

‘Pinholes in My Arms’: The Vicious Cycle of Vascular Access

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DECLARATION

I hereby declare that the work presented in this thesis has not been submitted for any other degree or professional qualification, and that it is the result of my own independent work.

ABSTRACT

BACKGROUND: Vascular Access Devices (VAD) are essential for the delivery of intravenous therapies. As patients often live with these devices in place for many months, it is important to understand how patients **with cancer** make sense of living with these devices.

AIM: To explore, in-depth, the lived experience of patients with a Vascular Access Device (VAD).

DESIGN / METHODS: **This study followed a qualitative approach using Interpretive Phenomenological Analysis (IPA) principles.** A purposive sampling technique was used to identify eleven patients **with cancer** who had a vascular access device in situ and were willing to share their experiences. Semi-structured interviews were the data collection tool. Interviews were digitally recorded, transcribed, and analysed using **IPA principles.**

FINDINGS: Four superordinate themes emerged from the interview data: The self under attack; Being rescued / Being robbed; Protection of self / Protection of others; and Bewilderment and dismay at the lack of staff competence. The study discovered that the insertion of a long-term VAD changes the self and affects the psychological, social, and personal self and impacts on self-esteem and self-image. The insertion of a VAD results in restrictions and limitations to life and can lead to living with distrust and fear. Despite this, VADs are accepted and are eventually embodied. These findings add to existing knowledge by developing the meaning of living with a VAD. To illuminate this understanding and articulate

the new knowledge, a conceptual framework entitled the *Vicious Cycle of Vascular Access* was developed.

DISCUSSION: When the decision is made to insert a long-term VAD, both the body and mind should be considered. Steps should be taken to improve the lives of people living with a VAD through improved education and training for Health Care Professionals and by increasing support for people with VAD.

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LIST OF ABBREVIATIONS

BMI	Body Mass Index
CAVA	Cancer and Venous Access
CDT	Cognitive Dissonance Theory
CINHAL	Cumulative Index of Nursing and Allied Health Literature
CLABSI	Central Line Associated Bloodstream Infection
CRBSI	Catheter-Related Bloodstream Infection
CT	Computerised Tomography
CVAD	Central Venous Access Device
CVC	Central Venous Catheter
DIVA	Difficult Intravenous Access
DOH	Department of Health
FoR	Fear of Return
HAI	Healthcare-Associated Infection
HPS	Health Protection Scotland
INS	Infusion Nurses Society
IPA	Interpretive Phenomenological Analysis
IR	Interventional Radiology
PICC	Peripherally Inserted Central Catheter
PIVC	Peripherally Inserted Vascular Access Device
PTSD	Post-Traumatic Stress Disorder
PSI	Pound-force per Square Inch
QOL	Quality of life
RCN	Royal College of Nursing
TCVC	Tunnelled Central Venous Catheter
TIVAD	Totally Implanted Vascular Access Device
UK	United Kingdom
VAD	Vascular Access Device
VHP	Vessel Health and Preservation
WHO	World Health Organisation

CHAPTER ONE: INTRODUCTION

1.1: CONTEXT AND BACKGROUND FOR THE RESEARCH

The insertion of ‘tubes’ to deliver medications has been amongst the most prominent revolutions in healthcare since the discovery of the circulatory system in the fifteenth century (Rivera *et al.*, 2005). Since then, there have been rapid advancements in techniques, technologies, and methods of intravenous (IV) access and therapy. IV therapy has continued to evolve into the twentieth century, particularly in the fields of blood transfusion, saline solutions, and nutritional support (Greenwalt, 2005; Stansbury and Hess, 2010). Such transfusions soon became widely accepted into practice and, as the field of IV therapy developed, the vascular access devices (VAD) used to deliver the therapies also began to evolve (Rivera *et al.*, 2005).

The insertion of a VAD may be necessary for a variety of reasons including to administer IV therapy such as blood or blood products, isotonic fluids and medications, or to deliver contrast media for diagnostic tests (Phillips, Collins and Dougherty, 2011). Indications for longer-term vascular access include chemotherapy, long-term antibiotic therapy, parenteral nutrition, haemodialysis, regular blood transfusion, and repeated venesection (Denton, 2016). Centrally placed VADs are necessary for the delivery of irritant or vesicant medications that must be delivered into the larger veins. This is done to prevent damage to the tunica intima (inner layer) of the smaller peripheral vein.

