comes in, does it for me, puts me on … I don't need to be in charge of it or anything like that.’* (Toby). A few described how they felt pressurised to contribute more than they were willing to:

> *‘I kept saying ‘no’ and he kept saying it that often I said to him ‘when did the NHS become self-service?’ and I don’t think he liked that comment … You know, he just kept going on about it and I said ‘look, you know, I’ve worked all my life, I’ve never been here before and you think I’m going to take a machine home and put needles in my arms? You’re joking’. They didn’t really like that comment, what I said, but it’s true.’* (Michael)

> *‘I still felt pressure … they know what I say to them now – I say ‘You do it, you get paid for it, I don't, I'm here against my will sort of thing!’ So, yeah, I’d definitely say I felt pressure … I've expressed that I don't want to do it and they should respect that.’* (Molly)

It almost felt like this pressure removed, rather than facilitated, control for participants. A few also described how they were not able to contribute to their cannulation due to declining health: *‘They always – because me legs are not very good now, I can’t stand up very well, so they lower the table for me where a lot of them have to do the table themselves. So I just get myself settled onto the chair and they do everything for me.’* (Adam).

5.1.2.4 What Influences Patients' Experiences of Cannulation

The analysis of semi-structured interviews has created three categories that describe what influences patients' experiences of cannulation for haemodialysis. this final section of the analysis describes the links identified between these categories, culminating in a model of an individual who copes with cannulation for haemodialysis, formulated from the analysis of semi-structured interviews.

The first category describes what participants do to try to make cannulation more comfortable. Cannulation is an unpleasant procedure that participants avoid if they possibly can. Various aspects of cannulation make it unpleasant and improving these aspects improves participants' experiences of cannulation. The cannulation procedure is alien and invasive, which is heightened at the start. Thus, familiarity of cannulation improves this. Cannulation is also painful, which varies between individuals and over time, and minimising and reducing this pain is important. The unpredictability of cannulation also makes the procedure difficult, with participants describing how this can lead to problems getting the needles in the right place for haemodialysis which is painful and distressing. The quality of the AV access and cannulator are sources of unpredictability. Reducing this unpredictability is important to improving experiences. Anxiety related to cannulation also varied and participants felt it made their experience worse, making the cannulation more painful and unpredictable. Thus, reducing this anxiety through relaxation and distraction was important. Whilst this category demonstrates how cannulation could be made more comfortable and less unpleasant, many of these interventions do not seem to provide a perfect solution but have their own advantages and disadvantages. This means they improve cannulation for some individuals but not for all.

The individual nature of cannulation is also evident in the second category, where a better experience of cannulation requires preservation of humanity and individuality throughout cannulation. Empathy from both cannulators and significant others makes cannulation easier to cope with but is also a reminder of patients’ humanity. Patients have to trust the cannulator with this precarious procedure and trust is built through their relationship. The necessity of cannulation for haemodialysis forces patients to cope with unpleasant and unpredictable cannulation. Stoicism, acceptance and contributing to cannulation facilitates coping, with positive thinking facilitating acceptance. These six categories, along with the detail in their sub-categories, describe the components of cannulation that work together to create an individual that copes with cannulation, driven by necessity.

The three categories, produced by the analysis of semi-structured interviews, describe the common experience of participants. However, individual stories demonstrate how the emphasis on certain components of cannulation can vary between individuals and over-time. Often the absence of one component of cannulation is partially, although not fully, balanced through a stronger emphasis on another component. This balancing of components is not static but dynamic, changing again how the individual copes over time.

The best way identified to describe this variation in coping and the components that facilitate it, is through a ‘sphere of coping’ around the individual that fluctuates between haemodialysis sessions to include or exclude cannulation. Provision of the components that facilitate coping ensure this sphere is large enough to include cannulation, meaning the individual copes more easily with the procedure (Figure 12). However, lack of these components shrinks the sphere, putting cannulation outside, making it much harder to cope with (Figure 13). The necessity of cannulation is the only constant component, forcing the patient to cope with cannulation even when they find it difficult. Whilst most of the components identified constructively facilitate coping, stoicism is a less constructive component. It appears to balance the absence of other components, often used when patients have nothing else to help them cope with cannulation. It is worth noting that whilst this model describes the sphere as a definitive line between coping and not coping, in reality this difference is more graduated and subtle.

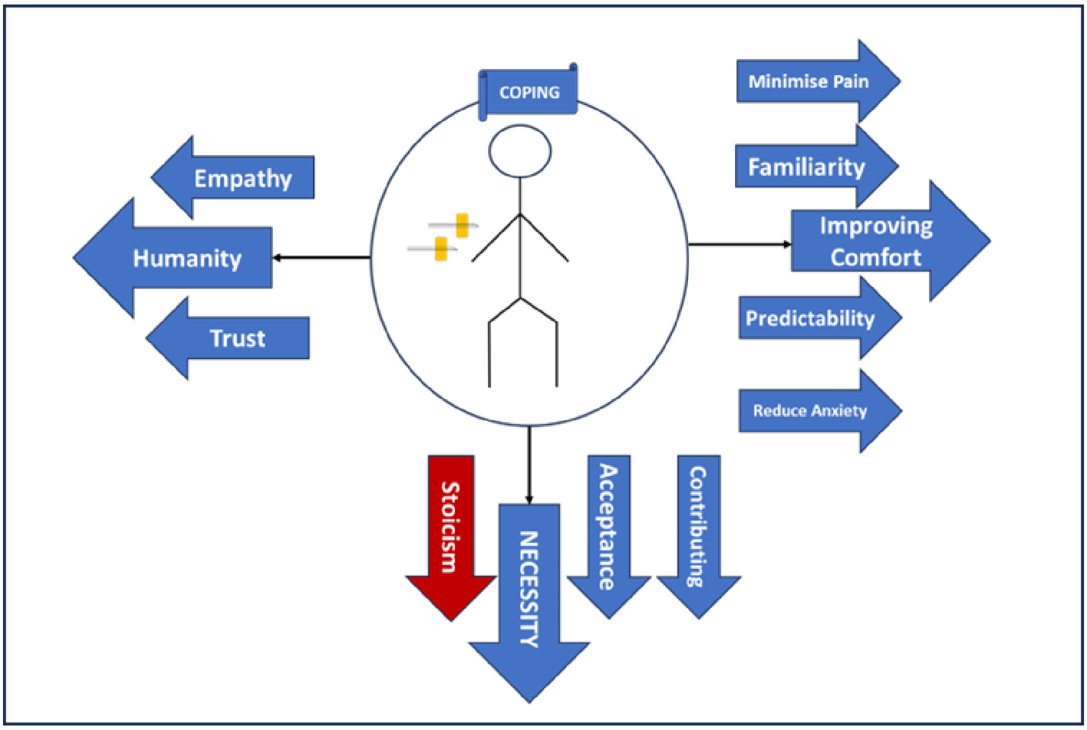


Figure 12: An Individual Coping Well with Cannulation for Haemodialysis

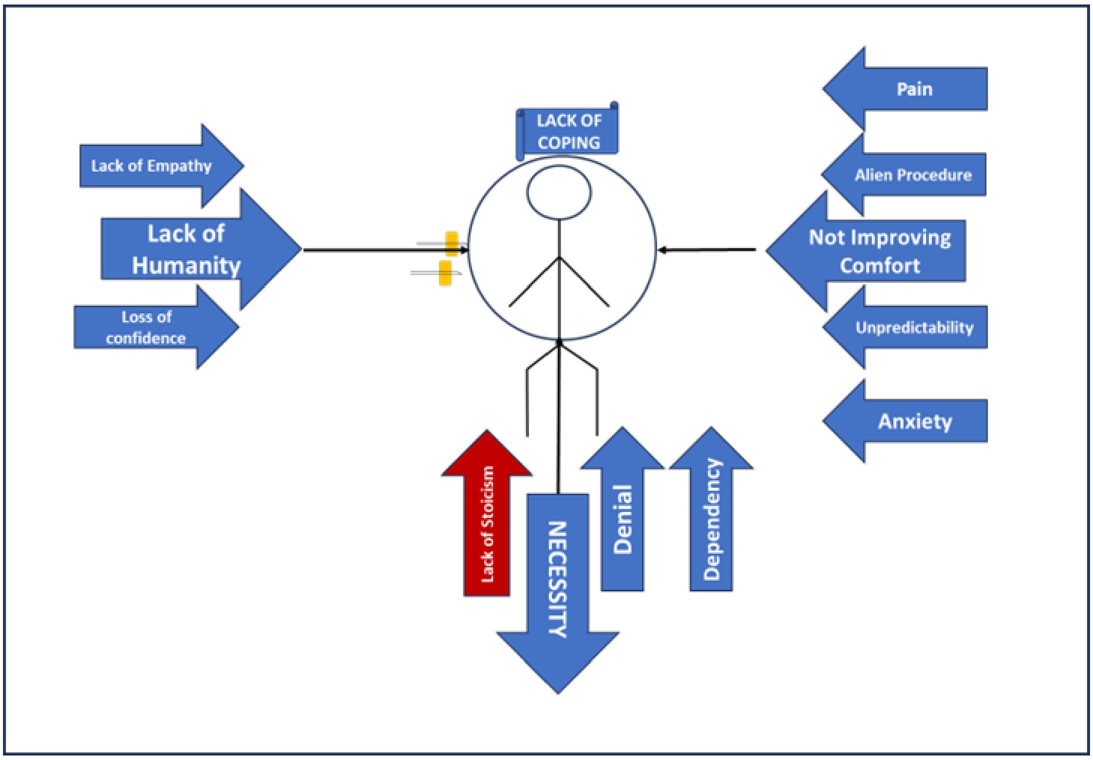


Figure 13 An Individual Coping Less Well with Cannulation for Haemodialysis

5.2 Discussion

ICE-HD has performed thirty semi-structured structured interviews using constant comparison analysis, intensive interviewing and theoretical sampling from grounded theory. The analysis of these interviews has developed three categories to describe factors that influence patients' experiences of cannulation for haemodialysis. The first of these is 'Trying to make Cannulation more Comfortable' where 'Familiarity makes cannulation less alien' and participants tried to 'Avoid or Minimise Pain from Cannulation', 'Make Cannulation more Predictable' and 'Reduce Anxiety about Cannulation'. However other aspects of the cannulation also influenced their experiences. 'Preserving humanity and individuality' through 'Empathy' from both the cannulator and others and 'Trustin the Cannulator' improved participants' experiences. 'The Necessity of Cannulation for Haemodialysis Forces Coping' where 'Stoicism gets me through Unpleasant and Necessary Cannulation, but 'Acceptance of an Unpleasant and Unpredictable but necessary procedure' and 'Being able to Contribute to Cannulaiton helps me makes cannulation easier. These three categories combine together to create a model of an individual coping with cannulation, with the factors that influence this identified.

In line with the aims, research question and objectives of this study, this discussion will explore the three categories generated in ICE-HD, exploring what influences patients' experiences of cannulation for haemodialysis to understand their experiences in greater depth and identify we can optimise this.

5.2.1 Making Cannulation more Comfortable

The unpleasantness of cannulation is a concept that has been evident throughout all the studies in this thesis. It was first recognised in the systematic review in Chapter 2, with the importance of pain from cannulation recognised in Chapter 3. However, the analysis of semi-structured interviews from ICE-HD shows how our understanding of pain from cannulation for haemodialysis has extended. This demonstrates that pain is an individual experience, with different participants describing it in different ways and with different levels of tolerance to it. The majority of participants describe how the pain varied over time, between haemodialysis sessions and even between cannulation sites and different needle types and sizes. ICE-HD starts to add to the depth of understanding of pain related to cannulation, that was lacking in current research (section 2.7.1.2).

It is also evident within ICE-HD that there are a number of elements that affect how much pain the participants experience, highlighting strategies that improve this. One popular method of minimising pain from cannulation was local anaesthesia. This has been evaluated in other studies, as discussed in section 3.4.5, although there is no definitive study to assess its effectiveness of reducing pain from cannulation for haemodialysis. ICE-HD summarises participants’ experiences of using local anaesthesia to reduce pain from cannulation, demonstrating that the effectiveness of local anaesthesia varied for individuals and between haemodialysis sessions. Therefore, research is not just needed into its effectiveness, but also to explore how to optimise its use, establishing for which individuals or at what time points it is most beneficial. Participants also mention other techniques, including ice spray, inserting the needles quickly and how the cannulator inserts the needles. These are elements not mentioned in previous research and likely bespoke to the individual participants included in ICE-HD. Therefore, whilst some techniques may improve pain from cannulation, apart from local anaesthesia, there are no other established techniques to achieve this. Therefore, further research is required into how we minimise this, especially as patients often avoid AV access due to the pain associated with cannulation (Murray, Thomas, Wald, Marticorena, Donnelly and Jeffs, 2016).

ICE-HD found that noxious nature of cannulation is more than pain. In this study, the alien and invasive nature of cannulation was highlighted as an element of this unpleasantness (section 5.1.2.1.1). Mafara et al.’s study (2016) previously recognising bodily invasion from cannulation. However, this is the only study on cannulation that recognises this. Interestingly, studies that have examined patients’ experiences of VA have identified bodily intrusion as an issue, linked both to the VA itself, but also cannulation (Taylor et al., 2016; Casey et al., 2014). Therefore, the findings from ICE-HD provides new insight into not just the invasiveness of cannulation but how it is an alien procedure for patients to cope with, which makes it unpleasant.

Subsequently, whilst the alien nature of cannulation worsens patients' experiences of cannulation, developing familiarity with cannulation made it less alien and thus, easier to cope with. Familiarity develops over time with repetition of cannulation and unfamiliarity was exacerbated at the start of cannulation, due to a lack of meaningful information, making cannulation harder to cope with. Similarly, Romyn et al. (2015) found that patients felt they did not receive adequate information when having vascular access for haemodialysis, but this study did not extend to cannulation. As ICE-HD highlights, participants were often given information on their haemodialysis, but very little on their cannulation. Cannulation is an integral part of haemodialysis using AV access, thus it was surprising that this was not included in more detail in information about haemodialysis. Information on cannulation needs to be available to patients before they have AV access formed, so that they can prepare themselves for this procedure.

In ICE-HD, this lack information continued once they started haemodialysis, although the level and type of information required varied between participants. Participants were often frustrated by this lack of information. Reasons for this need to be explored, understanding why information on cannulation is not volunteered or available to patients. This may be driven by healthcare professionals' discomfort to discuss cannulation, possibly because they do not know how to do this in a reassuring manner that does not cause distress, although research and this thesis have not explored this directly. However, both formal and informal information on cannulation needs to be provided to patients throughout, in a manner that is helpful for them and responds to individual need. Research needs to explore how to facilitate greater information sharing with patients on their cannulation.

Maintaining predictable cannulation to improve patients' experiences and its unpredictability nature is another novel finding from ICE-HD. Whilst variation in cannulation practices has previously been recognised (Fielding et al., 2021), this has not been explored in research, although it was often highlighted when discussing this research with patient and professional groups. Understanding this variation was identified as an issue for further investigation in the results of the PPN (section 3.3.5.2). However, the unpredictability identified in ICE-HD is slightly different to variability, not just meaning that cannulation changes, but that how it changes is unexpected and irregular, making cannulation unstable and 'unpredictable'. This unpredictability is difficult for participants to cope with, created by unpredictability of the success of cannulation, but also who will cannulate them. This links with a sub-theme in the systematic review, identifying that participants worried about the success of cannulation (section 2.5.4.2). This, in hindsight, indicates unpredictability, although the unpredictability identified in ICE-HD is more than this. The PPN also recognises this unpredictability in the problems section and individual questions within the worry section (Questions 8 and 9) (Appendix 2). Whilst both these sections scored lower than pain in Chapter 3, they both continued to be areas of concerns for patients. The unpredictability of cannulation is important to recognise to understand patients' experiences of cannulation for haemodialysis.

ICE-HD identified that if cannulation can be made more predictable, then cannulation experience improves for patients. It provides some ideas how to how participants believe this can be improved including: developing a strategy on how to cannulate them successfully and communicating this within the team of cannulators; use of ultrasound to guide cannulation (also discussed in section 2.6.3); keeping successful cannulation constant particularly with consistency in cannulators; and use of tourniquets. This is not an exhaustive list, but one that is generated from the experiences of participants. Studies that have explored nurses' experiences of cannulation for haemodialysis have also identified strategies that increase the success of cannulation, including a good assessment of the vessel prior to cannulation, taking their time inserting the needle, patient centred care and empathy, teamwork and self-awareness, as well as the opportunity to practice (Harwood et al., 2016; Wilson, Harwood, Oudshoorn and Thompson, 2010) These lists indicate there is much that can be done to improve the predictability of cannulation. However, participants described problems in ensuring strategies to reduce unpredictability are implemented consistently. Individual participants demonstrated frustration with delays waiting for someone to cannulate them under ultrasound and lack of communication between cannulators. Therefore, there needs to be consideration given to not just whether these practices reduce the unpredictability of cannulation, but what may be the barriers to implementing these consistently into clinical practice, likely driven by the culture in haemodialysis nursing teams.

The category on reducing anxiety about cannulation, also provides new insight into patients' experiences but also what may optimise their experience. Anxiety about cannulation interplayed with other factors, worsening the unpleasantness and unpredictability of cannulation. This anxiety was indicated in previous research but was not necessarily understood in depth. A scoping review identifies fear and anxiety as a common consequence to cannulation (Harwood et al., 2017), although most studies recognise this by trying to measure the difference in anxiety between different cannulation techniques rather than describe it (Smyth, Hartig and Manickam, 2013; Pergolotti, Rich and Lock, 2011; van Loon, Goovaerts, Kessels, van der Sande and Tordoir, 2010). The Dialysis Fear of Injections questionnaire (D-FIQ) (described in section 3.1.3) recognised an element of anxiety from fear of injections (Mulder et al., 2013). However, the D-FIQ only described the extent of this fear, with no further descriptions to facilitate our understanding of this. Mafara et al. (2016) describes fear as a theme related to experiences of cannulation of new AV access, but again the description lacks depth and appears to be related to haemodialysis, not cannulation itself. Anxiety related to cannulation is also evident in all three studies in this thesis. Within the systematic review in Chapter 2, again worry about the success of cannulation hints at an element of anxiety related to cannulation (section 2.5.4.2). When developing the PPN (Chapter 3), worry came to the fore, where patient representatives identified that many of the issues with cannulation generated worry, creating a whole section within the PPN and a recommendation to explore this further (section 3.5.1). However, only during ICE-HD did our understanding of this evolve to cover the extent of the anxiety, what caused this and how this impacted cannulation.

In ICE-HD, it was found that reducing anxiety about cannulation improved patients' experiences of cannulation, particularly interventions that promoted relaxation or distraction. Some interventions have been previously evaluated to examine whether they reduce both pain and anxiety related to cannulation. In a small study, lavender oil aromatherapy was found to reduce pain and anxiety related to cannulation (Sahin, Tokgoz and Demir, 2021), with a systematic review of seven studies concluding aromatherapy reduced AV fistula cannulation pain (Yildiz and Sahan, 2022). However, this review did not examine its effect on anxiety. Music therapy has also been evaluated, reducing pain related to cannulation, but not reducing anxiety (Kishida, Yamada, Inayama, Kitamura, Nishino, Ota, Shintani et al., 2019). Participants were required to listen to classical music of the researcher's choice rather than music of their own choice which may have influenced the benefit of this intervention. Within studies that evaluate interventions to reduce anxiety, there appears little recognition of how pain and anxiety may interact or the mechanism of action as to how they may reduce anxiety. ICE-HD demonstrates that pain and anxiety influence each other, with this complexity recognised in other fields (Wu, Buchanan and van Wijk, 2021). Understanding how interventions affect this interaction between anxiety and pain may demonstrate the best way to implement them in a manner that benefits patients. The MRC’s framework to evaluate complex interventions provides guidance on how to consider these interacting outcomes and the complexity this adds to evaluating cannulation (Skivington et al, 2021a and 2021b). Of note, again, within these studies, pain and anxiety were not measured by instruments validated to measure pain and anxiety related to cannulation for haemodialysis. Also, these interventions are yet to have an impact on clinical practice within the UK.