The number of VADs being inserted is growing year on year. This growth is due to the increasing prevalence of lifestyle diseases, the treatment of infections, various other diseases such as cystic fibrosis (Hurley *et al.*, 2014) and tuberculosis (Ravimohan *et al.*, 2018), and a rise in the number of chemotherapy procedures requiring long-term IV therapies (Torre *et al.*, 2015; Savage *et al.*, 2016). To provide an idea of this growth, the most recent reports estimate

that the global VAD market is projected to grow from 3,034 billion pounds sterling in 2017 to 4,272 billion pounds sterling by 2022 (Markets and Markets, 2016).

Technical advancements have resulted in three VADs that can be used for long-term vascular access, namely: Peripherally Inserted Central Catheters (PICC) that exit from the arm; Tunnelled Central Venous Catheters (TCVC) that exit from the chest; and Totally Implanted Vascular Access Devices (TIVAD) that are implanted under the skin. The indications for each of these devices is the same, as are the limitations. Importantly, depending on the treatment, patients can have these devices in place for many months or even years (Dougherty and Lamb, 2008).

As the number of patients living with VADs for extended periods of time continues to increase, a clear understanding of how patients make sense of their experiences of living with their VAD is necessary. Having this insight will provide patients and clinicians with an awareness of how a VAD can affect the self. Comparing the experiences of life with the different devices is also necessary to ensure we have the information to guide patients in the selection a device that suits them and their lifestyle. Finally, the knowledge gained from this study could help clinicians prepare patients for an altered self that includes the addition of an external or implanted device. This can be done in a more informative and sensitive way.

In order to understand and appreciate the origins and subsequent developments in IV therapy, and to set the scene for this thesis, the following section will provide a description of the range of long-term vascular access devices which are available for delivering intravenous medications. Although the long term VADs have the same indications and contraindications, the salient features vary greatly as do the final appearance of them on the body.

1.2 THE FAMILY OF VASCULAR ACCESS DEVICES

To put this thesis into context, it is important for the reader to have knowledge of the more complex features of each of the available VADs. This will allow an understanding of how each of the devices appears once inserted into the patient's body. Therefore, the aim of the following section is to proffer a deeper review of the more salient features of each device. The range of vascular access devices available include Peripheral Venous Catheters, Peripherally Inserted Central Catheters, Tunnelled Central Venous Catheters, and Totally Implanted Central Venous Catheters. The first device to be discussed is the short-term device, Peripheral Venous Catheters.

1.2.1 PERIPHERAL VENOUS CATHETERS

Peripheral Venous Catheters (PVCs), also known as cannulas, have been described as being indispensable to human health (Rivera *et al.*, 2005). Globally, approximately 80% of patients will have at least one PVC inserted during their stay in hospital (Tjon and Ansani, 2000; Waitt, Waitt and Pirmohamed, 2004; Alexandrou *et al.*, 2018).

A short PVC is typically less than three inches in length and, due to their tendency for dislodgement and infiltration, they are more commonly used for short-term treatments. Midline catheters, often referred to as long PVCs, are typically between eight and twenty-five centimetres in length (Moureau, 2019). They are inserted into the peripheral veins in the arm with the distal tip terminating before the axillary vein (Gorski, 2007). Midlines catheters offer a longer dwell time than short PVCs, and are routinely used for intravenous treatments that are required for more than five days (Denton, 2016).

The use of short and long PVCs is contraindicated for therapies such as vesicant chemotherapy, parenteral nutrition solutions, and/or medications with osmolarity greater than 900 Osm/L (Gorski, 2016). This is due to the potential risk of vein damage (Hallam *et al.*, 2016).

The vein is made up of three layers: the tunica externa or adventitia, the tunica media, and the tunica intima. Tunica externa is the outer covering of the vessel. It consists of elastic and collagen. Tunica media is the middle layer, consisting of smooth muscle and elastic connective tissue. It displays the greatest variation among the various vessel types. Tunica intima is the inner lining of the vessel and has direct contact with the blood as it flows through the lumen of the vessel (Tortora and Derrickson, 2014). Peripheral veins have relatively small lumen sizes, and, therefore, devices inserted into the backs of the hand or forearm terminate close to the vein intima. Travelling up the arm toward the central veins sees an increase in the size of vein lumen, and, therefore, device tips that terminate in these veins are not in direct contact with the inner vein lumen. This placement reduces the risk of inadvertent drug extravasation (Lamperti and Pittiruti, 2013).