There are also other relaxation and distraction techniques that were highlighted in ICE-HD. Of note, distraction is a well-recognised technique in clinical practice to reduce anxiety related to cannulation, both within and outside of haemodialysis (Welyczko, 2020; Fielding et al., 2018a). However, again how to do this well and optimise this technique is not yet understood. Paediatric haemodialysis units use a number of interventions to manage anxiety related to cannulation, that may be applicable in the adult setting (Fielding et al., 2018a), but are not currently evaluated by research due to small number of paediatric patients currently on haemodialysis and using AV access (Aitken et al., 2023). Future research needs to focus on techniques to reduce anxiety related to cannulation, especially distraction, but also recognise these are complex interventions where the mechanism of action needs to be determined to promote optimal implementation in practice that truly benefits patients.

This category about comfort is related to previous synthesised finding from the systematic review, describing the unpleasantness of cannulation. However, there is one aspect of this unpleasantness described in Chapter 2 that did not occur in the results of ICE-HD, which is whether cannulation creates vulnerability. Vulnerability is often defined as those susceptible to harm due to exposure to a risk or an inability to protect themselves (Sellman, 2005; Rogers, 1997). It is related to both physical and emotional integrity (Irurita, 1999) and the context the individual is in (Rogers, 1997). Vulnerability is evident in other studies, when exploring experiences of haemodialysis (Hagren, Pettersen, Severinsson, Lutzen and Clyne, 2005) and vascular access (Casey et al., 2014), and was also a sub-theme in our systematic review in Chapter 2. In ICE-HD, vulnerability was explored, but never volunteered by participants. When asked about it, most denied vulnerability, often quite passionately with some appearing offended by the word. The few who did mention vulnerability in quotes, only did this once asked about it, which felt led. This led to removal of this question in later versions of the interview guide (Appendix 5), as at the time participants did not seem to relate to this. However, exploring this further has highlighted further issues. The use of ‘vulnerability’ has been debated in healthcare, often considering that all human beings are vulnerable, with some being more vulnerable than others (Sellman, 2005; Rogers, 1997). The protection of vulnerable patients can become paternalistic rather than protective (Sellman, 2005). Whilst this appears a relatively old debate, vulnerability continues to be a term that is labelled onto people with chronic illness, without them actually determining themselves as vulnerable. For example, one study used the title is ‘Finding ways to carry on: stories of vulnerability in chronic illness’, where the words vulnerable or vulnerability are used 60 times in the article, but only present once in participant quotes (Synnes, Oroy, Raheim, Bachmann, Ekra, Gjengedal, Hoie et al., 2020). Caution needs to be used with application of the term ‘vulnerable’, particularly as this appears to be a concept healthcare applies to individuals rather than individuals recognising in themselves.

5.2.2 Preserving Humanity and Individuality in Cannulation

The importance of preserving the individual and their humanity within cannulation highlights the importance of the interaction with the cannulator during cannulation. Nursing as a profession within the UK recognises that people have physical, psychological and social needs that require kindness, respect and compassion (Nursing and Midwifery Council, 2018). Therefore, cannulation for haemodialysis as a nursing procedure should adhere to these principles, preserving the patient’s humanity. It was also evident through ICE-HD that cannulation is an individual experience, with variation throughout categories as how individuals describe their experience, but also recognised directly in the second category. Whilst the ICE-HD describes common aspects of experience, within this common framework there is individual variation. Therefore, it is likely solutions need to respond to individual need. Interventions may also be required not just to improve cannulation, but also to assess and enable to individualised cannulation, minimising those elements of most concern to that individual.

ICE-HD also identified that participants' humanity and individuality is preserved during cannulation through empathy. This was about being understood by others, which had the benefit of not feeling alone through the cannulation. Empathy itself is well known concept within healthcare and nursing. The Cambridge dictionary defines this as 'the ability to share someone else's feelings or experiences by imagining what it would be like to be in that person's situation' (Cambridge University Press and Assessment, 2023). However, whilst this is a succinct definition, within nursing, debates continue about what empathy is. Read (2019) describes a typology of empathy, where it has an affective dimension in 'sharing another's mental state', a cognitive dimension in understanding what another is feeling or thinking and a motivational dimension, where there is motivation to help or respond to another. It is different from sympathy and compassion, where empathy is about feeling 'with' someone, not feeling 'for' them (Read, 2019). This typology is helpful, as it starts to demonstrate what is needed from the cannulator to support patients through cannulation, through sharing the patient's mental state, understanding the patient's emotions and thoughts, and motivation to support the patient in this manner. Empathy can be used to build relationships, acknowledging the experience and the person, as well as promoting trust (Read, 2019). ICE-HD recognised that empathy was mutual, indicating a relationship between two individuals, with patients also displaying empathy for cannulators. It is important to recognise that empathy from the cannulator helps build a relationship that preserves patients' humanity and individuality and creates trust, with mutual empathy between the patient and cannulator possibly strengthening this relationship.

Whilst ICE-HD demonstrates that trust is critical to the relationship between the cannulator and the person being cannulated, participants also described significant situations where trust had been lost either with individuals or the whole team of cannulators. In the same context, Allen, Wainwright and Hutchinson (2011) found that adversarial relationships developed in haemodialysis settings between healthcare professionals and patients in, which were a reflection of lack of trust. Whilst Allen et al.'s (2011) study was set in haemodialysis, there was no content or quotes related to cannulation. However, there is evidence within ICE-HD that adversarial relationships undermine trust in the cannulator. Therefore, cannulators need to use empathy to build relationships of trust with patients, avoiding adversarial relationships. However, the reports of loss of trust within ICE-HD indicate that empathy and trust do not manifest in cannulation consistently but are reliant on exceptional cannulators, who make the effort to demonstrate this. Understanding patients' experiences, facilitating demonstrations of empathy, and knowing how to build trust need to be promoted. Incorporating this into training of cannulators, emphasising how this is essential to be a good cannulator, will help promote more consistent application of empathy that builds trust across the whole nursing team who cannulates.

This category also has congruence with findings in the qualitative systematic review on ‘Feeling Safe’ (section 2.5.4.3), which related to the cannulator, the environment and cannulation technique. However, when participants were asked about feeling safe both in the PPN (section 3.3.3.3.1) and ICE-HD, they struggled to relate to this concept even with probing during semi-structured interviews. Through reflection and discussion with collaborators, it was identified that nursing is increasingly becoming a safety conscious profession, with patient safety, as perceived by nurses, having both physical and psychological elements (Vaismoradi, Teila, Logan, Khakurel and Vizcaya-Moreno, 2020; Vaismoradi, Salsali and Marck, 2011). From a nurse’s perspective, safety could include all the elements described in the qualitative systematic review. However, whilst nurses may relate to this, patients did not, and thus did not relate safety in cannulation to attributes of the cannulator, the environment and the cannulation technique in the same way. However, in ICE-HD, participants did raise empathy and trust directly, which seemed to equate the content of the ‘Feeling safe’ theme in the systematic review in Chapter 2. Whilst empathy may be considered high level concept that not all patients would understand, being understood by others was. However, whilst ‘Feeling Safe’ in the systematic review highlighted the importance of cannulation technique and the environment, these appeared elsewhere in ICE-HD. The role of cannulation technique was discussed earlier, creating predictability. The effect of the environment appeared to be about both familiarity and creating or losing trust, not the environment itself. Therefore, the presence of both these elements Chapter 2 appears to be superficial representatives of deeper concepts described in ICE-HD.

5.2.3 Coping with Cannulation

The final category identified in ICE-HD was how the necessity of cannulation for haemodialysis forced participants to cope with cannulation. In this category, the context of haemodialysis is important. This is recognised in the systematic review in Chapter 2, where cannulation is recognised as part of haemodialysis, creating a context around cannulation. ICE-HD further reiterates this, with participants describing cannulation as an integral part of haemodialysis. Patient representatives also made it clear that cannulation should not be examined in isolation but is part of the experience of haemodialysis with AV access. Whilst care was taken in interviews for ICE-HD to clarify whether patients' experiences were directly related to their cannulation or to the wider haemodialysis treatment, it is also recognised that this context means that cannulation, vascular access and haemodialysis experiences are not always separate. This does not detract from findings in this thesis or the importance of patients' experiences cannulation for haemodialysis but reiterates the context that influences patients' experiences of cannulation. Cannulation's link with a life-sustaining procedure that occurs regularly for long periods of time, makes the context and experience of cannulation unique. This context acts as a motivator, albeit forced due to its life sustaining nature, to cope with cannulation.

Stoicism was one element that ICE-HD identifies as faciliatating coping. This is defined as 'silent endurance', 'lack of emotion' or 'making do' often in response to distress or pain, including an 'indifference to changes in fortune or in pleasure or pain' or a 'decreased willingness to complain about pain' (Moore, Grime, Campbell and Richardson, 2012). Pathak, Wieten and Wheldon (2017) define it as 'an idealisation of imperviousness to strong emotions', indicating it's not just a state of being, but also a value judgement about an individual. Cultures often value stoicism as a trait, associating it with strength and fortitude (Pathak et al., 2017; Moore et al., 2012). Whilst there continues to be a debate about the exact definition of stoicism and what behaviours may indicate this (Moore et al., 2012), it is evident that the words used by participants in ICE-HD indicate a stoical approach.

However, whether stoicism is constructive as a coping mechanism is debatable. In healthcare, stoicism can be considered positive, creating resilience and preservation of self in difficult circumstances, but it can also be negative, denying the individual's suffering and often leading to lack of awareness of interventions that may improve noxious symptoms (Pathak et al., 2017; Moore et al., 2012). Whilst stoicism can help patients 'get through' medical treatment that is unpleasant and for their own good, the benefits of stoicism can become contradictory to the individual patient's well-being, where their suffering is then ignored (Pathak et al., 2017; Moore et al., 2012). In this context, cannulation for haemodialysis, stoicism had this contradictory role, helping patients get through cannulation which is necessary, but also asking them to just 'put up' with the pain and distress. There is a danger that a heavy focus on stoicism to get through cannulation can potentially distract focus away from improving cannulation, as the unpleasant nature of the procedure is ignored. During interviews, it often felt that stoicism was used when the participant had nothing else to get them through cannulation. It did not appear to make the cannulation anymore pleasant or easier cope with, but it was the solely driven by necessity. Therefore, whilst stoicism may get patients through cannulation, there needs to be consideration as to the tools patients and nurses have available to them to support the patient through cannulation without relying on stoicism.

Contrary to stoicism, acceptance demonstrated more constructive coping with cannulation. Participants often described acceptance positively, accepting that cannulation was going to be painful and unpredictable, but that it would be brief and worthwhile. Herbert and Brandsma (2015) describe psychological acceptance as ‘the active embracing of subjective experience, particularly distressing experiences. The idea is not merely to grudgingly tolerate negative experiences but to embrace them fully and without defence’ (p.64). It involves reaching a status quo with a new life situation often in response to difficult experiences or circumstances (Herbert and Brandsma, 2015). Interviews were congruent with this, with participants mentioning how acceptance of cannulation helped them, but they also recognised periods of denial. Participants often described how acceptance takes time, indicating an adjustment period.

Adjustment to chronic illness over time is a commonly researched area, with many studies describing this process of adjustment (e.g. Synnes et al., 2020; Whittemore and Dixon, 2008; Shotton, Simpson and Smith, 2007). The majority of studies explore adjustment to a chronic illness, leading to alteration in a person’s state of being, rather than adjustment to an intermittent, but regular and life-saving medical procedure. Despite this focus on illness, there remains congruence between acceptance of chronic illness and acceptance of cannulation. There are commonalities in the complexity of this adjustment process and the fluctuation between stages of adjustment, with eventual integration into their life (Helgeson and Zajdel, 2017; Whittemore and Dixon, 2008; Shotton et al., 2007). The degree to which individuals adapt to a change in their health due to chronic illness varied, with both positive thinking and optimism promoting adjustment (Kapadi, Elander, Burton, Taylor, Coyne, Selby, Taal et al., 2023; Helgeson and Zajdel, 2017; Whittemore and Dixon, 2008). This complexity and variation in adjustment was evident in ICE-HD, alongside positive thinking and optimism. Participants were often able to view cannulation positively due the perceived benefit of enabling haemodialysis which is keeping them alive. Similarly, Mafara et al. (2016) also found that some patients undergoing new cannulation could have a ‘sense of hope’, feeling grateful for the service they received as it gave them a future. This adjustment to cannulation as part of their life leading to acceptance, whilst adjustment to a medical procedure, is similar to adjustment to chronic illness.

Whilst this recognition of adjustment to cannulation, a regular medical procedure, is novel, one study explored adjustment to haemodialysis (Kapadi et al., 2023). They found the necessity of haemodialysis drove participants to accept the treatment (Kapadi et al., 2023), mirroring the findings from ICE-HD. This is unsurprising, as cannulation is part of haemodialysis. However, whilst cannulation is key part of haemodialysis using AV access and often evident in studies that explore experiences of haemodialysis (i.e. Kapaldi et al's (2023) study includes quotes related to cannulation; the systematic review in Chapter 2 included studies related to experience of haemodialysis), these studies rarely explicitly acknowledge cannulation, or its impact on the individual, as part of the treatment. Whilst it is unclear why this is the case, this again reiterates the reluctance to talk about cannulation. ICE-HD is the first study to show acceptance of cannulation as key part of the acceptance of haemodialysis, with some participants indicating that acceptance of cannulation is the hardest part.

Whilst acceptance was evident in interviews, denial and struggles to accept cannulation were also evident, both through direct acknowledgement and the use of stoicism to get through cannulation. These aspects were also evident in the systematic review in Chapter 2, in the ‘Learning to tolerate cannulation’ sub-theme. Therefore, cannulation could be improved by actions and therapies to promote acceptance. Some interventions that may promote acceptance are cognitive behavioural therapies, including acceptance and commitment therapies, and behavioural activation (Herbert and Brandsma, 2015). Herbert and Brandsma (2015) also recognise that practising mindfulness to achieve self-awareness of experiences and articulating values and goals is also a route to promoting acceptance, as well as detachment and distancing from the experience. It is beyond the remit of this thesis to explore the detail of how these therapies can be applied, but they may be useful to explore in future research. The design and implementation of these therapies currently sit within the remit of a clinical psychologist, whose presence on dialysis units is sparse. Therefore, whilst psychological intervention may be ideal, it is worth exploring whether nurses can adopt or share with patients any of these approaches to support them through cannulation. This would likely still require support with escalation pathways to clinical psychology support when nurses' basic knowledge cannot support patients. However, this could facilitate promotion of acceptance rather than stoicism.

Control is one key part of promoting acceptance (Helgeson and Zajdel, 2017), also evident in patients on haemodialysis (Kapadi et al., 2023). This was a concept highlighted to explore in ICE-HD, also evident in the qualitative systematic review in Chapter 2. However, in our interviews, control was not a concept most participants related to. Being able to contribute to cannulation was found to be more relatable concept. Participants consistently made it clear that considering control was almost ridiculous, when they perceived a dependency on nursing staff. The analysis highlights contributing rather than control, acknowledging that participants could not have complete control and had to work together with the cannulator to achieve cannulation, and thus haemodialysis. The partnership and ‘teamwork’ between the patient and healthcare staff, from the patient’s perspective, was evident. This is a novel finding, possibly as ICE-HD focusses on patients who undergo healthcare professional cannulation, thus working with the cannulator becomes key. This also highlights the difference between this and self or carer cannulation. Being able to contribute to cannulation and having a partnership with the cannulator appeared to promote acceptance, but also combat the dependency described in Chapter 2. However, it was evident through ICE-HD that how patients contribute needs to again be individualised, with patients being allowed to not contribute if that is appropriate for them. Ideally patients need to be given control of this contribution rather than healthcare professionals’ imposing it on them.

5.2.4 Strengths and Limitations

ICE-HD was designed to enable in-depth exploration of what influences patients’ experiences of cannulation, which is also a strength of the study. CCA and intensive interviewing were used were to promote a depth of understanding in findings. The response to revelations during interviews that this approach facilitated, led to changes in the interview guide to explore concepts. This also created theoretical sensitivity, enabling identification when concepts appeared in interviews, leading to further probing. This led to novel findings that are a strength of this study. To add to this, as described in section De, good qualitative practices, reflexivity, peer debrief and member checking all increased the trustworthiness of findings.

The breadth of diversity in the sample was also a strength of ICE-HD. Purposive and theoretical sampling promoted this diversity, alongside an inclusive approach. ICE-HD did not just recruit participants who wanted to discuss their negative cannulation experiences, but purposefully also approached and recruited patients who were not known to have a problem with their cannulation. These interviews provided balance to the sample, but also created a different perspective on cannulation, increasing the novelty of findings. The diversity of the sample was increased by recruiting participants whose first language was not English, including one participant who required support from an interpreter. Whilst this did not make the interviews easy at times, it increased the relevance of findings to the haemodialysis population.

Whilst there are strengths within ICE-HD, there are also limitations. At this stage, it should be recognised that qualitative research aims not to create generalisability, but aims to have transferability, where findings reflect the experiences of individual participants but may be transferable to other individuals or contexts (Holloway and Galvin, 2017). To interpret transferability of findings appropriately, the context it is set in and the limitations of the application of the results to clinical practice need to be understood. ICE-HD was set across two renal centres, aiming to explore the breadth of scope of cannulation experience in different centres using different cannulation techniques. Whilst this broadens the scope beyond a single centre and technique, both centres have a high proportion of AV access within their dialysis populations (UK Renal Registry, 2022). Thus, the experiences described may not truly reflect the experiences of participants in other renal centres, particularly those with a lower proportion of AV access in their haemodialysis population, who may have less expertise in cannulation. Whilst there may be elements of the analysis that are applicable to more general cannulation, the regularity and necessity of cannulation for haemodialysis makes it unique. It is also important to recognise that ICE-HD was implemented during an exceptionally busy period of the NHS in the UK, due to the COVID 19 global pandemic, followed by unprecedented strikes by the NHS workforce. This may have influenced findings, although in interviews it appeared this context emphasised specific components of their experience that already existed, bringing these to the fore (e.g support form family through cannulation, the workload and busy-ness of cannulators), rather than introducing new components.

It is important to acknowledge that ICE-HD is an interview study where participants verbally disclosed what they believe to be their cannulation experience in response to the questions asked. Therefore, the analysis reflects the questions asked and the responses the participants chose to disclose rather than a pure reflection of their experiences. Participants were only able to verbalise thoughts and feelings that are directly in their consciousness. Whilst intensive interviewing aimed to uncover sub-conscious thoughts and feelings, with participants verbally stating after interviews that they had disclosed more than they expected, there is likely still unrecognised elements of participants’ experiences not included in the analysis.

The wider context of the haemodialysis unit where cannulation occurs also affected how participants were describing their experiences. At times it appeared that participants were playing a role or reciting views and language influenced by the context of the haemodialysis unit around them. Two concerns were identified that may have influenced how participants described their experiences. Firstly, participants demonstrated gratitude for their haemodialysis throughout interviews. Participants can be influenced by gratitude for receiving a life-saving treatment, and thus more likely present their experiences positively (Sampson et al., 2010). As this was evident in interviews, this potentially created a more positive account from participants than is true. Secondly, the context of the haemodialysis unit was also evident through the language used by participants, which often reflected jargon unique to the nursing profession and common statements nurses use to placate or help patients cope with cannulation (e.g. you’ve just got to get through it). It is important to recognise that cannulation by healthcare professionals happens within the context and culture of the haemodialysis unit, run by nursing staff. Therefore, participants do not sit in isolation when they describe their experiences of cannulation, but experiences are influenced by this context and culture, which also influences how participants express these experiences.