Extravasation refers to a situation in which drugs accidentally leak into the tissue (Gorski *et al.* 2016). Certain chemotherapy drugs might cause local damage to tissue if they extravasate into the subcutaneous tissues surrounding the intravenous site. Intravenous therapies such as non-cytotoxic vesicant chemotherapy drugs are known to be damaging to the intima of the peripheral veins (Al-Benna, O'Boyle and Holley, 2013). However, since there is no centralised register of chemotherapy extravasation, information about such incidences is limited (Jackson-Rose *et al.*, 2017). To prevent damage to the peripheral veins, Central Venous Access Devices are used to access the larger veins of the body.

1.3 CENTRAL VENOUS ACCESS DEVICES

Central venous access is defined as catheter placement in the caval atrial region (Lewis, Allen and Burke, 2003). Central Venous Access Devices (CVADs) allow drugs to be delivered directly into the larger veins of the venous system, therefore reducing the risk of extravasation (Langer, 2010). Also, according to various studies (Nifong and McDevitt, 2011; Elen Hughes, 2011; Evans *et al.*, 2013 and Spencer and Mahoney 2017), a catheter to vein ratio of 3:1 is crucial to reduce the risk of thrombotic complications. This means that the placement of CVADs into larger veins, such as the superior vena cava or right atrium, reduces the likelihood of such a complication.

The first documentation and demonstration of central venous catheterisation is attributed to the German physician and physiologist Werner Forssmann (Meyer, 1990). In 1929, Forssmann discussed his idea of central catheterisation with his operating room nurse Gerda Ditzen, who offered her full support and even agreed to act as his first subject. However, Forssmann decided to put himself under local anaesthetic and inserted a catheter into his antecubital vein. The catheter was advanced and was confirmed radiologically as being in the correct chamber of the heart. Forssmann convinced his chief that the procedure was successful, and he was given permission to perform the procedure once more, this time on a terminally ill patient. The catheter was again successfully inserted and used to transfuse medication into the right ventricle. Forssmann then published his work 'Ueber die Sondierung des rechten Herzens' (by probing of the right heart). He continued to practice medicine as a military surgeon and urologist. In 1956, Forssmann won a Nobel Peace Prize for his work.

In the meantime, Meng, Cress and Youmans (1956) documented the use of the subclavian vein for IV therapy infusion. This approach became popular, predominately being used to deliver IV fluids with high concentrations such as proteins and dextrose. It was also largely used in the

paediatric population for the delivery of total parenteral nutrition. Later, Aubaniac described his experiences with the subclavian approach for IV access for rapid fluid resuscitative to treat military casualties (Ganeshan, Warakaulle and Uberoi, 2007).

Vascular Access Devices are now inserted into many veins, and an array of long term VADs that allow the delivery of treatments over an extended period into central veins now exists (Hallam *et al.*, 2016). The following section will provide a description of the three long-term VADs in the order they came into clinical use.

1.3.1 TUNNELLED CENTRAL VENOUS CATHETERS (TCVC)



Figure 1.1: TUNNELLED CENTRAL VENOUS CATHETERS (TCVCs) (COPYRIGHT: PICTURES USED WITH KIND PERMISSION)

Tunnelled Central Venous Catheters (TCVCs) are plastic tubes which are available as single or multiple lumen. They allow the simultaneous delivery of multiple medications or fluids into the central system. One of the first tunnelled catheters was developed by Broviac and colleagues (Broviac, Cole and Scribner, 1973). It was designed for use in the paediatric population and was used for total parenteral nutrition (TPN). Subsequently, Hickman *et al.* (1979) altered the design of the device to include a larger internal diameter.