Finally, the use of remote interviews necessitated by the COVID-19 global pandemic, was both a strength and a limitation on the study, changing the influence of the researcher on the interview. Remote interviews led to a loss of non-verbal cues, particularly during telephone interviews. Therefore, verbal prompts were required in greater depth during the interview to show participants they were being listened to. This sometimes interrupted the flow of the interview and on occasions, the lack of non-verbal prompts from participants' meant interruptions increased. However, during interviews it appeared as if the influence of the researcher was minimised, especially on the telephone, through the lack of face-to-face contact. It appeared that enabling participants to 'speak into a void', to a faceless person, made them forget who they were talking to and may have increased the integrity of experiences described. Whilst, faces were visible during video calls, it appeared easy for participants to not look directly into the camera or watch the screen, thus this phenomenon still seemed to be present. However, as no interviews were completed face to face, it is difficult to determine the true effect of this and most participants vocalised prior to the interview that they would have preferred a face-to-face interview.

5.3 Conclusions

In conclusion, ICE-HD develops our understanding of patients' experiences of cannulation for haemodialysis in more depth, exploring the factors that influence this. This has created three categories to outline these factors. Firstly, participants describe actions and factors that aim to make cannulation more comfortable. This includes familiarity with cannulation, avoiding or minimising pain from cannulation, increasing the predictability of cannulation and reducing anxiety about cannulation. Whilst participants describe specific actions that may achieve these aspects, currently there is now single intervention that will improve this for everyone. Further research is needed to identify and evaluate interventions that may improve these factors including: information for patients both before starting cannulation, but also whilst undergoing cannulation; local anaesthesia and other techniques to reduce pain; techniques to promote predictability including use of ultrasound, how to develop a strategy to cannulate individuals successfully and communicate this, use of tourniquets and how to promote more consistency in cannulation; and relaxation and distraction techniques to reduce anxiety including aromatherapy and music therapy.

However, beyond this, there are other factors of the cannulation procedure that can influence patients' experiences. Preserving humanity and individuality throughout cannulation is important and is largely related to the relationship with the cannulator. Empathy can help build this relationship that generates trust. The necessity of cannulation drives individuals to cope, but then various strategies help them to cope. Whilst stoicism assists individuals to 'get through' cannulation, focussing on stoicism as a technique ignores the distress cannulation causes. Therefore, acceptance of unpleasant and unpredictable but necessary cannulation and being able to contribute to cannulation provide more constructive mechanisms of coping. However, further research is needed to explore how to facilitate acceptance of cannulation, considering how cannulators can facilitate this as well as formal psychological therapies. Cannulators also need to consider how to enable patients to contribute to cannulation in a manner that suits that individual.

These factors provide a model of an individual coping with cannulation, where increasing these elements promotes coping and denying these elements reduces coping with cannulation. As cannulation and the individual vary day to day and over time, so does the coping with cannulation.

5.3.1 Summary of Recommendations

ICE-HD has generated a number of recommendations for the future, either for clinical practice or explored further in future research. These are summarised below.

5.3.1.1 Clinical Practice

For clinical practice, the following aspects are recommended, although it is recognised that the impact of implementing some of these may also be evaluated through research or quality improvement projects:

- Develop detailed information on cannulation for patients preparing for haemodialysis, especially those having AV access, exploring what may be the best way to deliver this (discussed section 5.2.1, paragraph 4)
- Consider how cannulators can promote greater information sharing for patients on their cannulation (discussed section 2.2.1, paragraph 5)

- Consider how to make cannulation more predictable, examining how to communicate individual cannulation strategies between teams of cannulators consistently and promote consistency in cannulators, either through duty allocations or training (discussed section 5.2.1, paragraph 7)
- Consider how to individualise cannulation to meet individual needs, possibly through structured conversations with patients or a cannulation plan (discussed section 5.2.2, paragraph 1)
- Include understanding of patients' experiences of cannulation, including the importance of promoting empathy from cannulators, building a relationship of trust with patients and avoiding promotion of stoicism as a sole coping mechanism, as part of normal training for cannulators (discussed section 5.2.2, paragraph 3)
- Consider how to facilitate patients contributing to cannulation that is flexible and responds to their individual needs, including an option to not contribute if that is their wish (discussed section 5.2.3, paragraph 8)

5.3.1.2 Research

The recommendations for research include recommendations on subjects that require further investigation. The following subjects have been identified as warranting further research:

- Strategies to minimise pain from cannulation, including local anaesthesia (discussed section 5.2.1, paragraph 2)

- Strategies to increase the predictability of cannulation, especially the use of ultrasound by cannulators (discussed section 5.2.1, paragraph 7)
- Strategies to reduce anxiety during cannulation, including relaxation techniques, music therapy and distraction (discussed section 5.2.1., paragraphs 10 and 11)
- Strategies to promote acceptance and positive thinking, and how cannulators could be equipped to support this (discussed section 5.2.3, paragraph 7)

This chapter has described the results of ICE-HD. The combination of categories creates a model of an individual who is coping with cannulation for haemodialysis, thus defining the factors of cannulation that facilitate coping. Recognising these components generates ideas as to how cannulation could be improved. The next chapter will bring the thesis to a conclusion, discussing the conclusions of the thesis, the strengths and limitations of the whole thesis and future recommendations for practice and research, identifying strategies to improve cannulation and meeting the final objective of the thesis.

6 Chapter 6: Understanding Patients’ Experiences of Cannulation: Conclusion

This final chapter will start by summarising the findings generated from the research in this thesis, which has also been discussed in the chapters describing individual studies. This summary highlighting novel findings and how this extends our understanding of patients’ experience of cannulation for haemodialysis. It then progresses to explore the strengths and limitations of the whole thesis before finishing with recommendations for clinical practice and future research.

6.1 Summary of Findings

This thesis aims to understand patients’ experiences of cannulation for haemodialysis, from the patient’s perspective. This has been achieved through three studies. The first study is a systematic review of qualitative research that explores patients’ experiences of cannulation for haemodialysis. A meta-aggregation of 26 studies developed a model o understand patients’ experiences of cannulation for haemodialysis and this the first systematic review to achieve this. The second study developed and evaluated the Patients’ Perspective of Needling (PPN) questionnaire, to measure the symptoms patients experienced due to cannulation. This questionnaire was designed specifically to be used within research studies. Face validity testing with twelve participants from two renal centres and further validity and reliability testing with 99 participants from two renal centres demonstrated the questionnaire behaved in a valid and reliable manner. This is the first questionnaire that specifically assesses this experience. The third study is an in-depth qualitative study that aims to further our understanding of patients’ experiences of cannulation, focussing on factors that patients perceive influence their experiences of cannulation. Semi-structured interviews with 30 participants from two renal centres were analysed using constant comparison analysis, with theoretical sampling and intensive interviewing to support this process. This analysis furthered our understanding of patients’ experiences of cannulation and what influenced this, but also developed a model of a patient coping with cannulation, identifying the factors that contribute to this coping and difficulty coping. Again, this nuanced understanding has produced novel findings in this area. Throughout the thesis, the outcomes of studies have focussed on how we can improve cannulation for patients and also identified further areas for investigation, to continue to develop our understanding of patients’ experiences of cannulation. This led to each study developing a set of novel recommendations and aim to progress clinical practice and further research in this field.

The culmination of these three studies has furthered our understanding of cannulation for haemodialysis, which did not previously exist. This does not only provide insight into this but also indicates how this procedure could be improved for patients. The model of patients’ experiences of cannulation developed through the systematic review identified three synthesised findings with ten categories to explain these further. This identified that cannulation is an unpleasant, abnormal and unique procedure associated with pain, abnormal appearance and feelings of vulnerability and dependency. Cannulation is necessary for haemodialysis where successful cannulation means having an unproblematic haemodialysis treatment as well as minimising pain. This leads patient to worry about the success of cannulation. Patients survive unpleasant, necessary and repetitive cannulation through learning to tolerate cannulation. Feeling safe and being able to exert control improves cannulation but patients still try to avoid cannulation. These synthesized findings were then used to structure the development of the PPN questionnaire. This final questionnaire includes 17 questions on pain, worry and problems with cannulation, with pain scoring the highest but all problematic for patients. Whilst this tells us what patients' experiences are, free text comments also provide further. In particular, the variability in cannulation experience over time was highlighted as an important issue that required further exploration.

This led to the third study, ICE-HD which aimed to explore this variability, examining the factors that influence patients' experiences of cannulation for haemodialysis. This study developed three categories and nine sub-categories to describe this. The unpleasant and noxious nature of cannulation was evident throughout interviews, but ICE-HD extended our understanding of this, identifying factors that can make the cannulation more comfortable for patients. Familiarity with cannulation is important to facilitate coping and lack of familiarity is an issue at the start of cannulation. Pain continued to be an issue of importance for patients leading to patients avoiding cannulation, as indicated previously in the model generated by the systematic review. However, ICE-HD extended our understanding of this, also demonstrating the importance of minimising pain from cannulation. A new and unique finding from ICE-HD was the unpredictability of cannulation and how increasing the predictability of cannulation improves this for patients. Our understanding of anxiety from cannulation is extended in ICE-HD with reducing this anxiety helping to improve cannulation for patients. Whilst various strategies were identified throughout ICE-HD that create familiarity, minimise the pain, increase predictability and reduce anxiety, cannulation for haemodialysis continues to be a difficult procedure for patients to cope with. Strategies to improve these aspects need to be explored.

As well as factors that make cannulation more comfortable, ICE-HD also identified that preserving patients' humanity and individuality also improved cannulation for haemodialysis. Whilst this has been hinted at in previous studies, with hindsight allowing identification of this throughout the systematic review, ICE-HD is the first study to identify this as a concept and describe this in detail. As patients' individuality throughout cannulation is important, solutions to improving experience need to be individualised. Empathy from others, especially the cannulator, help to improve cannulation for patients. Empathy from the cannulator build a trusting relationship that makes cannulation easier. These findings provide insight into the influence of the cannulator on the cannulation procedure, which was identified from both the systematic review and free text comments on the PPN, but not fully understood at this point. As the relationship with the cannulator is central to patients' experiences of cannulation, cannulators must be equipped with the knowledge to understand patients' experiences of cannulation, facilitating empathy, and the skills to demonstrate empathy and build trust.

The necessity of cannulation to enable a life sustaining treatment, haemodialysis, drives patients to cope with this procedure in the best way they can. The systematic review initially identified that patients learn to tolerate cannulation due to its necessity, but ICE-HD clarifies this further. The necessity of haemodialysis provides a unique context to the cannulation procedure. Acceptance of unpleasant and unpredictable cannulation facilitates coping but takes time to develop. However, possibly due to the absence of other coping strategies, stoicism is currently a common coping mechanism. Equipping patients with the skills to promote acceptance of cannulation would help improve their experiences. Cannulators should be equipped with the skills to facilitate and support this. Facilitating patients to be able to contribute to their cannulation in a manner that suits the individual also appears to facilitate acceptance. However, it is important to note this is not about control, as previous studies have indicated (identified in the systematic review), but rather being part of the procedure in a manner that is congruent with the patient's aims and wishes. The concepts discussed in this paragraph were indicated in the systematic review and free text comments from the PPN, but not fully understood at this point in time. ICE-HD provides further insight and understanding of these concepts.

How the findings of each study relate to the current research and clinical context is explored individually in each study chapter. However, the above discussion highlights the novel findings generated by the three studies in this thesis and how this extends our understanding of patients' experiences of cannulation for haemodialysis. Some of the recommendations made in earlier chapters have been achieved by later studies, whilst some recommendations still stand. It is acknowledged that whilst this thesis has extended our understanding of patients' experiences of cannulation for haemodialysis, it also raises further questions, indicating further research is still required in this area.

6.2 Strengths and Limitations of the Thesis

The strengths and limitations of each individual study have been discussed in the relevant chapters. However, it is also valuable to explore the strengths and limitations relevant to the whole thesis. However, these add to rather than replace the strengths and limitations of individual studies, which remain relevant. As will be discussed below, many strengths discussed in this section also have associated limitations and vice versa. Therefore, this discussion provides context for interpretation of the results of this thesis. Individual opinion may vary as to whether they strengthen or detract for the results of this thesis, or do both.

The research findings within this thesis aim to understand of patients' experiences of cannulation undertaken by healthcare professionals. Whilst the systematic review includes studies that explore experiences of cannulation performed by anyone, the final two studies focus solely on cannulation performed by healthcare professionals. However, cannulation performed by healthcare professionals is only one facet of cannulation. Cannulation can also be performed by the patient themselves or by carers. As discussed in section 3.1.4, the focus on cannulation performed by healthcare professionals was developed this was considered a different concept to cannulation performed by patients or carers. This viewpoint has been confirmed throughout the research in this thesis, where the cannulator has been identified as key part of the cannulation process that influences patients’ experiences and the novel finding where patients discuss how they contribute rather than control cannulation, which may be unique to cannulation performed by healthcare professionals. Whilst experiences of cannulation performed by carers may have congruence with that performed by the healthcare professional, due the difference in the relationship, skills and context, this cannot be assumed to be the case. Whilst there is a clear rationale for focussing on cannulation performed by healthcare professionals, this means the findings of this thesis are only relevant to patients who undergo cannulation for haemodialysis by healthcare professionals.

This thesis examined patients’ experiences of cannulation from the patient’s perspective. There is a clear rationale for this set out in section 1.3.1. Whilst this is a strength of the thesis, as the patient is the person experiencing cannulation, this provides two further considerations when interpreting these results. Firstly, cannulation also involves others, including the cannulator, the wider healthcare team and social support networks around the patient. These individuals may have different views, opinions and experiences of cannulation that are not reflected in this thesis. Secondly, it should also be recognised that the patient is not a technical expert in cannulation, but an expert in how it feels to them. Therefore, some aspects of patients' descriptions of their experiences of cannulation may not be technically accurate but demonstrate their perspective. These should not be interpreted as creating facts about the technical aspects of cannulation.

My role as both a healthcare professional who performs cannulation and a researcher also needs to be considered. As discussed in section 1.4.2, this can be seen as both a strength and weakness. It has driven the subject of the thesis and eased the creation of relationships with both research participants and patient representatives. My background knowledge provides a context of understanding around the analysis and interpretation of data. However, it is also important to recognise that this context means I bring assumptions about what patients' experiences are and how to make them better. Techniques have been employed throughout this thesis to manage this dual role, including maintaining a reflexive diary to recognise and examine my assumptions and avoidance of cannulation of research participants whilst conducting the research, which became harder to achieve when I was redeployed back to clinical practice in the middle of this thesis due the COVID-19 global pandemic. However, it is important to recognise that my role as a healthcare professional who cannulates patients may have influenced the findings of the research within this thesis, with a non-clinical researcher possibly interpreting and understanding findings differently.

Throughout this thesis, existing theories have not been used to structure the research or analysis. This is a point that has been discussed in relation individual studies and was an intentional decision to ensure that findings were grounded in participants experiences, not a pre-defined structure. The inductive approach ensured that the research truly illuminated what patients' told us about their experiences. This was important when examining an area where there was a paucity of research. Whilst the relationship between patients' experiences of cannulation and existing theories (e.g. acceptance and adaption to chronic illness) are now evident following completion of this research, prior to starting this research they were not. Whilst the inductive approach has ensured that findings truly reflect patients' experiences, at times organising and analysing the data has felt over-whelming, especially in an area where the individual's experiences may not be fully consciously recognised. Therefore, this inductive approach may mean findings do not always fit into expected structures, which for those not familiar with cannulation may make them difficult to understand. However, feedback from patient representatives, colleagues and patients at work and conferences has been very clear that the findings of this thesis truly reflect and provide insight into their reality.

Since the completion of this research, little has progressed the field of patients' experiences of cannulation for haemodialysis. Within the discussions of individual studies, recent research has been referred to where appropriate, including studies completed at the time of conducting this research and writing the thesis. Of note, after completion of the systematic review, one further study has been identified that would have been suitable for inclusion (by Kuo et al. (2020)), which has been included in the discussion section of this chapter (section 2.6). A further study into patients' adjustment to haemodialysis also has relevance to the research within this thesis (Kapadi et al, 2023), which again has been discussed in the relevant discussion section for ICE-HD (section 5.2). Two studies of note in the field of cannulation have been published whilst this research was undertaken, but do not directly relate to the content of this thesis. Staaf, Fernstrom and Uhlin (2023) completed a mixed methods study exploring how nurses make decisions about cannulation. However, this was focussed on the technical aspects of cannulation rather than any consideration of experience, either the nurses or patients. Smith, Schoch, Zu and Bennett (2022) performed a small-scale study evaluating use of plastic cannula versus metal needles. They found that plastic cannulas had a slightly higher rate of miscannulation, which reduced as cannulators became more proficient at cannulating with plastic cannulas. They found low rates of anxiety and needle related fear for both plastic and metal needles, although it was unclear how much these questionnaires explored anxiety related to cannulation in the context of haemodialysis. Of interest, plastic cannulas were mentioned briefly by a few participants in ICE-HD, as they felt these may male their cannulation less painful (section 5.1.2.1.2). The lack of other studies in the field of patients' experiences of cannulation for haemodialysis during the period of this research and thesis reiterates the novelty of this thesis but also indicates that the profile of this type of research needs to be raised, especially considering the impact on patient's experiences of haemodialysis.

The final perspective to consider in this section it that this thesis and research has been conducted as part of the PhD process. Although a PhD is a learning journey, the PhD process itself ensures that the research methodology and methods are explored and considered in-depth, potentially strengthening the quality of the research. I have endeavoured to describe the rationale and conduct of the research with honesty and transparency.

It is also important to consider my learning throughout this PhD process. Firstly, whilst I was an experienced haemodialysis nurse who regularly cannulated prior to starting this PhD, the findings of this research remain enlightening for me. They provide form and insight into thoughts and emotions that previously were difficult to describe. This will affect my own practice going forwards, but also those around me and hopefully the recommendations will impact future clinical practice and training as well as future research. However, my greatest learning throughout this PhD has been how to design and conduct research. Implementing this research within the NHS has provided understanding of ethics and governance processes and also manage research across multiple sites. These will be invaluable skills to take forward in my future research. Consideration of the design of the research, alongside the opportunity to attend training and critically appraise research on this subject, has developed my skills, knowledge and application of research methodology and methods. The varied research included in this thesis has provided breadth of knowledge in this area.

It is also recognised that no research is perfect and reflection in hindsight is always beneficial. Firstly, in hindsight I would have altered the order of the research within this thesis. At the time, the development of the PPN seemed a natural progression after the systematic review. At this time, the information obtained in the systematic review appeared adequate to do this. However, in hindsight, development of the PPN may have been better situated after ICE-HD when further knowledge and clarification had been obtained. However, regardless of this, the PPN appears to behave in a valid and reliable manner. Secondly, having a larger sample size for evaluation of the PPN may have facilitated a confirmatory factor analysis of the questionnaire.

As mentioned previously, these strengths and limitations provide context for interpretation of the results of the research within this thesis. However, this does not detract from the findings of this thesis or the importance of conducting research into patients’ experiences of cannulation for haemodialysis.

6.3 Recommendations For Clinical Practice and Research

The final objective for this thesis was to provide recommendations for how cannulation can be improved. To clarify the status of individual recommendations from each studies, these have been summarised in Table 26, Table 27 and Table 28, with detail provided to determine whether these have been met in the thesis or remain a priority for the future. The final part of this chapter will then set out a final set of recommendations for the future.

Clinical or Future Research	**Recommendation**	**Achieved in Thesis Research ***
Clinical	Develop strategies to minimise miscannulation, including the evaluation of the efficacy of POCUS	Not applicable
	Training of cannulators needs to recognise the social interaction that happens during cannulation as well as technical aspects	
	Haemodialysis units and staffing schedules need to be designed to create a calm environment for cannulation to occur	
Research	Future qualitative studies into patients' experience of cannulation for haemodialysis need to explore specifically how cannulation is unpleasant, including an in-depth exploration of pain and further exploration of vulnerability, rather than just identifying that the procedure is unpleasant	Fully
	Studies that claim to explore or measure patients' experience of needling when evaluating interventions to improve this, need to include all the elements of unpleasantness, not just pain	Fully (Measure provided in Chapter 3)
	The concepts of feeling safe and control during needling requires further exploration, particularly considering the effect of the cannulator, the environment and needling technique on feeling safe, as well as how to facilitate control in cannulation	Fully

Table 26: Summary of Recommendations from Chapter 2

* categorised as Fully, Not at all or Not applicable

Clinical or Future Research	Recommendation	Achieved in Thesis Research*
Clinical	Consideration needs to be given to how the team of cannulators can better support patients better through cannulation and how to facilitate patients adapting to cannulation as part of their everyday life	Not applicable
Research	Results indicate the PPN is valid and reliable for use within research studies evaluating cannulation for haemodialysis undertaken by healthcare professionals • Whilst section and individual question scores can add granularity to data, the overall PPN score should be the main focus of any research. Questions 1, 4, 7, 8, 10, 14 are the ones most likely to distinguish between different experiences	Not at all
	Further studies are also required to: • Explore and understand worry about cannulation for haemodialysis • Understand the variability in patients' experiences of cannulation for haemodialysis	Fully
	A confirmatory factor analysis with a larger sample size may provide further reassurance of construct validity	Not at all
	Cross-cultural validation work will enable the PPN to be used in non-English speaking patients	
	Collection of longitudinal data over time could provide reassurance of the PPN's responsiveness to change	

Table 27: Summary of Recommendations from Chapter 3

* categorised as Fully, Not at all or Not applicable

Clinical or Future Research	**Recommendation**	**Achieved in Thesis Research***
Clinical	Develop detailed information on cannulation for patients preparing for haemodialysis, especially those having AV access, exploring what may be the best way to deliver this	Not applicable
	Consider how cannulators can promote greater information sharing for patients on their cannulation	
	Consider how to make cannulation more predictable, examining how to communicate individual cannulation strategies between teams of cannulators consistently and promote consistency in cannulators, either through duty allocations or training	
	Consider how to individualise cannulation to meet individual needs, possibly through structured conversations with patients or a cannulation plan	
	Include understanding of patients' experiences of cannulation, including the importance of promoting empathy from cannulators, building a relationship of trust with patients and avoiding promotion of stoicism as a sole coping mechanism, as part of normal training for cannulators	
	Consider how to facilitate patients contributing to cannulation that is flexible and responds to their individual needs, including an option to not contribute if that is their wish	
Research	Evaluation of strategies to minimise pain from cannulation, including local anaesthesia	Not at all
	Evaluation of strategies to increase the predictability of cannulation, especially the use of ultrasound by cannulators	
	Evaluation of strategies to reduce anxiety during cannulation, including relaxation techniques, music therapy and distraction	
	Evaluation of strategies to promote acceptance and positive thinking, and how cannulators could be equipped to support this	

Table 28: Summary of Recommendations from Chapters 4 and 5

* categorised as Fully, Not at all or Not applicable

6.3.1 Summary of Final Recommendations

6.3.1.1 Clinical Practice

The following recommendations have been amalgamated from individual studies, to provide a summary of ongoing recommendations for clinical practice. Some clinical practice recommendations have been removed, as later studies identify the need for further research into this area. They are also re-ordered to follow the patient journey through cannulation. The final recommendations for clinical practice generated by this thesis are summarised below:

- Detailed information needs to be developed on cannulation for patients preparing for haemodialysis, especially those having AV access, exploring what may be the best way to deliver this (from Chapter 5)
- Cannulation needs to be individualised, aiming to meet individual needs, possibly through structured conversations with patients or a cannulation plan (from Chapter 5)
- Cannulators need to promote greater information sharing with patients on their cannulation (Chapter 5)
- Haemodialysis units and staffing schedules need to be designed to create a calm environment for cannulation to occur and promote consistency in cannulators (from Chapters 2 and 5)
- Strategies need to be developed to make cannulation more predictable, including those that promote communication of cannulation plans for individual patients between teams of

cannulators and those that help avoid miscannulation (Chapters 2 and 5)

- Cannulation needs to be performed in a manner that enables patients to contribute as they wish to, including an option to not contribute if that is their wish (Chapter 5)
- Training of cannulators needs to include understanding of patients' experiences of cannulation, including the importance of promoting empathy from cannulators, building a relationship of trust with patients and avoiding promotion of stoicism as a sole coping mechanism, recognising the social interaction that happens during cannulation as well as technical aspects (Chapters 2, 3, and 5)

6.3.1.2 Research

Recommendations for research are divided into two subjects:

- How to measure patients' experiences of cannulation within research, incorporating how to improve the PPN questionnaire
- The subject of future research into strategies to improve cannulation.

Again, similar recommendations from individual studies have been merged, where appropriate.

The final recommendations for future research that aims to measure patients' experiences of cannulation are below:

- The PPN provides a valid and reliable questionnaire for use within research studies evaluating cannulation for haemodialysis undertaken by healthcare professionals. Whilst section and individual question scores can add granularity to data, the overall PPN score should be the main focus of measurement in any research. Questions 1, 4, 7, 8, 10, 14 are the ones most likely to distinguish between different experiences (from Chapter 3)

- To further develop the PPN (from Chapter 3):
  - A confirmatory factor analysis with a larger sample size may provide further confirmation of construct validity
  - Cross-cultural validation work will enable the PPN to be used in non-English speaking patients
  - Collection of longitudinal data over time may provide evidence of the PPN’s responsiveness to change

Recommendations on future research into strategies to improve cannulation are below and include research studies to evaluate:

- Strategies to minimise pain from cannulation, including local anaesthesia (from Chapter 5)
- Strategies to increase the predictability of cannulation, especially the use of ultrasound by cannulators (from Chapter 5)
- Strategies to reduce anxiety during cannulation, including relaxation techniques, music therapy and distraction (from Chapter 5)
- Strategies to promote acceptance and positive thinking, and how cannulators could be equipped to support this (from Chapter 5)

Cannulation for haemodialysis is a noxious and unpleasant procedure that causes distress for patients on haemodialysis. Developing understanding of patients' experiences of cannulation for haemodialysis is important, as it generates knowledge about how to improve this procedure for patients, making it less noxious and unpleasant. The studies described in Chapters 2, 3, 4, and 5 meet the first three objectives of this thesis, extending our understanding of patients' experiences of cannulation for haemodialysis as performed by healthcare professionals, from the patient's perspective. The above recommendations meet objective four of the thesis, pragmatically linking the outcomes of the three studies to clinical practice and future research.

7 References

Aitken E, Anijeet H, Ashby D, Barrow W, Calder F, Dowds B, Fielding C, Gilbert J, Jones R, Karunanithy N, Khawaja Z, Roberts E, Robson M, Scgroff R. Stacey H, Thomson P and Waters D (2023) *UK Kidney Association Clinical Practice Guideline Vascular Access for Haemodialysis* https://ukkidney.org/sites/renal.org/files/FINAL%20FORMATTED%20Vascular%20access%20for%20haemodialysis%20April%202023.pdf – accessed 27/08/2023

Aitken E, McLellan A, Glen J, Serpell M, MacTier R and Clancy M (2013) ‘Pain resulting from arteriovenous fistulae: prevalence and impact’ *Clinical Nephrology* 80(5) p328-33 doi:10.5414/cn107917

Aiyegbisi O, Kyte D, Cockwell P, Anderson N and Calvert M (2017) ‘A patient-centred approach to measuring quality in kidney care: patient-reported outcome measures and patient-reported experience measures’ *Current Opinion Nephrology Hypertension* 26(6) p442-9 doi:10.1097/MNH.0000000000000357

Al Shakarchi J, Houston J, Jones R and Inston N (2015) ‘A Review on the Hemodialysis Reliable Outflow (HeRO) Graft for Haemodialysis Vascular Access’ *European Journal of Vascular and Endovascular Surgery* 50(1) p108-13 doi:10.1016/j.ejvs.2015.03.059

Allen D, Wainwright M and Hutchinson T (2011) ‘Non-compliance' as illness management: Hemodialysis patients' descriptions of adversarial patient-clinician interactions’ *Social Sciences Medicine* 73(1) p129-34 doi:10.1016/j.socscimed.2011.05.018

Alobayli F (2019) ‘Factors Influencing Nurses’ Use of Local Anesthetics for Venous and Arterial Access’ *Journal of Infusion Nursing* 42(2) p91-107 doi:10.1097/NAN.0000000000000316

Altman DG (1991) *Practical Statistics for Medical Research* Chapman and Hall, USA

Appleton JV and King L (2002) ‘Journeying from the philosophical contemplation of constructivism to the methodological pragmatics of health services research’ *Journal of Advanced Nursing* 40(6) p641-8 doi:10.1046/j.1365-2648.2002.02424.x

Aromataris E and Munn Z (Eds) (2020) *JBI Manual for Evidence Synthesis* Joanna Briggs Institute https://synthesismanual.jbi.global https://doi.org/10.46658/JBIMES-20-01 – accessed 27/08/2023

Axley B and Rosenblum A (2012) ‘Learning why patients with central venous catheters resist permanent access placement’ *Nephrology Nursing Journal* 39 (2) p99-103

Blankestijn PJ, Vernooij RWM, Hockham C, Strippoli GFM, Canaud B, Hegbrant J, Barth C, Covic A, Cromm K, Cucui A, Davenport A, Rose M, Torok M, Woodward M, Bots ML and Convince Scientific Committee Investigators (2023) ‘Effect of Hemodiafiltration or Hemodialysis on Mortality in Kidney Failure’ *New England Journal of Medicine* IN PRESS doi:10.1056/NEJMoa2304820

Boeije H (2002) ‘A Purposeful Approach to the Constant Comparative Method in the Analysis of Qualitative Interviews’ *Quality and Quantity,* 36**,** 391-409

Bond M, Crathorne L, Peters J, Coelho H, Haasova M, Cooper C, Milner Q, Shawyer V, Hyde C and Owell R (2016) ‘First do no harm: pain relief for the peripheral venous cannulation of adults, a systematic review and network meta-analysis’ *BMC Anaesthesiology* 16(81) doi:10.1186/s12871-016-0252-8

Bourbonnais FF and Tousignant KF (2012) ‘The pain experience of patients on maintenance hemodialysis’ *Nephrology Nursing Journal* 39(1) p13-9

Braun V and Clarke V (2020) ‘Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches’ *Counselling and Psychotherapy Res* 21(1) p37-47 doi:10.1002/capr.12360

Braun V and Clarke V (2006) ‘Using thematic analysis in psychology’ *Qualitative Research in Psychology* 3(2) p77-101 doi:10.1191/1478088706qp063oa

Bravo G and Potvin L (1991) ‘Estimating the reliability of continuous measures with Cronbach Alpha or the Intraclass Correlation Coefficient: Toward the Integration of the two traditions’ *Journal of Clinical Epidemiology* 44(4-5) p381-90

Bredart A, Marrel A, Abetz-Webb L, Lasch K and Acquadro C (2014) ‘Interviewing to develop Patient-Reported Outcome (PRO) measures for clinical research: eliciting patients' experience’ *Health Qual Life Outcomes* 12(15) doi:10.1186/1477-7525-12-15

Butler A, Hall H and Copnell B (2016) ‘A Guide to Writing a Qualitative Systematic Review Protocol to Enhance Evidence-Based Practice in Nursing and Health Care’ *Worldviews Evidence Based Nursing* 13(3) p241-9 doi:10.1111/wvn.12134

Cafazzo JA, Leonard K, Easty AC, Rossos PG and Chan CT (2009) ‘Patient-perceived barriers to the adoption of nocturnal home hemodialysis’ *Clinical Journal of the American Society of Nephrology* 4(4) p784-789 doi:

Cafazzo JA (2007) ‘Facilitating patient self-care through remote patient monitoring: Validation, design, and evaluation of an intervention for nocturnal hemodialysis’ *Dissertation Abstracts International: Section B: The Sciences and Engineering* 69(6-B) 3540 https://tspace.library.utoronto.ca/handle/1807/118278 - accessed 27/08/2023

Cambridge University Press and Assessment (2023) *Cambridge Dictionary [Online]* https://dictionary.cambridge.org/dictionary/english/understanding - accessed 05/03/2023

Cappelleri JC, Lundy JJ and Hays RD (2014) ‘Overview of classical test theory and item response theory for the quantitative assessment of items in developing patient-reported outcomes measures’ *Clin Ther,* 36(5) 648-62 doi: 10.1016/j.clinthera.2014.04.006

Carter SM and Little M (2007) ‘Justifying knowledge, justifying method, taking action: epistemologies, methodologies, and methods in qualitative research’ *Qual Health Res* 17(10) 1316-28 doi:10.1177/1049732307306927

Casey JR, Hanson CS, Winkelmayer WC, Craig JC, Palmer S, Strippoli GFM and Tong A (2014) ‘Patients' perspectives on hemodialysis vascular access: A systematic review of qualitative studies’ *American Journal of Kidney Diseases* 64(6) 937-953 doi:10.1053/j.ajkd.2014.06.024

Caskey FJ, Procter S, MacNeill SJ, Wade J, Taylor J, Rooshenas L, Liu Y, Annaw A, Alloway K, Davenport A, Power A, Farrington K, Mitra S, Wheeler DC, Law K, Lewis-White H, Ben-Shlomo Y, Hollingworth W, Donovan J and Lane JA (2022) ‘The high-volume haemodiafiltration vs high-flux haemodialysis registry trial (H4RT): a multi-centre, unblinded, randomised, parallel-group, superiority study to compare the effectiveness and cost-effectiveness of high-volume haemodiafiltration and high-flux haemodialysis in people with kidney failure on maintenance dialysis using linkage to routine healthcare databases for outcomes’ *Trials,* 23(532) doi:10.1186/s13063-022-06357-y

Chan Z, Fung Y and Chien W (2013) ‘Bracketing in Phenomenology: Only Undertaken in the Data Collection and Analysis Process’ *The Qualitative Report* 18(30) p1-9.

Charmaz K (2017) ‘The Power of Constructivist Grounded Theory for Critical Inquiry’ *Qualitative Inquiry* 23(1) p34-45 doi:10.1177/1077800416657105

Charmaz K (2014) *Constructing Grounded Theory* Sage, London

Charmaz K (1990) 'Discovering' chronic illness: using grounded theory. *Soc Sci Med* 30(11) p1161-72 doi:10.1016/0277-9536(90)90256-r

Cherryholmes C (1992) Notes on Pragmatism and Scientific Realism' *Educational Researcher* 21(6) p13-7

Chun Tie Y, Birks M and Francis K (2019) 'Grounded theory research: A design framework for novice researchers' *SAGE Open Med* 7 2050312118822927 doi:10.1177/2050312118822927

Collins (2023) *Collins English Dictionary [Online]* https://www.collinsdictionary.com/dictionary/english/understanding -accessed 05/03/2023.

Collins C and Stockton C (2018) 'The Central Role of Theory in Qualitative Research' *International Journal of Qualitative Methods',* 17(1) 1-10 doi:10.1177/1609406918797475

Colvin CJ, Garside R, Wainwright M, Munthe-Kaas H, Glenton C, Bohren MA, Carlsen B, Tuncalp O, Noyes J, Booth A, Rashidian A, Flottorp S and Lewin S (2018) 'Applying GRADE-CERQual to qualitative evidence synthesis findings-paper 4: how to assess coherence' *Implementation Science* 13(Supplement 1) 13 doi:10.1186/s13012-017-0691-8

Cooney A (2011) Rigour and grounded theory *Nurse Researcher* 18(4) p17-22 doi:10.7748/nr2011.07.18.4.17.c8631

Coventry LL, Hosking JM, Chan DT, Coral E, Lim WH, Towell-Barnard A, Twigg DE and Rickard CM (2019) 'Variables associated with successful vascular access cannulation in hemodialysis patients: a prospective cohort study' *BMC Nephrology* 20(1) 197 doi:10.1186/s12882-019-1373-3

Cowan D, Smith L and Chow J (2016) 'Care of a patient's vascular access for haemodialysis: A narrative literature review' *Journal of Renal Care* 42(2) 93-100 doi:10.1111/jorc.12139

Creswell J (2014) *Research Design: Qualitative, Quantitative and Mixed Methods Approaches* Sage, London

Creswell J and Poth C (2018) *Qualiatative Enquiry and Research Design: Choosing among five approaches* Sage, London

Da Silva DM, Silva RMCRA, Pereira ER, Ferreira HC, De Alcantara VCG and Da Silva Oliviera F (2018) 'The body marked by the arteriovenous fistula: a phenomenological point of view' *Revista Brasileira de Enfermagem* 71(6) p2869-75 doi:10.1590/0034-7167-2017-0898

Da Silva DM, Gurgel JL, Escudeiro CL and Ferreira HC (2015) ‘Satisfacao dos pacientes com a tecnica de buttonhole / Satisfaccion de los pacientes con la tecnica de buttonhole / Patient satisfaction with the buttonhole technique’ *Cogitare Enfermagem* 20 (3) p482-486

Da Souza AC, Alexandre NMC and Guirardello EB (2017) ‘Psychometric properties in instruments evaluation of reliability and validity’ *Epidemiol Serv Saude* 26(3) 649-659 doi:10.5123/S1679-49742017000300022

Darter B, Rodriguez K and Wilken J (2013) ‘Test–Retest Reliability and Minimum Detectable Change Using the K4b2: Oxygen Consumption, Gait Efficiency, and Heart Rate for Healthy Adults During Submaximal Walking’ *Res Q Exerc Sport* 84(2) p223-31

Deforge R and Shaw J (2012) ‘Back- and fore-grounding ontology: exploring the linkages between critical realism, pragmatism, and methodologies in health & rehabilitation sciences’ *Nursing Inquiry* 19(1) p83-95 doi:10.1111/j.1440-1800.2011.00550.x

Dengu F, Hunter J, Vrakas G and Gilbert J (2021) ‘Haemodialysis reliable outflow graft (HeRo®) in intestinal failure patients with end-stage vascular access’ *Journal of Vascular Access* 22(6) p1021-5 doi:10.1177/1129729820961972

DeVellis F (2012) *Scale Development: Theory and Applications* Sage, London

Duncanson E, Le Leu RK, Shanahan L, Macauley L, Bennett PN, Weichula R, McDonald S, Burke ALJ, Collins KL, Chur-Hansen A and Jesudason S (2021) ‘The prevalence and evidence-based management of needle fear in adults with chronic disease: A scoping review’ *PLoS One* 16(6) e0253048 doi:10.1371/journal.pone.0253048

Dunne C (2011) ‘The place of the literature review in grounded theory research’ *International Journal of Social Research Methodology* 14(2) p111-24 doi:10.1080/13645579.2010.494930

Erguven M (2013) ‘Two approaches to psychometric process: Classical test theory and item response theory’ *Journal of Education* 2(2) 23-30

Eves J, Cai P, Latham R, Leung C, Carradice D, Chetter I & Smith G (2021) ‘A randomised clinical trial of ultrasound guided cannulation of difficult fistulae for dialysis access’ *Journal of Vascular Access* 22(4) p635-41 doi:10.1177/1129729820954725

Field M, Khawaja AZ, Ellis J, Nieto T, Hodson J and Inston N (2019) ‘The vascular access questionnaire: a single centre UK experience’ *BMC Nephrology* 20 (299) doi:10.1186/s12882-019-1493-9

Fielding C, Bramley L, Stalker C, Brand S, Toft S and Buchanan H (2022b) ‘Patients’ experiences of cannulation of arteriovenous access for haemodialysis: A qualitative systematic review’ *Journal of Vascular Access* In Press doi:10.1177/11297298211067630

Fielding C, Glover S and Kumwenda M (2016a) ‘Vascular Access Special Interest Group: a multiprofessional initiative’ *Journal of Kidney Care* 1(3) p150-2 doi:10.12968/jokc.2016.1.3.150

Fielding C, Hadfield A, White K, Waters D, James C, Buchanan H, Fluck RJ and Selby NM (2022a) ‘A narrative systematic review of randomised controlled trials that compare cannulation techniques for haemodialysis’ *Journal of Vascular Access* 23(3) p212-24 doi:10.1177/1129729820983174

Fielding C, Oliver S, Swain A, Gagen A, Kattenhorn S, Waters D, Graham M, Gallagher H, Kumwenda M and Aitken M (2021) ‘Managing Access by Generating Improvements in Cannulation: A national quality improvement project’ *Journal of Vascular Access* 22(3) 450-6 doi:10.1177/1129729820939334

Fielding C, Rhodes C, Chesterton L, Fluck R, Lambe G, Inacay G and Taal M (2016b) ‘Development of a trigger tool to detect harm during haemodialysis’ *Journal of Kidney Care* 1(2) p72-7 doi:10.12968/jokc.2016.1.2.72

Fielding C, Spooner H and Aitken M (2018b) ‘Cannulation of arteriovenous fistulae and grafts for dialysis’ *Journal of Kidney Care* 3(2) p74-83 doi:10.12968/jokc.2018.3.2.74

Fielding C, Stronach L, Roberts E, Lahart C and Brogan R (2018a) ‘Needling recommendations for arteriovenous fistulae and grafts’ *Journal of Kidney Care* 3(6) p378-9 doi:10.12968/jokc.2018.3.6.378

Figueiredo A, Viegas A and Monteiro M (2008) ‘Research into pain perceptions with arteriovenous fistula (AVF) cannulation’ *Journal of Renal Care* 34(4) p169-172 doi:10.1111/j.1755-6686.2008.00041.x

Fischer CT (2009) ‘Bracketing in qualitative research: conceptual and practical matters’ *Psychotherapy Research* 19(4-5) p583-90 doi:10.1080/10503300902798375

Foley G and Timonen V (2015) ‘Using Grounded Theory Method to Capture and Analyze Health Care Experiences’ *Health Services Research* 50(4) p1195-1210 doi:10.1111/1475-6773.12275

Fotheringham J, Barnes T, Dunn L, Lee S, Ariss S, Young T, Walters SJ, Laboi P, Henwood A, Gair R and Wilkie M (2021) ‘A breakthrough series collaborative to increase patient participation with hemodialysis tasks: A stepped wedge cluster randomised controlled trial’ *PLoS One* 16(7) e0253966 doi:10.1371/journal.pone.0253966

Furtado AM and Lima FET (2006) ‘Knowledge of the patients in treatment of hemodialise about arteriovenous fistula’ *Revista da Rede de Enfermagem do Nordeste,* 7(3) p15-25.