A TCVC is fed under the subcutaneous tissue, hence the term *tunnelled catheters*. Another feature of a TCVC is the Dacron® cuff, which is important as it aids catheter stabilisation, and helps prevent infection by providing a seal between the catheter and its entry point (Hamilton

and Bodenham, 2009). It also acts as a barrier to the tracking of infection along the catheter wall (Ramsey *et al.*, 2013). The TCVC typically has an initial entry point in one of the neck or chest veins, namely: the internal jugular, subclavian, or axillary vein; the TCVC then exits at the chest area (Funaki, 2002) (Figure 1). However, there are also alternative TCVC access sites that include transfemoral, trans lumbar, and transhepatic (Maya and Allon, 2005; Hamilton and Bodenham, 2009; Marik, Flemmer and Harrison, 2012).

The insertion of a TCVC requires a minimally invasive surgical technique. The aim is to leave the tip of the catheter in one of the large central veins, whilst leaving part of the device outside the body to allow medication or fluids to be administered, or bloods to be taken. The next long-term Vascular Access Device used for extended IV access is the Totally Implanted Vascular Access Device.

1.3.2 TOTALLY IMPLANTABLE VASCULAR ACCESS DEVICE (TIVAD)

This is a device that removes the requirement to exit outside of the body. Instead, it is implanted underneath the skin.



Figure 1.2: TOTALLY IMPLANTED VENOUS ACCESS DEVICE (TIVAD)
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The TIVAD was first described by Belin *et al.* (1972) and later introduced by John Niederhuber in 1982. The TIVAD consists of a reservoir (the portal) and a tube (the catheter). The portal is implanted under the muscular fascia in either the chest or arm, with the catheter being tunneled before terminating in a central vein (Figure 1.2). This technique means that no part of the device is situated outside of the body.

As with the TCVC, these devices allow the administration of chemotherapy, antibiotics, and blood sampling without the need for repeated venous access (Hamilton and Bodenham, 2009). The insertion procedure was initially performed using a surgical cut down technique, which involved accessing the cephalic vein (Niederhuber *et al.*, 1982). The insertion technique has been modified over the years, and now involves using the internal jugular or auxiliary vein as an initial access point (Hamilton and Bodenham, 2009). Araújo *et al.*, (2008) demonstrated that the internal jugular vein resulted in fewer complications than subclavian vein access. More recently, Seo *et al.* (2014) discussed their technique of a single incision for insertion of TIVAD via the axillary vein. This technique appears to offer a high technical success rate with reduced

complications. The final long-term vascular access device to be discussed is the Peripherally Inserted Central Catheter.

1.3.3 PERIPHERALLY INSERTED CENTRAL CATHETERS (PICCS)



Figure 1.3: PERIPHERALLY INSERTED CENTRAL CATHETER (PICC) (COPYRIGHT: PICTURES USED WITH KIND PERMISSION)

PICCs were first introduced into practice in the United States of America (USA) in the 1970s. They were initially thought of as short-term percutaneous central venous catheters, and were used for patients who required IV access for days or weeks rather than longer-term (Alexander *et al.*, 1994). The main uses of PICCs at this time was for post-operative care and acute care purposes. They subsequently gained popularity in the United Kingdom (UK) in the 1990s (Gabriel, 1994). The PICC is inserted via one of the large veins in the arm and is threaded until the tip terminates in the superior vena cava or right atrium. The end of the catheter remains visible and accessible to allow access to deliver treatment (Figure 1.3).

PICCs have become a popular device for long-term vascular access, being used regularly in oncology (Parás-Bravo *et al.*, 2016). More recently, PICCs have become the device of choice for delivering other treatments in a variety of specialities, including: long-term antibiotic therapy (Kim-Saechao, Almario and Rubin, 2016); fluid optimisation in patients following proximal femoral fracture (Tutton and Gray, 2009); patients with recalcitrant maxillary facial infections (Islam, Loewenthal and Hoffman, 2008); as well as in patients with mitochondrial disease (Codier and Codier, 2014). The PICC is also becoming an alternative device of choice

within critical care (Griffiths and Philpot, 2002; Lamperti and Pittiruti, 2013; Zochios *et al.*, 2014; Cotogni *et al.*, 2015).