Gagen A, Aitken M, Glover S, Kumwenda M and Fielding C (2018) ‘Reflecting on vascular access group project over the last year’ *Journal of Kidney Care* 3(2) 111-2 doi:10.12968/jokc.2018.3.2.111

Geerinck A, Alekna V, Beaudart C, Bautmans I, Cooper C, De Souza Orlandi, Konstantynowicz J, Montero-Errasquin B, Topinkova E, Tsekoura, Reginster JY and Bruyere O (2019) ‘Standard error of measurement and smallest detectable change of the Sarcopenia Quality of Life (SarQoL) questionnaire: An analysis of subjects from 9 validation studies’ *PLoS One* 14(4) e0216065 doi:10.1371/journal.pone.0216065

George A, George P, Masih D, Philip N, Shelly D, Das J and Rajamanickam T (2014) ‘Topical anesthetic versus lidocaine infiltration in arteriovenous fistula cannulation’ *Chrismed Journal of Health and Research* 1(2) p95-8

Giles S (2004) ‘A Phenomenological Investigation into the Life-World of Home Haemodialysis’ *Social Work in Health Care* 38(2) p29-50 doi:10.1300/J010v38n02_02

Glenton C, Carlsen B, Lewin S, Munthe-Kaas H, Colvin CJ, Tuncalp O, Bohren MA, Noyes J, Booth A, Garside R, Rashidian A, Flottorp S and Wainwright M (2018) ‘Applying GRADE-CERQual to qualitative evidence synthesis findings-paper 5: how to assess adequacy of data’ *Implement Science* 13(Supplement 1) 14 doi:10.1186/s13012-017-0692-7

Greenhalgh T, Hinton L, Finaly T, MacFarlane A, Fahy N, Clyde B and Chant A (2019) ‘Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot’ *Health Expectations* 22 p.785-801 doi: 10.1111/hex.12888

Greenwood S, Kingsmore D, Ricarz S, Thomson P, Bouamrane M, Meiklam R, Dunlop M and Stevenson K (2022) ‘ ‘It's about what I'm able to do’: Using the capabilities approach to understand the relationship between quality of life and vascular access in patients with end-stage kidney failure’ *Qualitative Research in Health* 2, 100187 doi:10.1016/j.ssmqr.2022.100187

Grudzinski A, Mendelssohn D, Pierratos A and Nesrallah G (2013) ‘A systematic review of buttonhole cannulation practices and outcomes’ *Seminars in Dialysis* 26(4) p465-475 doi:10.1111/sdi.12116

Hagren B, Pettersen IM, Severinsson E, Lutzen K and Clyne N (2005) ‘Maintenance haemodialysis: patients' experiences of their life situation’ *Journal of Clinical Nursing* 14(3) p294-300 doi:10.1111/j.1365-2702.2004.01036.x

Hagren B, Pettersen IM, Severinsson E, Lutzen K and Clyne N (2001) ‘The haemodialysis machine as a lifeline: experiences of suffering from end-stage renal disease’ *Journal of Advanced Nursing* 34(2) p196-202 doi:10.1046/j.1365-2648.2001.01745.x

Hanson CS, Chapman JR, Craig JC, Harris DC, Kairaitis LK, Nicdao M, Mikaheal M and Tong A (2017) ‘Patient experiences of training and transition to home haemodialysis: A mixed-methods study’ *Nephrology* 22(8) p631-641

Harwood L, Wilson B and Goodman M (2017) ‘Cannulation Outcomes of the Arteriovenous Fistula for Hemodialysis: A Scoping Review’ *Nephrol Nursing Journal* 44(5) p411-425.

Harwood LE, Wilson BM and Oudshoorn A (2016) ‘Improving vascular access outcomes: attributes of arteriovenous fistula cannulation success’ *Clinical Kidney Journal* 9(2) 303-9 doi:10.1093/ckj/sfv158

Hawkins J, Wellsted D, Corps C, Fluck R, Gair R, Hall N, Bushby A, Rider B, Farrington K, Sharma S and van der Veer S (2022) ‘Measuring patients’ experience with renal services in the UK: development and validation of the Kidney PREM’ *Nephrology Dialysis Transplantion* 37 p1507-19 doi:10.1093/ndt/gfac030

Helgeson VS and Zajdel M (2017) ‘Adjusting to Chronic Health Conditions’ *Annual Review Psychology* 68 p545-571 doi: 10.1146/annurev-psych-010416-044014

Herbert J and Brandsma L (2015) ‘Understanding and Enhancing Psychological Acceptance’ In: Lynn S, O'Donohue W and Klillenfield S (Eds) *Health, Happiness, and Well-Being: Better Living Through Psychological Science* Sage Publications, London

Herlin C and Wann-Hansson C (2010) ‘The experience of being 30–45 years of age and depending on haemodialysis treatment: a phenomenological study *Scandinavian Journal of Caring Sciences* 24 p693-9

Hinman R, Dobson F, Takla A, O'Donnell J and Bennell K (2013) ‘Which is the most useful patient-reported outcome in femoroacetabular impingement? Test–retest reliability of six questionnaires’ *British Journal of Sports Medicine* 48 p458-63 doi:10.1136/bjsports-2012-092072

Holloway I and Galvin K (2017) *Qualitative Research in Nursing and Healthcare* Wiley Blackwell, West Sussex

Hunter A, Murphy K, Grealish A, Casey D and Keady J (2011a) 'Navigating the grounded theory terrain. Part 2' *Nurse Researcher* 19(1) p6-11 doi:10.7748/nr2011.10.19.1.6.c8765

Hunter A, Murphy K, Grealish A, Casey D and Keady J (2011b) 'Navigating the grounded theory terrain. Part 1' *Nurse Researcher* 18(4) p6-10 doi:10.7748/nr2011.07.18.4.6.c8636

Information Commissioner's Office (2018) '*UK General Data Protection Regulation'* https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/ - accessed 23/09/2022

Irurita VF (1999) 'The problem of patient vulnerability' *Collegian* 6(1) p10-5 doi:10.1016/s1322-7696(08)60310-8

Jackson T, Pinnock H, Liew SM, Horne E, Ehrlich E, Fulton O, Worth A, Sheikh A and De Simoni A (2020) 'Patient and public involvement in research: from tokenistic box ticking to valued team members' *BMC Med,* 18(79) doi:10.1186/s12916-020-01544-7

Jaensch A, Hill KE and Qunyan X (2019) 'Cannulation in haemodialysis: when the pointy end misses the mark' *Renal Society of Australasia Journal* 15(3) p78-91

Joanna Briggs Institute (2017) *Checklist for Qualitative Research* https://jbi.global/sites/default/files/2019-05/JBI_Critical_Appraisal-Checklist_for_Qualitative_Research2017_0.pdf - accessed 27/08/2023

Kapadi R, Elander J, Burton AE, Taylor J, Coyne E, Selby NM, Taal MW, Mitchell K and Stalker C (2023) 'An exploration of successful psychosocial adjustment to long-term in-centre haemodialysis' *Psychol Health* IN PRESS doi:10.1080/08870446.2023.2231007

Kelly L and Cordeiro M (2020) 'Three principles of pragmatism for research on organizational processes' *Methodological Innovations* 13(2) doi:10.1177/2059799120937242

Kidney Care UK and Renal Association (2019) *Patient Reported Experience of Kidney Care in the UK 2018*. https://ukkidney.org/sites/renal.org/files/PREM-report-2018-final.pdf - accessed 27/08/2023

Kidney Care UK and Renal Association (2018) *Patient Reported Experience of Kidney Care in England and Wales 2017* https://ukkidney.org/sites/renal.org/files/PREM-2017_report-final-2.pdf - accessed 27/08/2023

Kidney Care UK and UK Kidney (2022) *Patient Reported Experience of Kidney Care in the UK 2021* https://ukkidney.org/sites/renal.org/files/PREM%20report%202021.pdf - accessed 26/02/2023

Kidney Care UK and UK Kidney Association (2021) *Patient Reported Experience of Kidney Care in the UK 2020* https://ukkidney.org/sites/renal.org/files/KQuIP/KCUK%20Prem%20report%20leaflet%202020_web.pdf – accessed 27/08/2023

Kidney Care UK and UK Kidney Association (2020) *Patient Reported Experience of Kidney Care in the UK 2019* https://renal.org/sites/renal.org/files/PREM-report-2019-final-web-copy.pdf - accessed 02/04/2021

Kidney Disease Improving Global Outcomes Acute Kidney Injury Working Group (2012) KDIGO Clinical Practice Guideline for Acute Kidney Injury' *Haemodialysis International* 2(1) Supplement 1, p1-138 doi:10.1038/kisup.2012.6

Kidney Disease Improving Global Outcomes Chronic Kidney Disease Working Group (2013) 'KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease' *Haemodialysis International* 3(1) Supplement 1, 1-150

Kishida M, Yamada Y, Inayama E, Kitamura M, Nishino T, Ota K, Shintani A and Ikenoue T (2019) 'Effectiveness of music therapy for alleviating pain during haemodialysis access cannulation for patients undergoing haemodialysis: a multi-facility, single-blind, randomised controlled trial' *Trials* 20(1) 631 doi:10.1186/s13063-019-3773-x

Koo T and Li M (2016) 'A Guideline of Selecting and Reporting Intraclass Correlation Coefficients for Reliability Research' *Journal of Chiropractic Medicine* 15 p155-163 doi:10.1016/j.jcm.2016.02.012

Kosa SD, Bhola C and Lok CE (2016) 'Hemodialysis patients' satisfaction and perspectives on complications associated with vascular access related interventions: are we listening?' *Journal of Vascular Access* 17(4) p313-9 doi:10.5301/jva.5000560

Kosa SD, Bhola C and Lok CE (2015) 'Measuring patient satisfaction with vascular access: vascular access questionnaire development and reliability testing' *Journal of Vascular Access* 16(3) p200-5 doi:10.5301/jva.5000339

Kumbar L, Soi V, Adams E, Brown Deacon C, Zidan M and Yee J (2018) ‘Coronal mode ultrasound guided hemodialysis cannulation: A pilot randomized comparison with standard cannulation technique’ *Hemodial International* 22(1) p23-30 doi:10.1111/hdi.12535

Kuo PY, Saran R, Argentina M, Heung M, Bragg-Gresham J, Krein S, Gillespie BW, Zheng K and Veinot TC (2020) ‘Cramping, crashing, cannulating, and clotting: a qualitative study of patients' definitions of a "bad run" on hemodialysis’ *BMC Nephrology* 21(1) 67 doi:10.1186/s12882-020-01726-8

Lauridsen E & Higginbottom G (2014) ‘The roots and development of constructivist grounded theory’ *Nurse Researcher* 21(5) p8-13

Leech N and Onwuengbuzie A (2007) ‘An Array of Qualitative Data Analysis Tools: A Call for Data Analysis Triangulation’ *Scholl Psychology Quarterly* 22(4) p557-584 doi:10.1037/1045-3830.22.4.557

Lewin S, Booth A, Glenton C, Munthe-Kaas H, Rashidian A, Wainwright M, Bohren MA, Tuncalp O, Colvin CJ, Garside R, Carlsen B, Langlois EV and Noyes J (2018) ‘Applying GRADE-CERQual to qualitative evidence synthesis findings: introduction to the series’ *Implement Science* 13(Supplement 1) 2 doi:10.1186/s13012-017-0688-3

Lima Nogueira FL, de Freitas LR, da Silva Cavacante N and dos Santos Pennfort VP (2016) ‘Perception of patients with chronic kidney disease regarding care towards their hemodialysis access’ *Cogitare Enferm.* 21(3) p1-7

Lin CC, Lee B and Hicks FD (2005) ‘The Phenomenology of Deciding About Hemodialysis Among Taiwanese’ *Western Journal of Nursing Research* 27(7) p915-29 doi:10.1177/0193945905278390

Lok C, Huber T, Lee T, Shenoy S, Yevzlin A, Abreo K, Allon M, Asif A, Astor B, Glickman M, Graham J, Moist L, Rajan D, Roberts C, Vachharajani T and Valentini R (2020) ‘KDOQI clinical practice guideline for vascular access: 2019 update’ *American Journal of Kidney Diseases,* 75 (Supplement 2) pS1-S64

Luehr A (2018) ‘Use of Ultrasound Guidance During Cannulation of Arteriovenous Fistulas’ *Nephrology Nursing Journal* 45(5) p423-434

MacFarland TW and Yates JM (2016) ‘Friedman Twoway Analysis of Variance (ANOVA) by Ranks’ In: MacFarland TW and Yates JM (Eds) ‘*Introduction to Nonparametric Statistics for the Biological Sciences Using R’* Springer International Publishing

Mafara K, Magarey J and Rasmussen P (2016) ‘The lived experience of haemodialysis patients who have had a new arteriovenous fistula cannulated in a satellite unit’ *Renal Society of Australasia's Journal* 12(3) p88-92

Maguire M and Delahunt B (2017) ‘Doing a Thematic Analysis: A Practical, Step-by-Step Guide for Learning and Teaching Scholars’ *All Ireland Journal of Teaching and Learning in Higer Education* 9(3)

Mallios A, Malik J and Jennings W (2022) ‘Endovascular Arteriovenous Fistula Creation—Review of Current Experience’ *Diagnostics* 12(20) doi:10.3390/diagnostics12102447

Malterud K, Siersma VD and Guassora AD (2016) ‘Sample Size in Qualitative Interview Studies: Guided by Information Power’ *Qual Health Res* 26(13) p1753-1760 doi:10.1177/1049732315617444

Memon S, Umrani S and Pathan H (2017) ‘Application Of Constant Comparison Method in Social Sciences: A Useful Technique to Analyze Interviews’ *Grassroots* 51(1) p152-165.

Mendelssohn DC, Malmberg C and Hamandi B (2009) ‘An integrated review of "unplanned" dialysis initiation: reframing the terminology to "suboptimal" initiation’ *BMC Nephrology* 10(22) doi:10.1186/1471-2369-10-22

Mirzaei S, Javadi M, Eftekhari A, Hatami M and Hemayati R (2017) ‘Efficacy of application of eutectic mixture of local anesthetics and lidocaine spray in pain management of arteriovenous fistula cannulation in hemodialysis patients’ *Journal of Renal Injury Prevention* 6(4) p369-74 doi:10.15171/jrip.2017.51

Mohamed H, Ali A, Browne L, O'Connell N, Casserly L, Stack A and Hussein W (2019) ‘Determinants and outcomes of access related blood-stream infections among Irish haemodialysis patients; a cohort study’ *BMC Nephrology* 20(68) doi:10.1186/s12882-019-1253-x

Moher D, Liberati A, Tetzlaff J and Altman DG (2009) ‘Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement’ *British Medical Journal* 339(b2535) doi:10.1136/bmj.b2535

Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Knol DL, Bouter LM and De Vet HC (2010a) ‘The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study’ *Qual Life Res* 19(4) p539-49 doi:10.1007/s11136-010-9606-8

Mokkink LB, Terwee CB, Knol DL, Stratford PW, Alonso J, Patrick DL, Bouter LM and De Vet HC (2010b) ‘The COSMIN checklist for evaluating the methodological quality of studies on measurement properties: a clarification of its content’ *BMC Medical Research Methodology* 10(22) doi:10.1186/1471-2288-10-22

Moore A, Grime J, Campbell P and Richardson J (2012) ‘Troubling stoicism: Sociocultural influences and applications to health and illness behaviour’ Health (London) 17(2) p159-73 doi:10.1177/1363459312451179

Moore C, Majeed-Ariss R, Jayanti A, Mitra S, Skevington S and Wearden A (2018) ‘How an ordeal becomes the norm: A qualitative exploration of experiences of self-cannulation in male home haemodialysis patients’ *British Journal of Health Psychology* 23(3) p544-560

Morse J (2015) ‘Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry’ *Qualitative Health Researcher* 25(9) p1212-22 doi:10.1177/1049732315588501

Morton RL, Tong A, Howard K, Snelling P and Webster AC (2010) ‘The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies’ *British Medical Journal* 340(c112) doi:10.1136/bmj.c112

Mulder M, De Vries J, Op't Hoog J and Buytene S (2013) ‘Validation of a screening instrument for the fear of injection in dialysis patients’ *Journal of Renal Care* 39(4) p214-21 doi:10.1111/j.1755-6686.2013.12039.x

Munn Z, Porritt K, Lockwood C, Aromataris E and Pearson A (2014) ‘Establishing confidence in the output of qualitative research synthesis: the ConQual approach’ *BMC Medical Research Methodology* 14(108) doi:10.1186/1471-2288-14-108

Munthe-Kaas H, Bohren MA, Glenton C, Lewin S, Noyes J, Tuncalp O, Booth A, Garside R, Colvin CJ, Wainwright M, Rashidian A, Flottorp S and Carlsen B (2018) ‘Applying GRADE-CERQual to qualitative evidence synthesis findings-paper 3: how to assess methodological limitations’ *Implement Science* 13(Supplement 1) 9 doi:10.1186/s13012-017-0690-9

Murray MA, Thomas A, Wald R, Marticorena R, Donnelly S and Jeffs L (2016) ‘Are you SURE about your vascular access? Exploring factors influencing vascular access decisions with chronic hemodialysis patients and their nurses’ *CANNT Journal* 26(2) 21-8

Nasa P, Jain R and Juneja D (2021) ‘Delphi Methodology in helathcare research: How to decide its appropriateness’ *World Journal of Methodology* 11(4) p. 116-29 doi: 10.5662/wjm.v11.i4.116

National Institute for Health Research (2018) *Patient and Public Involvement in Health and Social Care Research* *https://www.google.com/url?q=https%3A%2F%2Fwww.rds-london.nihr.ac.uk%2Fwpcms%2Fwp-content%2Fuploads%2F2018%2F10%2FRDS_PPI-Handbook_2018_WEB_VERSION.pdf&sa=D&sntz=1&usg=AOvVaw3ppePlrC0FQeJrBfDVLVnH - accessed 06/09/2022*

Noyes J, Booth A, Lewin S, Carlsen B, Glenton C, Colvin CJ, Garside R, Bohren MA, Rashidian A, Wainwright M, Tunvarsigmaalp O, Chandler J, Flottorp S, Pantoja T, Tucker JD and Munthe-Kaas H (2018) ‘Applying GRADE-CERQual to qualitative evidence synthesis findings-paper 6: how to assess relevance of the data’ *Implement Science* 13(Supplement 1) 4 doi:10.1186/s13012-017-0693-6

Nursing and Midwifery Council (2018) *The Code: Professional Standards of Practice and Behaviour for Nurses, Midwives and Nursing Associates* https://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf - accessed 09/07/2023

O'Brien BC, Harris IB, Beckman TJ, Reed DA and Cook DA (2014) ‘Standards for reporting qualitative research: a synthesis of recommendations’ *Acad Med* 89(9) p1245-51 doi:10.1097/ACM.0000000000000388

O’Cathian A, Croot L, Duncan E, Rousseau N, Sworn K, Turner KM, Yardley L and Hoddincott P (2019) ‘Guidance on how to develop complex interventions to improve health and healthcare’ *BMJ Open* 9(e029954) doi: 10.1136/bmjopen-2019-029954

Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, Shamseer L, Tetzlaff JM, Akl EA, Brennan SE, Chou R. Glanville J, Grimshaw JM, Hrobjartsson A, Lalu MM, Li T, Loder EW, Mayo-Wilson E, McDonald S, McGuinness LA, Stewart LA, Thomas J, Tricco AC, Welch VA, Whiting P and Moher D (2021) ‘The PRISMA 2020 statement: an updated guideline for reporting systematic reviews’ *BMJ* 372(n71) doi:10.1136/bmj.n71

Pandya-Wood R, Barron DS and Elliot, J (2017) ‘A framework for public involvement at the design stage of NHS health and social care research: time to develop ethically conscious standards’ *Research Involvement and Engagement* 3(6) doi:10.1186/s40900-017-0058-y

Parisotto MT, Pelliccia F, Grassmann A and Marcelli D (2017) ‘Elements of dialysis nursing practice associated with successful cannulation: result of an international survey’ *The Journal of Vascular Access* 18(2) p114-9 doi:10.5301/jva.5000617

Pathak EB, Wieten SE and Wheldon CW (2017) ‘Stoic beliefs and health: development and preliminary validation of the Pathak-Wieten Stoicism Ideology Scale’ *BMJ Open* 7(11) e015137 doi:10.1136/bmjopen-2016-015137

Pergolotti A, Rich E and Lock K (2011) ‘The Effect of the Buttonhole Method Vs. the Traditional Method of AV Fistula Cannulation on Hemostasis, Needle Stick Pain, Pre-Needle Stick Anxiety, and Presence Of Aneurysms in Ambulatory Patients On Hemodialysis’ *Nephrology Nursing Journal* 38(4) p333-6.

Phillipi J and Lauderdale J (2018) ‘A Guide to Field Notes for Qualitative Research: Context and Conversation’ *Qualitative Health Research* 28(3) p381-388 doi:10.1177/1049732317697102

Piccoli GB, Bechis F, Pozzato M, Ettari G, Alloatti S, Vischi M, Mezza E, Iacuzzo C, Quaglia M, Burdese M, Anania P, Gai M, Quarello F, Jeantet A and Segoloni GP (2001) ‘Daily Dialysis: Toward a New Standard in Well-Being’ *Hemodialysis international* 5(1) 19-27

Polit DF (2015) ‘Assessing measurement in health: Beyond reliability and validity’ *International Journal of Nursing Studies* 52(11) p1746-53 doi:10.1016/j.ijnurstu.2015.07.002

Pope C and Mays N (1995) ‘Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research’ *British Medical Journal* 311(6996) p42-5 doi:10.1136/bmj.311.6996.42

Quinn RR, Lamping DL, Lok CE, Meyer RA, Hiller JA, Lee J, Richardson EP, Kiss A and Oliver MJ (2008) ‘The Vascular Access Questionnaire: assessing patient-reported views of vascular access’ *Journal of Vascular Access* 9(2) p122-8

Ravanshad Y, Golsorkhi M, Ravanshad S, Azarfar A, Esmaeeli M and Ghodsi A (2021) ‘Analgesia for Pediatric Arterioveous Fistula Cannulation in Hemodialytic Patients: A Comparison of Lidocaine Gel, Lidocaine Spray and Needle Plate’ *Indian Journal of Nephrology* 31(4) p349-52 doi:10.4103/ijn.IJN_151_20

Read H (2019) ‘A typology of empathy and its many moral forms’ *Philosophy Compass* 14 e12623 doi:10.1111/phc3.12623

Ren C, Han X, Huang B, Yuan L, Cao Y and Yang X (2016) ‘Efficacy of buttonhole cannulation (BH) in hemodialysis patients with arteriovenous fistula: A meta-analysis’ *International Journal of Clinical and Experimental Medicine* 9(8) p15363-70

Richard CJ and Engebretson (2010) ‘Negotiating living with an arteriovenous fistula for hemodialysis’ *Nephrol Nursing Journal* 37(4) 363-74

Richarz S, Greenwood S, Kingsmore DB, Thomson PC, Dunlop M, Bouamrane MM, Meiklem R and Stevenson K (2021) ‘Validation of a vascular access specific quality of life measure (VASQoL)’ *Journal of Vascular Access* IN PRESS doi:10.1177/11297298211046746

Romyn A, Rush KL and Hole R (2015) ‘Experiences of Patients on Hemodialysis’ *Nephrology Nursing Journal,* 42(5) p445-54.

Rogers AC (1997) ‘Vulnerability, health and health care’ *Journal of Advanced Nursing* 26(1) p65-72 doi:10.1046/j.1365-2648.1997.1997026065.x

Sahin S, Tokgoz B and Demir G (2021) ‘Effect of Lavender Aromatherapy On Arteriovenous Fistula Puncture Pain and the Level of State and Trait Anxiety in Hemodialysis Patients: A Randomized Controlled Trial’ *Pain Manag Nurs* 22(4) p509-15 doi:10.1016/j.pmn.2021.01.009

Sampson F, O'Cathian A and Goodacre S (2010) ‘Is primary angioplasty an acceptable alternative to thrombolysis? Quantitative and qualitative study of patient and carer satisfaction’ *Health Expectations* 13 p350-8

Sanz Turrado M, Perez LG and Dominguez CC (2017) ‘Factores que influyen en la satisfaccion del paciente de dialisis con enfermeria / Factors influencing the degree of satisfaction of the hemodialysis patient with nursing’ *Enfermeria Nefrologica* 20(1) p66-75

Schmidli J, Widmer MK, Basile C, De Donato G, Gallieni M, Gibbons CP, Haage P, Hamilton G, Hedin U, Kamper L, Lazarides MK, Lindsey B, Mestres G, Pegoraro M, Roy J, Setacci C, Shemesh D, Tordoir JHM, van Loon M, ESVS Guidelines Committee, Kolh P, De Borst GJ, Chakfe N, Debus S, Hinchliffe R, Kakkos S, Koncar I, Lindholt J, Naylor R, Vega de Ceniga M, Vermassen F, Verzini F, ESVS Guidelines Reviewers, Mohaupt M, Ricco JB and Roca-Tey R (2018) ‘Clinical Practice Guidelines of the European Society for Vascular Surgery (ESVS)’ *European Journal of Vascular and Endovascular Surgery* 55(6) p757-818 doi10.1016/j.ejvs.2018.02.001

Schober P, Boer C and Schwarte L (2018) ‘Correlation Coefficients: Appropriate Use and Interpretation’ *Anesthesia and Analgesia* 126(5) p1763-68 doi:10.1213/ANE.0000000000002864

Schoch M, Bennett PN, Currey J and Hutchinson AM (2020) ‘Point-of-care ultrasound use for vascular access assessment and cannulation in hemodialysis: A scoping review’ *Seminars in Dialysis* 33(5) p355-68 doi:10.1111/sdi.12909

Schoch M, Bennett PN, Currey J, Smith V, Orellana L and Hutchinson AM (2022) ‘Point-of-care ultrasound-guided cannulation versus standard cannulation in hemodialysis vascular access: A controlled random order crossover pilot feasibility study’ *Journal of Vascular Access* IN PRESS doi:10.1177/11297298211069821

Sellman D (2005) ‘Towards an understanding of nursing as a response to human vulnerability’ *Nursing Philosophy* 6 p2-10.

Shamseer L, Moher D, Clarke M, Ghersi D, Liberati A, Petticrew M, Shekelle P and Stewart LA (2015) ‘Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation’ *British Medical Journal* 349(g7647) doi:10.1136/bmj.g7647

Shannon-Baker P (2016) ‘Making Paradigms Meaningful in Mixed Methods Research’ *Journal of Mixed Methods Research* 10(4) p319-34 doi:10.1177/1558689815575861

Shotton L, Simpson J and Smith M (2007) ‘The experience of appraisal, coping and adaptive psychosocial adjustment following traumatic brain injury: a qualitative investigation’ *Brain Injury* 21(8) p857-69 doi:10.1080/02699050701481621

Skivington K, Matthews L, Simpson SA, Craig P, Baird J, Blazeby JM, Boyd KA, Craig N, French DP, McIntosh E, Petticrew M, Rycroft-Malone J, White M and Moore L (2021a) ‘A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance’ *BMJ Open* 374:n2061 doi: 10.1136/bmj.n2061

Skivington K, Matthews L, Simpson SA, Craig P, Baird J, Blazeby JM, Boyd KA, Craig N, French DP, McIntosh E, Petticrew M, Rycroft-Malone J, White M and Moore L (2021b) ‘Framework for the development and evaluation of complex interventions: gap analysis, workshop and consultation-informed update’ *NIHR Technology Assessment* 25(57) doi: 10.3310/hta25570

Slattery P,. Saeri AS and Bragge P (2020) ‘Research co-design in health: a rapid overview of reviews’ *Health Research Policy and Systems* 18(17) doi: 10.1186/s12961-020-0528-9

Smith V, Schoch M, Xu Q and Bennett P (2022) ‘The use of haemodialysis plastic cannula in prevalent patients with kidney failure: A feasibility crossover randomised trial study’ *Journal of Renal Care* 48 p.253-61 doi: 10.1111/jorc.12411

Smyth W, Hartig V and Manickam V (2013) ‘Outcomes of buttonhole and rope-ladder cannulation techniques in a tropical renal service’ *Journal of Renal Care* 39(3) p157-65

Snoek FJ, Mollema ED, Heine RJ, Bouter LM and van der Ploeg HM (1997) ‘Development and validation of the diabetes fear of injecting and self-testing questionnaire (D-FISQ): first findings’ *Diabetes Medicine* 14(10) p871-6 doi:10.1002/(SICI)1096-9136(199710)14:10<871::AID-DIA457>3.0.CO;2-Y

Staaf K, Fernstrom A and Uhlin F (2023) ‘How to needle: A mixed methods study on choice of cannulation technique for arteriovenous fistula’ *Journal of Clinical Nursing* 32(15-16) p.4559-4573 doi: 10.1111/jocn.16454

Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, Altman DG, Moher D, Barber R, Denegri S, Entwistle A, Littlejohns P, Morris C, Suleman R, Thomas V and Tysall C (2017) ‘GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research’ *British Medical Journal* 358(j3453) doi:10.1136/bmj.j3453

Synnes O, Oroy AJ, Raheim M, Bachmann L, Ekra EMR, Gjengedal E, Hoie M, Jorgensen E, Michaelsen RKA, Sundal H, Vatne S and Lykkeslet E (2020) ‘Finding ways to carry on: stories of vulnerability in chronic illness’ *Int J Qual Stud Health Well-being* 15(1) doi:10.1080/17482631.2020.1819635

Tan J (2010) ‘Grounded theory in practice: issues and discussion for new qualitative researchers’ *Journal of Documentation* 66(1) p93-112 doi:10.1108/00220411011016380

Tavalok and Derrick R (2011) ‘Making sense of Cronbach’s alpha’ *International Journal of Medical Education* 2 p53-5 doi:10.5116/ijme.4dfb.8dfd

Taylor MJ, Hanson CS, Casey JR, Craig JC, Harris D and Tong A (2016) ‘ "You know your own fistula, it becomes a part of you"--Patient perspectives on vascular access: A semistructured interview study’ *Hemodialysis International* 20(1) p5-14

Terwee C, Bot S, De Boer M, van der Windt D, Knol D, Dekker J, Bouter L and De vet H (2007) ‘Quality criteria were proposed for measurement properties of health status questionnaires’ *Journal of Clinical Epidemiology* 60 p34-42 doi:10.1016/j.jclinepi.2006.03.012

Timonen V, Foley G and Conlon C (2018) ‘Challenges When Using Grounded Theory: A Pragmatic Introduction to Doing GT Research’ *International Journal of Qualitative Methods* 17 1-10 doi:10.1177/1609406918758086

Tong A, Flemming K, McInnes E, Oliver S and Craig J (2012) ‘Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ’ *BMC Medical Research Methodology* 12(181) doi:10.1186/1471-2288-12-181

Tong A, Sainsbury P, Carter SM, Hall B, Harris DC,Walker RG, Hawley CM, Chadban S and Craig JC (2008) ‘Patients’ priorities for health research: focus group study of patients with chronic kidney disease’ *Nephrology Dialysis and Transplantation* 23 p3206-14 doi:10.1093/ndt/gfn207

UK Renal Registry (2022) *UK Renal Registry 24th. Annual Report - Data to 31/12/2020* https://ukkidney.org/audit-research/annual-report - accessed 23/11/2022

US Department of Health and Human Services Food and Drug Administration (2009) *Guidance for Industry Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labelling Claims* https://www.fda.gov/media/77832/download - accessed 27/08/2023

Vaismoradi M, Salsali M and Marck P (2011) ‘Patient Safety: nursing students' perspectives and the role of nursing education to provide safe care’ *International Nursing Review* 58 p434-42 doi:10.1111/j.1466-7657.2011.00882.x

Vaismoradi M, Teila S, Logan P, Khakurel J and Vizcaya-Moreno F (2020) ‘Nurses’ Adherence to Patient Safety Principles: A Systematic Review’ *International Journal of Environmental Research and Public Health* 17(6) 2028 doi:10.3390/ijerph17062028

van Loon MM, Goovaerts T, Kessels AGH, van der Sande FM and Tordoir JHM (2010) ‘Buttonhole needling of haemodialysis arteriovenous fistulae results in less complications and interventions compared to the rope-ladder technique’ *Nephrology, Dialysis, Transplantation* 25(1) p225-30 doi:10.1093/ndt/gfp420

van Loon MM, Kessels AGH, van der Sande FM and Tordoir JHM (2009) ‘Cannulation practice patterns in haemodialysis vascular access: predictors for unsuccessful cannulation’ *Journal of Renal Care* 35(2) p82-9 doi:10.1111/j.1755-6686.2009.00092.x

Wasse H (2022) ‘Vascular Suitability for an Endovascular Arteriovenous Fistula: Getting Beyond the Velvet Rope’ *Kidney360* 3(2) p201-3 doi:10.34067/KID.0008012021

Wells S (2009) ‘Occupational Performance of Mexican Americans with End-Stage-Renal-Disease living on Dialysis in the Lower Rio Grande Valley’ https://digitalcommons.library.tmc.edu/dissertations/AAI3350230/ - accessed 27/08/2023

Welyczko N (2020) ‘Peripheral intravenous cannulation: reducing pain and local complications’ *British Journal of Nursing* 29(8) pS12-S19 doi:10.12968/bjon.2020.29.8.S12

Wener P and Woodgate RL (2013) ‘Use of a qualitative methodological scaffolding process to design robust interprofessional studies’ *Journal of Interprofessional Care* 27 p305-12 doi:10.3109/13561820.2013.763775

White K, Fielding C, Rhodes C, Chesterton L, Fluck R and Taal M (2018) ‘Development of a haemodialysis patient safety index’ 3(2) p96-101 doi:10.12968/jokc.2018.3.2.96

Whitley E and Ball J (2002) ‘Statistics review 6: Nonparametric methods’ *Critical Care* 6(6) p509-13 doi:10.1186/cc1820

Whittaker AA and Albee BJ (1996) ‘Factors influencing patient selection of dialysis treatment modality’ *ANNA Journal* 23(4) p369-77

Whittemore R and Dixon J (2008) ‘Chronic illness: the process of integration’ *Journal of Clinical Nursing,* 17(7B) 177-87 doi:10.1111/j.1365-2702.2007.02244.x

Wilson B and Harwood L (2017) ‘Outcomes for Successful Cannulation of the Arteriovenous Fistula: Perspectives from Patients on Hemodialysis’ *Nephrology Nursing Journal* 44(5) p381-389

Wilson B, Harwood L, Oudshoorn A and Thompson B (2010) ‘The culture of vascular access cannulation among nurses in a chronic hemodialysis unit’ *CANNT Journal* 20(3) p35-42

Wilson Scott K and Howell D (2008) ‘Clarifying Analysis and Interpretation in Grounded Theory: Using a Conditional Relationship Guide and Reflective Coding Matrix’ *International Journal of Qualitative Methods* 7(2) p1-15

Wise M, Schatell D, Klicko K, Burdan A and Showers M (2010) ‘Successful daily home hemodialysis patient-care partner dyads: Benefits outweigh burdens’ *Hemodialysis International* 14(3) p278-88 doi:10.1111/j.1542-4758.2010.00443.x

Wolf J, Niederhauser V, Marshburn D and Lavela S (2014) ‘Defining Patient Experience’ *Patient Experience Journal* 1(1) Article 3

Wong B, Muneer M, Wiebe N, Storie D, Shurraw S, Pannu N, Klarenbach S, Grudzinski A, Nesrallah G and Pauly RP (2014) ‘Buttonhole versus rope-ladder cannulation of arteriovenous fistulas for hemodialysis: a systematic review’ *American Journal of Kidney Diseases* 64(6) p918-36 doi:10.1053/j.ajkd.2014.06.018

Wu L, Buchanan H and van Wijk AJ (2021) ‘Translation and Validation of the Short Form of the Fear of Dental Pain Questionnaire in China’ *Frontiers in Psychology* 12 doi:10.3389/fpsyg.2021.721670

Xi W, Harwood L, Diamant MJ, Brown JB, Gallo K, Sontrop JM, MacNab JJ and Moist LM (2011) ‘Patient attitudes towards the arteriovenous fistula: a qualitative study on vascular access decision making’ *Nephrology, Dialysis, Transplantation* 26(10) p3302-8 doi:10.1093/ndt/gfr055

Yildiz A and Sahan S (2022) ‘Effect of aromatherapy on the pain of arteriovenous fistula puncture in patients on hemodialysis: a systematic review’ *Journal of Health Research* 36(6) p1187-97 doi:10.1108/JHR-05-2021-0280

Yodchai K, Dunning T, Savage S, Hutchinson AM and Oumtanee A (2014) ‘How do Thai patients receiving haemodialysis cope with pain?’ *Journal of Renal Care* 40(3) p205-15

8 Appendices

8.1 Appendix 1: Data Extraction form for Systematic Review in Chapter 2

Data Extractor:

Study Name (electronic document name):

Is the study population (please indicate one for each row):

Haemodialysis patient only	Mixture of haemodialysis and non-haemodialysis patients	Not specified

In-centre haemodialysis patients only	Home haemodialysis patients only	Mixture of home haemodialysis and in-centre haemodialysis patients	Not specified

Adults only (18 years and older)	Mixture of adults and children under 18 years old	Not specified

In what country is the study set?