The reason for this rise in the use of PICCs has been attributed to the fact that they are typically inserted by specially-trained nurses rather than general medical staff (Walker and Todd, 2013). They are usually easier and quicker to insert than the other devices which makes them more accessible for patients (Walker and Todd, 2013), and are also the least costly of the three devices (Moss *et al.*, 2017). The insertion procedure is usually done at the patient's bedside, in treatment rooms, ward areas, or even in outpatients' areas. There is no need for theatre space, nor the sophisticated C-Arm commonly used for radiological placement. Thus, the procedure and lower price of the device mean it is a more cost-effective option than the other two devices (Walker and Todd, 2013). The use of PICC teams has also been associated with higher device insertion success rates (Alexandrou *et al.*, 2012; Krein *et al.*, 2015).

Despite many advantages, PICCs are associated with complications such as occlusions and thrombotic episodes (Parás-Bravo *et al.*, 2016; Grau *et al.*, 2017). Over the years, these catheters have evolved and now offer a choice of dual or triple lumens. They are also available in materials that will withstand the pressure of power injectable pumps, developed with the addition of valves which claim to help prevent device occlusion and with added materials such as silver technology, antimicrobials to help reduce infective complications (Gorski, 2016).

As mentioned, nurses have responsibility for the insertion of this device in many cases. However, in general, VAD insertion is performed by many professionals in the healthcare system.

1.4 SELECTION AND INSERTION OF VASCULAR ACCESS DEVICES

It is important to consider the range of clinicians responsible for the selection and insertion of Vascular Access Devices. As vascular access is not a specialty, and as VADs are inserted for a variety of patient conditions, the vascular access journeys of patients can be fragmented and varied. There appears to be no ownership of it and, therefore, little or no comprehensive approach to considering how patients might be experiencing life with them.

1.4.1 THE ROLE OF THE SURGEON IN VAD INSERTION

Historically, the procedure of VAD insertion fell into the remit of surgeons. The catheters were inserted using a technique which involved the vein being exposed surgically before the catheter was inserted (Hamilton and Bodenham , 2009). This was normally performed using the subclavian vein. The main advantage of this approach was that the vein could be readily identified and accessed using a landmark technique; in addition, it provided a straightforward route directly to the superior vena cava, which is the ideal catheter tip termination point. There were, however, disadvantages with the use of the subclavian vein. Complications related to this approach included; catheter related venous thrombosis, subclavian vein stenosis, and pinch off syndrome (Mirza, Vanek and Kupensky, 2004). Puncture of the subclavian vein was also associated with a high incidence of the procedural complication of pneumothorax (Macdonald *et al.*, 2000). Recently, due to such complications, the surgical approach, although still performed, has become less common (Cho *et al.*, 2013). A technique that removed the need for a surgical cut down to the subclavian vein, thus reducing complications, was developed by radiologists.

1.4.2 THE ROLE OF THE RADIOLOGIST IN VAD INSERTION

In the 1960s, radiologists began to perform many procedures formally performed by surgeons. One of these procedures was the insertion of VADs (Lakhan *et al.*, 2009). Interventional radiology techniques for the insertion of a TCVC were initially used to provide access in challenging cases. Subsequently, technological advancements in the form of new access techniques and ultrasound guidance were instrumental in the procedure eventually being performed by radiologists (Lamperti *et al.*, 2012). Real-time ultrasound guidance of VAD insertion provided the operator with visualization of the desired vein and the surrounding anatomic structures prior to and during insertion of the needle, guidewire, and catheter (Simon and Saad, 2012).

Early studies of ultrasound location of vessels, followed by subsequent catheter placement with landmark techniques, found no advantages over standard landmark techniques (Mansfield *et al.*, 1994). The landmark technique involves using anatomical landmarks such as the clavicle and carotid artery to estimate where the target vessel is. Subsequent studies, however, demonstrate that real-time ultrasound guidance does appear to improve the success rate and decrease the complication rate associated with VAD placement.

In addition to ultrasound guidance, radiologists utilised a minimally-invasive percutaneous technique known as the Seldinger Technique. First described by Sven-Ivar Seldinger (1953), this technique provided a safer alternative to the traditional surgical cut-down technique. The technique involves the target vein being punctured with a sharp, thin-walled, hollow needle; following this, a guide wire is passed through the needle and into the vessel. Leaving the guidewire within the vessel, the needle is withdrawn. Finally, the catheter is fed over the wire directly into the vessel, or through a guiding sheath that is peeled away following catheter

insertion. The technique allows access to any part of the body via the circulatory system through a minimal puncture site (Galloway and a Bodenham, 2004).