What is the sample size used in the study?

Did they achieve saturation / include justification and discussion of sample size that is commensurate with methodological underpinnings?

Y / N / Not stated

Please provide any description of baseline demographic data of the study population (if ‘not stated’, please state this):

Demographic	Data
Gender	
Age	
Ethnic Background	
Chronic Kidney Disease Stage	
Renal Replacement (RRT) modality RRT includes transplantation. For pre-RRT, please classify as ‘none’.	
Dialysis Vintage	
Vascular access type	
Vascular access age	
Co-morbidities	
Cannulation Technique	
Other:	
Other:	
Other:	
Other:	
Other:	

Is any further textual description provided of the study population?

What is the Phenomena of Interest being study?

Does the study clarify (Please indicate all relevant):

a) The cannulation technique participants experienced:

Buttonhole	Rope Ladder	Area Puncture	None specified

b) Who the cannulation technique is performed by:

Registered nurses	Unregistered nursing staff	All nursing staff	Patient	Carer	Not specified

Does it provide any further description of the cannulation? Y / N

If so, please describe the detail provided.

What type of study is it?

Qualitative	Mixed Methods	Other: (Please specify)

What is the qualitative methodology used (e.g. phenonmenology, ethnography)?

What methods were used to collect the data (e.g. focus groups, interviews)? Please describe how these were administered (e.g. via telephone, face-to-face).

What methodological perspective & / or methods were used to analyse data?

Research Findings

Please state each research theme, sub-theme or finding verbatim as identified by the research. Include the theme as well as sub-theme, when inserting sub0themes into the findings column. Add any verbatim quotes from the text of the article that help explain the theme / sub-theme / finding, in the Qualifying Text Column. Provide 1-3 verbatim illustrations of patient quotes used to demonstrate each theme / sub-theme / finding. If more than 1-3 illustrations are available then choose the most relevant / best illustrations. Please add more rows to the table as required. Do not extract illustrations that are obviously not related to cannulation of AV fistulae or grafts.

Finding	Qualifying Text	Illustration

Did they develop any theory from the themes identified?   Y / N

If so, please describe the theory or if demonstrated pictorially, refer to image / copy image and provide any further description.

Please describe any further conclusions described by the study. Please leave blank if all conclusions are outlined previously.

Were there any limitations to the study, that were:

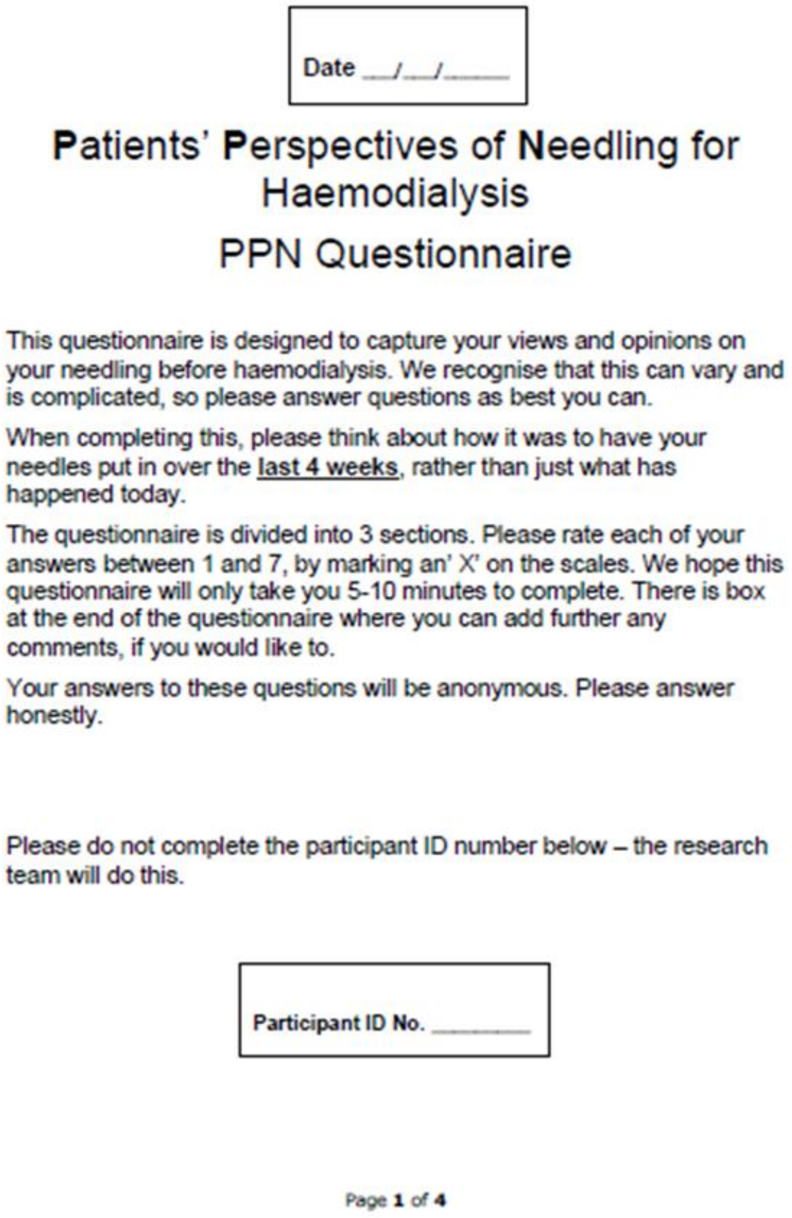
a) Stated by the article?

b) Not stated, but you detected?

Was anything of further note within the study?

8.2 Appendix 2: Final Patients' Perspective of Needling Questionnaire

This is inserted as images to preserve the formatting of the questionnaire.



Date __/__/____

Patients' Perspectives of Needling for Haemodialysis

PPN Questionnaire

This questionnaire is designed to capture your views and opinions on your needling before haemodialysis. We recognise that this can vary and is complicated, so please answer questions as best you can.

When completing this, please think about how it was to have your needles put in over the **last 4 weeks**, rather than just what has happened today.

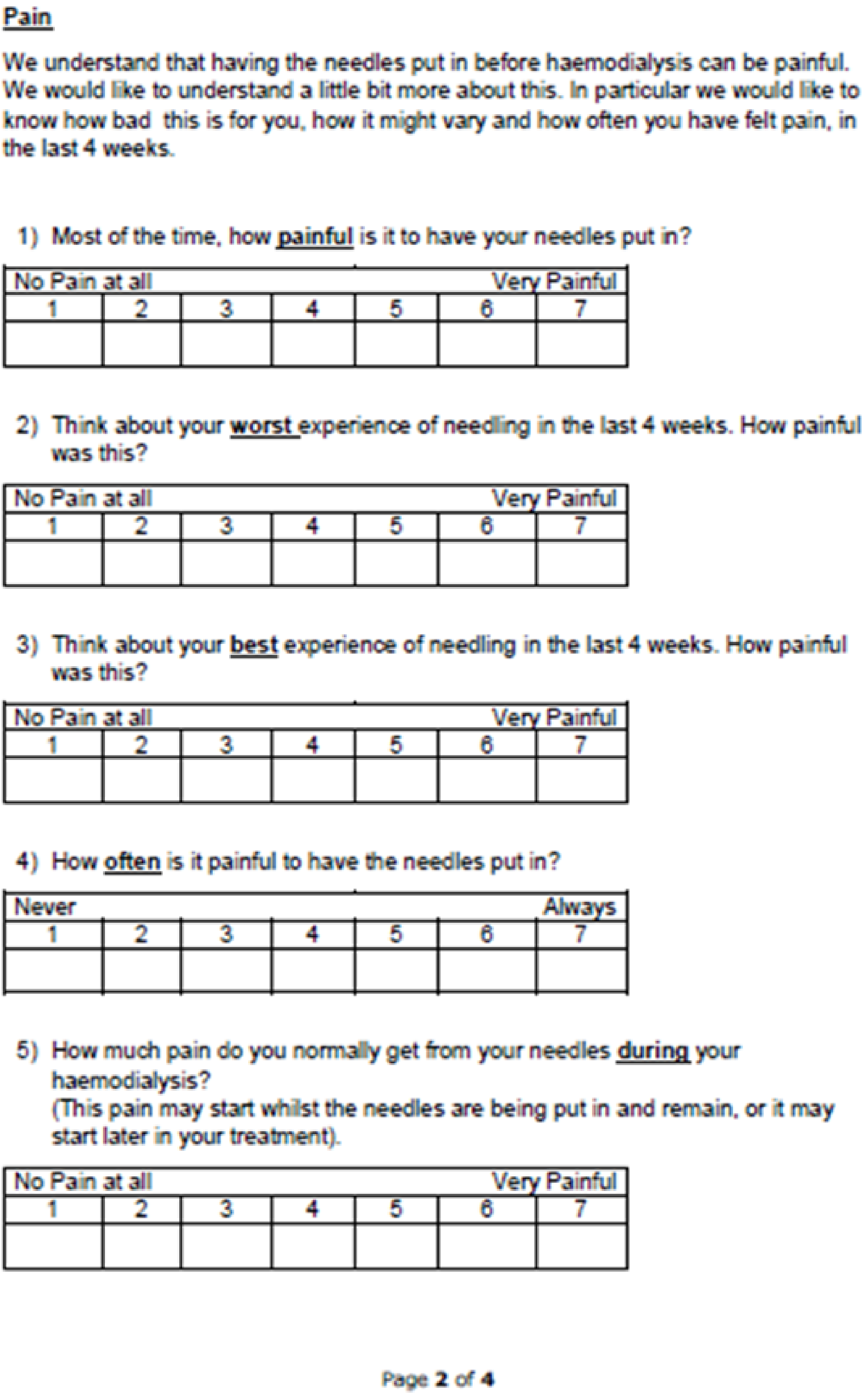
The questionnaire is divided into 3 sections. Please rate each of your answers between 1 and 7, by marking an' X' on the scales. We hope this questionnaire will only take you 5-10 minutes to complete. There is box at the end of the questionnaire where you can add further any comments, if you would like to.

Your answers to these questions will be anonymous. Please answer honestly.

Please do not complete the participant ID number below – the research team will do this.

Participant ID No. ________

Page **1** of **4**



Pain

We understand that having the needles put in before haemodialysis can be painful. We would like to understand a little bit more about this. In particular we would like to know how bad this is for you, how it might vary and how often you have felt pain, in the last 4 weeks.

1) Most of the time, how **painful** is it to have your needles put in?

No Pain at all						Very Painful
1	2	3	4	5	6	7

2) Think about your **worst** experience of needling in the last 4 weeks. How painful was this?

No Pain at all						Very Painful
1	2	3	4	5	6	7

3) Think about your **best** experience of needling in the last 4 weeks. How painful was this?

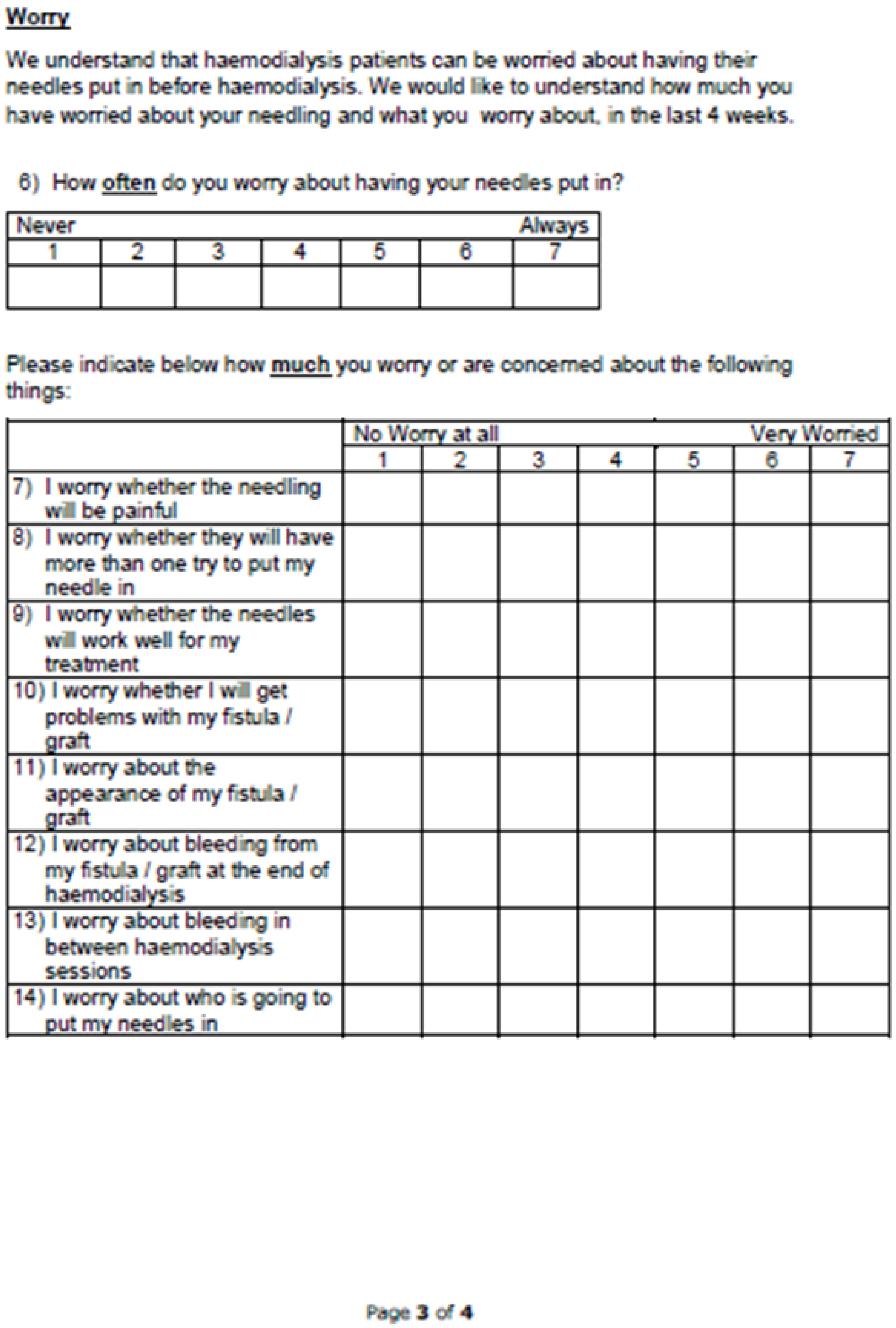
No Pain at all						Very Painful
1	2	3	4	5	6	7

4) How **often** is it painful to have the needles put in?

Never						Always
1	2	3	4	5	6	7

5) How much pain do you normally get from your needles **during** your haemodialysis?
(This pain may start whilst the needles are being put in and remain, or it may start later in your treatment).

No Pain at all						Very Painful
1	2	3	4	5	6	7



Worry

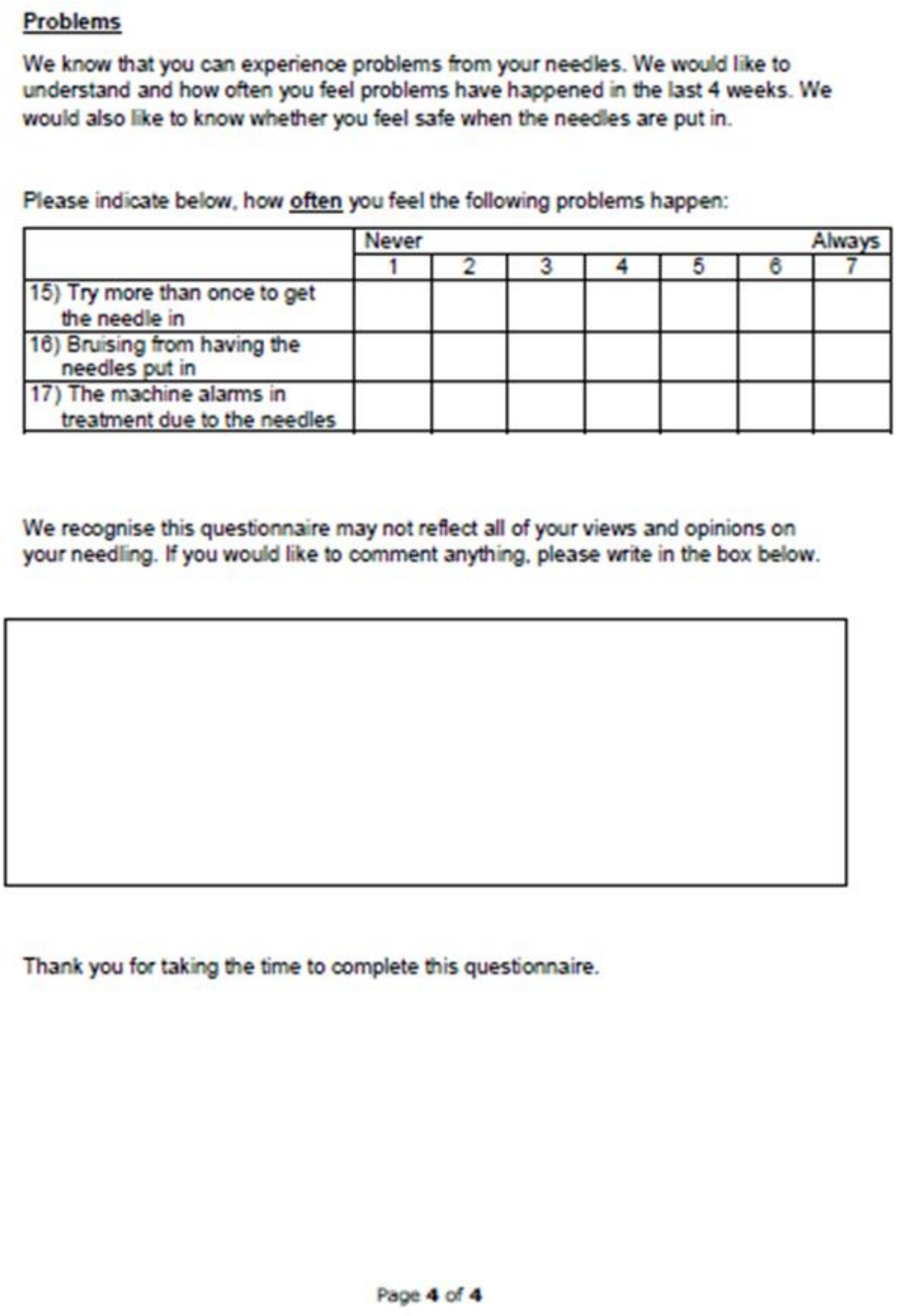
We understand that haemodialysis patients can be worried about having their needles put in before haemodialysis. We would like to understand how much you have worried about your needling and what you worry about, in the last 4 weeks.

6) How **often** do you worry about having your needles put in?

Never						Always
1	2	3	4	5	6	7

Please indicate below how **much** you worry or are concerned about the following things:

	No Worry at all						Very Worried
	1	2	3	4	5	6	7
7) I worry whether the needling will be painful							
8) I worry whether they will have more than one try to put my needle in							
9) I worry whether the needles will work well for my treatment							
10) I worry whether I will get problems with my fistula / graft							
11) I worry about the appearance of my fistula / graft							
12) I worry about bleeding from my fistula / graft at the end of haemodialysis							
13) I worry about bleeding in between haemodialysis sessions							
14) I worry about who is going to put my needles in							



Problems

We know that you can experience problems from your needles. We would like to understand and how often you feel problems have happened in the last 4 weeks. We would also like to know whether you feel safe when the needles are put in.

Please indicate below, how **often** you feel the following problems happen:

	Never						Always
	1	2	3	4	5	6	7
15) Try more than once to get the needle in							
16) Bruising from having the needles put in							
17) The machine alarms in treatment due to the needles							

We recognise this questionnaire may not reflect all of your views and opinions on your needling. If you would like to comment anything, please write in the box below.

Thank you for taking the time to complete this questionnaire.

8.3 Appendix 3: Initial Interview Questions for ICE-HD

Prior to the interview

- Check the participant is still happy to proceed with the interview and explain:
    - It will be likely be 60-90 minutes long, but it can be longer or shorter if needed.
    - The interview is confidential, but I may need to disclose any information which shows you are putting themselves or others at risk e.g. intent to murder / commit suicide.
    - I cannot be over-heard, as I am in a private office.
    - The interview can be paused or stopped at anytime, if you feel tired or upset. If needed we can also re-start on another day.
    - The interview will be recorded.
    - Once the interview is finished, you may not be able to withdraw consent for use of the information collected – we may still use this information in the study.
    - The interview transcript may be seen by others, but they will not know your identity.
- I am going to ask you questions and then plan to talk very little whilst you share your views and opinions. I will not share my own opinions or thoughts, as I am solely here to get their thoughts and opinions. I

will not judge any of their thoughts or opinions and will not become unhappy if you make comments that are about mine or another staff member's ability.

- If is there is anything you are not sure of or you do not understand, please let me know and I can explain further.
- At times, it may feel like you are repeating yourself. Please do not worry about this.
- If you mention others, including other patients or staff, try to avoid using their name, but you can use their role e.g nurse, haemodialysis patient.
- I will let you know when I am going to start and stop the recording, but please feel free to check if you're unsure.

Section 1: Your experience of cannulation

1) *We are going to start the interview by talking about the needle insertion at the start of your haemodialysis treatments. Do you understand what I mean by needle insertion?* (Find out what terms works for them and use that throughout the interview – needling has been used consistently throughout but can be replaced by whatever term the patient uses).

2) *I wanted to hear about your needling at start of haemodialysis and what it is like for you. Can you tell me a bit about this?*

If the interviewee responds with mono-syllabic answers / struggles with this, probing questions can be used to draw this out, if needed:

- In your opinion, what is good or bad about your needling?
- In your opinion (do not repeat if already stated), what do you like / not like about your needling?
- How do you feel about your needling? How does it make you feel?
- Some people find it easiest to start at the beginning and talk it thought to the end, so I wondered if you could describe your needling starting from the beginning (questions can then be asked about how they felt at key point)?

The interviewee will also be asked to expand on points raised in response to these questions.

3) *Some people talk about having problems with their needling. I wondered if you've had any problems with your needling recently?*

If the interviewee responds with mono-syllabic answers / struggles with this, examples of problems getting the needles in at the start of treatment , like some people experiencing bruising or pain from the needles, can be used.

How about in the past / in the beginning / at the start of being cannulated – did you have any problems then? Have you ever had any problems with your needling?

If you have had problems:

- Could you describe these to me? / Can you explain what happens?
- Did the problems happen recently or a long time ago?
- Did the problems only happen once or do they happen regularly? Does it come and go? Is it common? Are you still getting problems now?
- How did they make you feel?
- Was there any reason why you thought you go these problems? Did anything change to make this better?
- Does anything make this better / prevent this happening again?

If you've not had problems, is there any reason why you think you've not had problems?

- Is there something about your access that means you don't get problems?
- Do things always go smoothly or do you get hiccups but don't see it as problems / cope with it / manage it?

- Is there anything else that you think helps prevent problems with your needling?

4) *Some people have told us that needling varies from session to session and over longer periods of time. From your perspective is the needling always the same or does it change?*

If it changes:

- How does it change?
- Does it change over short periods or longer periods?
    - E.g. day-to-day, week-to-week, month-to-month or year-to year?
- What changes about the needling? What is different about it? Does it get better or worse?
- Is it now better or worse than it was in the past?
- Is there any reason why you think it changes?
- How does it make you feel to have it vary / change?

If it does not change, is there anything that keeps it consistent / the same?

- Is what makes it consistent, good or bad, in your opinion (i.e. is it consistently good or consistently bad)?

- Do you think there is any reason why it is consistent with you?
- How do you feel about it being consistent?

Section 2: What influences your experience of cannulation

5) *Is there anything you can think of that makes a difference about how you feel about your needling?*

If so:

- What makes it feel good or bad?
- What makes it different?

The interviewer can explore concepts that have previously been mentioned by the interviewee. For example, if the interviewee has raised pain previously, the interviewer may ask what makes it more or less painful, here or earlier in the interview. This may also lead to the specific questions in the remainder of this section.

6) *Some people say they worry about having their needles put in for haemodialysis. However, we are not sure if the applies to everyone. Do you feel relaxed or worried when the needles are put in?*

Probing questions can be used to draw this out, if needed:

- Do you ever worry about whether the needles will go in OK or do you always feel relaxed about this?

- Is there anything that makes you worry about your needling?
- Is there anything that makes you feel relaxed about your needling?
- Does how much you worry or feel relaxed vary between different days / sessions / needling(s)?
    - What then makes you feel more or less relaxed on different days?

If you feel relaxed:

- What (helps) makes you feel relaxed?
- Do you always feel relaxed or does it vary?
- Is there anything that makes you feel more or less relaxed?
- Is there anything that you feel helps you to stay relaxed?
- Do you think being relaxed makes a difference to your needling?

If you feel worried:

- What are you worried about?
- Are you always worried about your needling or does it vary?
- Is there anything that makes you feel more or less worried?
- Do you think worrying makes a difference to your needling?

7) *I would like to ask about how safe you feel during the needle insertion. What sort of things make you feel safe or unsafe during the needle insertion procedure?*

- Is there anything that makes you feel like everything will be OK?
- Is there anything that makes you feel scared or fearful?

Probing questions can be used to draw this out, if needed:

- What might make you feel more or less safe?
    - Does it vary day to day, with how you feel?
- Is there anything that makes you feel more or less safe?
- Do you always feel safe / unsafe or does it vary?
- Is there anything that makes feeling safe / unsafe vary?
    - Is there anything that makes it better or worse?
- Does feeling safe / unsafe make a difference to your needling?

8) *I now would like to hear about whether you feel protected / looked after or vulnerable during the needling and what helps you feel this way.* ('Looked after' can be used as an alternative to protected if the interviewee feels more comfortable with this term. If the interviewee struggles with the term vulnerable, the interviewer can explain it is

about feeling ‘exposed’ or ‘under threat’ and that this is often about whether they feel ‘at risk’.)

What makes you feel protected or vulnerable during the needle insertion procedure?

- Is there anything that makes you feel protected / looked after / cared for during the needle insertion?
- Is there anything that makes you feel vulnerable / exposed / at risk of harm?
- Do you always feel protected or vulnerable or does it vary?
- Is there anything that makes feeling vulnerable / protected vary?
    - Is there anything that makes it better or worse?
- Does feeling protected or vulnerable make a difference to your needling?

9) *Some people have stated it is important for them to feel in control of their needling. (*If required examples can be given, like inserting their own needles, having information about their needling, knowing where they are going to put the needles or who puts the needles in).
What does it mean to you to be in control of your needling?

Is it important for you to feel in control during the needling or do you like to release control of this to rely on someone else?

Probing questions can be used to draw this out, if needed:

- Do you feel you are given the opportunity to be part of the needling process? How does this make you feel?
- Do you like to be involved in decisions about your needling or do you leave this to the person inserting the needles? How does this make you feel?
- Do you feel you get the information you need about your needling or do you feel like you need more information?
    - How about at the very beginning when you started needling?
- Are there any barriers to you having the control you want over your needling?
- Is there anything that helps you to be in control of your needling?
- Can you describe any times when you have felt in control / out of control of your needling? How did this make you feel?
- Does how much control you are given vary or is it consistent? If so, what causes this to vary?

10) *Some people have said that the person putting the needles in can make a difference to how they feel about needling. Does the person inserting the needles make a difference to how you feel about the needling?*

   Is it always the same staff members that out your needles in or do lots of different people do this?

   Does this make a difference to how you feel about your needling?

Probing questions can be used to draw this out, if needed:

- Does the person inserting the needles do anything to make you feel better / worse about your needling?
- Is there any person you like putting your needles in?
    - If so what do they do, say or how do they behave to make you feel like this?
    - Can you describe how they put your needles in?
- Is there any person you do not like putting your needles in?
    - If so, what do they do, say or how do they behave to make you feel like this?
    - Can you describe how they put your needles in?
- Do all the people who put you needles in treat you the same and do the needle insertion the same or does it vary?

    - How does this make you feel?

11) *Do you feel there is anything about you or your access that makes you feel the needling easier or harder?*

Probing questions can be used to draw this out, if needed:

- Do you feel your fistula / graft is good or has problems that make needling better or worse?
- Has your fistula or graft changed to make needling better or worse?
- Does how you feel emotionally before the needling make a difference to your needling? If so, does vary on different days / sessions / needling?

12) *I would now like to ask you about your needling technique. Do you know if you use buttonhole or rope ladder technique?* (If required, an explanation can be provided that talks about how buttonhole cannulation goes into the same site each time, whilst rope ladder goes into a different site each time. For the purposes of the interviews, area puncture is considered the same as rope ladder.)

    Have you experienced any other techniques?

    Some people say it makes a difference to them which technique they use. How do you feel about this?

- Do you feel like you get lots of problems due to your cannulation technique or is it relatively problem free?
    - If you do get problems, what are these problems and what is the impact on how you feel about your cannulation?
- Is there anything about your technique that you feel makes your needle insertion better? If so, what is this?

13) *How do you feel when changes are made to your needling?* (If required further examples of this can be given which can include changing the sites where the needles go, using a new access, having a different team of nurses look after you, changes to the needle size, changes to the blood flow rate or any other changes to the needling or how it is used for haemodialysis).

- Have you experienced any changes to your needling?
    - If so, what were these?
    - How did they make you feel?
- Are there any other changes that may make a difference to how you feel about your needling?

14) *Is there anything else that affects how you feel about your needling?*

Section 3: What could improve your cannulation?

These questions may occur earlier in the interview as concepts are uncovered. However, it is also important these questions are covered even if these concepts have emerged previously. These questions also bring the interview to a close and becoming more positive, focussing on what can make needling better rather than what the problems are. Therefore, the interviewer will ask these questions at the end, but can also summarise and signpost to earlier content in the interview and adapt to allow this.

15) *Is there anything (else) that you think could make needling better?*

Probing questions could include, if required:

- Is there anything that would make you worry less?
- Is there anything that would make you feel safer?
- Is there anything that would make you feel less vulnerable?
- Is there anything that would make you feel more in control?

This question could link to issues they have raised earlier, asking the interviewee what might improve issues raised.

16) *Is there anything (else) you would like to change about your needling or anything good practice you'd like to highlight is helpful to you when going through needling?* This can be realistic or unrealistic

17) *The interview is now coming to a close. Is there anything else you would like to say about your cannulation / needle insertion?*

18) *Do you have any further questions or comments before we finish the interview?*

Thank you so much for your time. We will be in touch with a summary of the interview for you to review and check for accuracy. When would it suit you to do this?

Once the Interview has finished

1) Arrange time to do summary check – where to send document and when to discuss
2) Voucher – which one the interviewee wants and where to send it

8.4 Appendix 4: Changes made to Interview Questions in ICE-HD

8.4.1 Changes made after 16 interviews

Following the first 16 interviews, questions around safety, vulnerability and the AV fistula / graft (Qu 7, 8 and 11 in the initial interview guide) were removed as participants did not understand or relate to these questions. Question 13 in the initial interview guide, asking about changes made to their needling, was merged with Question 4 (in both interview guides) as participants had found the two separate questions repetitive. Minor edits were made to existing questions to reflect what worked and did not work in interviews (these changes have not been recorded). The order of questions was also altered to reflect the expected flow of the interview. The altered and added questions are shown below:

Question 5 (new question)

Do you feel the needling affects your haemodialysis at all or does it make no difference to it?

If it does make a difference:

- How does it affect your haemodialysis? What difference does it make?
- Does it always make a difference or does this vary?
- Has this changed over time?
- How does this make you feel:
    a. About your haemodialysis?

b. About your needling?

If does not make a difference:

- Does the needling make any difference to how you feel about your haemodialysis or does it make no difference what so ever?
- How do you feel the needling is separate / distinct / independent to the haemodialysis?

Question 6 (new question)

I was wondering if you can remember how prepared you felt for needling when you first had it. Did this make a difference to how you felt about your needling at the time?

Does this make a difference to how you feel about your needling now?

Probing questions to draw this out could include:

- Can you remember how your very first needle insertion felt?
- Do you think you were ready for needling when it first happened? How did this make you feel?
- Did you know what to expect for your first needling? How did this make you feel?
- Did you receive any information about your needling before it happened? How did this make you feel?

- Is there anything that could have made you feel better prepared for needling or do you think you had everything you needed / that could be done?
- Did you first needle insertion coincide with your first haemodialysis session? Do you feel this made a difference to how you felt?

Question 8 (new question)

Some people say that they find the needling painful. I wondered whether you find the needling painful or not?

If it is painful:

- Could you describe to me what the pain is like?
- Has it always been like this or has this changed over time?
- How does the pain make you feel?
- Have you noticed whether anything makes it more or less painful?
- How does that make you feel about your needling?

If it is not painful:

- Is there anything that you think makes it not painful?
- Has it always been like this or has it changed over time?
- Is always not painful or can it be painful sometimes?
- How does that make you feel about your needling?

Question 10 (new question)

Some people say that the people around them can make a difference to how they feel about their needling. Do / Would other people being around you during the needling make a difference to your needling, or do they make no difference?

Probing questions to draw this out can include:

- Do you have other patients around you / in the same area as you during the needling? How does this make you feel?
- Does anyone sit with you during the needling? How does that make you feel?
- Do other people make a difference to how you feel about your needling?
- Do you feel other people make needling easier or harder or make no difference? What is it that other people do to make it better / worse / different?

Question 11 (new question)

Some people have said that the environment can make a difference to how they feel about their needling. Does the environment or the atmosphere around you during your needling make a difference to you or not?

Probing questions can be used to draw this out, if needed:

- Does where the needling happens make a difference to you?

- Does the atmosphere on the unit affect your needling at all? If so, how does it make a difference?

- Do you dialyse on a large or small unit? Does this make a difference to how you feel about your needling?

- Is there anything you like or don’t like on the unit that makes a difference to your needling?

Question 14 (was Question 12) – extra text and questions added

‘*I would now like to ask you about buttonhole and rope ladder needling. Do you know which technique you have?*

At this point the interviewer will check understanding with the interviewee about what buttonhole and rope ladder means to them and provide an explanation where needed.

- Buttonhole goes into the same site each time. They normally remove the scab from the previous needling before inserting the needle. They develop a track using sharp needles and then move you over onto blunt or dull needles.
- Rope ladder goes into a different site each time and the needle sites move up (and sometimes down) your arm. Needles sites are meant to cover as much of fistula / graft as possible. (For the purposes of the interviews, area puncture is considered the same as rope ladder.)

Some people say it makes a difference to them which technique they use. Does this make a difference to you?

Probing questions can be used to find out about their opinions on their technique and the one they do not use (*= alter question according to which technique they use):

- How does it feel to be needled in the same place / different place* each time?
    - How would you feel if you were needled in the same place / different place* each time?
- Does using dull / sharp needles* make any difference to how you feel about your needling?
    - How would you feel if they started using dull / sharp needles* on your fistula?
- Review explanation of their technique*
    - Is there anything you like / dislike about your needling technique?
- Review explanation of other technique*
    - Is there anything you like or do not like about the idea of the other technique?
- How do you feel about the appearance of your fistula?

Question 17 and 18 (was Question 16, now split into two questions)

17) *Is there anything (else) that you think could make needling better for you?*

This question could link to issues they have raised earlier, asking the interviewee what might improve issues raised.

18) *Is there anything (else) you would like to change about your needling? This can be realistic or unrealistic.*

There were also emerging concepts that were difficult to ask participants about in direct questions, but through theoretical sensitivity detected the appearance of these concepts and then explored these further. These concepts were:

- Empathy from the person inserting the needle
- Being treated with humanity and as an individual
- The unpredictability of needling
- Acceptance of the procedure

8.4.2 Changes made of 21 interviews

This was a minor change to the interviewing guide to reflect one further emerging concepts. This added one further question, which became question 6:

‘Some people have mentioned that the frequency of needling for haemodialysis alters how they feel about their needling. I wondered how you feel about having the needling X (insert how often they dialyse) times a week?

Probing questions to draw this out can include:

- What difference do you think the frequency of your needling makes or does it make no difference at all?
- Do you think having the needling this frequently (x times a week) makes a difference to your needling or how you feel about it?
- If it was only a one-off procedure or less frequent, would you feel differently about your needling?
- If you're needling was more frequent (e.g. every day), would this change how you felt about it?
- Does anything make the frequency of needling easier or harder to manage?'

One further concept was added to explore further without a direct extra question, but to use theoretical sensitivity to identify when it appeared and then probe deeper into its meaning. This was stoicism.

8.5 Appendix 5: Categories, Sub-Categories and Case generated by ICE-HD

Category 1: Trying to make cannulation more comfortable

- Code 1: Cannulation is unpleasant and will never be nice
- Code 2: Avoiding cannulation
- Sub-Category 1: Familiarity makes cannulation less alien
    - Code 1: Cannulation is an alien procedure that is invasive
    - Code 2: Stepping into the unknown – starting cannulation
- Sub-Category 2: Avoiding or minimising pain from cannulation
    - Code 1: Cannulation is painful
    - Code 2: Pain from cannulation varies
- Sub-Category 3: Making cannulation more predictable: Getting the needles in easily
    - Code 1; Cannulation is unpredictable
    - Code 2: Problems getting the needles in the right place
    - Code 3: Unpredictability varies with the quality of the access and cannulator
    - Code 4: Developing a strategy to cannulate me successfully
    - Code 5: Wanting no changes to cannulation to avoid problems
- Sub-Category 4: Reducing anxiety about cannulation
    - Code 1: Anxiety about cannulation
    - Code 2: Anxiety makes cannulation more unpleasant and unpredictable, which makes me more anxious
    - Code 3: Trying to relax during cannulation

        - Code 4: Distracting yourself from cannulation
        - Code 5: Relief the cannulation has gone OK

Category 2: Preserving humanity and individuality during cannulation

    - Sub-Category 1: Empathy: Being understood and not being alone through cannulation
        - Code 1: Empathy from the cannulator makes cannulation easier
        - Code 2: Peer support from other patients and family
        - Code 3: Cannulation is challenging for the cannulator too: Patients' empathise with the cannulator
    - Sub-Category 2: Trusting the cannulator
        - Code 1: Loosing confidence in the cannulator
        - Code 2: I don't have the expertise to cannulate myself, so I trust the cannulators

Category 3: The necessity of cannulation for haemodialysis forces coping

    - Code 1: Cannulation is repetitive and can feel endless
- Sub-Category 1: Stoicism gets me through unpleasant but necessary cannulation
- Sub-Category 2: Acceptance of an unpleasant and unpredictable, but necessary procedure
    - Code 1: Feeling positive about cannulation because I'm grateful to receive my treatment
- Sub-Category 3: Being able to contribute to cannulation helps me cope