The Seldinger technique revolutionised both radiology and cardiology, but also provided the catalyst for innovation in the field of vascular access (Hull, Hunter and Luiken, 1992).

1.4.3 THE ROLE OF THE ANAESTHETIST IN VAD INSERTION

The insertion of VADs by anaesthetic staff was a natural progression of their role as they were required to insert IV device for pre-procedure preparation; their skills were already honed to adapt to VAD insertion (Bradley, Teare and Milner, 2017). Equally, anaesthetic staff within intensive care units were often the natural choice of profession to take ownership of this skill. To this day, many anaesthetists have a dual role of anaesthetist and for VAD insertion (Hamilton and Bodenham, 2009). Again, the addition of ultrasound guidance and other tools, devices, and techniques ‘borrowed’ from the radiology world has meant that the number and selection of devices that they are able to insert has increased (Galloway and a Bodenham, 2004).

The development of the Seldinger technique, in addition to the availability of portable ultrasound machines, meant that patients no longer had to undergo a surgical procedure in a theatre setting or radiological environment. Subsequently, this opened up the door for nursing staff to extend their roles and, in the late 1990s, nurses began to insert VADs, either as bedside procedures or within designated clinic areas (Kelly, 2002; Hamilton, 2004).

1.4.4 THE ROLE OF THE NURSE IN VAD INSERTION

During the late 1990s, due to an ageing population, increased consumer expectations, technological advances, and the growth in radiological procedures there was an increased pressure on radiological services. This subsequently led to an increase in the workload of radiologists (Sabharwal, Fotiadis and Adam, 2007). One solution to fill this gap in service provision was for nurses to be trained in the procedure of VAD insertion. Nurses recognised that the skill of VAD insertion could be acquired, and initially felt that it could be a procedure performed in radiology by the radiology nurse. This, consequently, allowed time for the radiologist to perform more challenging invasive procedures (Youngmann and Barnes, 2016).

However, many nurses soon recognised that, rather than performing the procedure in a radiology department, they could set up services outside of radiology; nurse-led services soon began to be developed. Unlike the doctor-led services, the nurse-led services involved more aspects of total patient care (Kelly, 2002). Over the years, many more successful vascular access services have been developed (Waterhouse, 2002; Hamilton, 2004; Beerman, 2009; Kelly *et al.*, 2009; Alexandrou *et al.*, 2012; Walker and Todd, 2013; Reeves, Morrison and Altmiller, 2017).

Evidence suggests that nurses can perform minor surgical procedures safely and effectively. For example, Casey and Davies (2003) conducted a study of advanced nurse practitioners performing TCVC access. The findings suggested that complications were low and outcomes good. These findings were echoed in a study carried out in Greater Manchester in 1998 by Chapple and Sergison, (1999). There are many similar examples of evidence supporting the view that adding nurse interventions to treatment improves outcomes for patients in many varied health care settings (Faithfull and Hunt, 2005; Heale, 2012; Hines, Munday and Kynoch, 2015). Therefore, as suggested by literature and in accordance with Winslow, Trammell and

Camp-Sorrell (1995); Camp-Sorrell (2007) Kelly *et al.*, (2009) Alexandrou *et al.*, (2012) and Gorski, (2016), nurse-led vascular access services can be effective and produced good outcomes.

1.4.5 THE PROBLEM

Despite the availability of three different long-term VADs, there remains a lack of literature pertaining to the experience of patients living with them, or which device might be most suitable. The selection and insertion of specific devices is ultimately associated with clinician preference, role, or skill. As demonstrated, the number and range of clinicians responsible for the insertion of VADs is large. Therefore, vascular access is not a specialty and decisions made regarding device insertion often lies with clinicians and their personal equipoise with little patient input.

The decision on which device is inserted is mostly based on issues such as: type of therapy to be administered, duration of treatment, costs, and device availability (Cowley, 2004; Cook, 2007; Ludeman, 2007; Di Giacomo, 2010). Guidelines are available to further support device choice (D'Angelo *et al.*, 1997; Freytes, 1998, O'Grady *et al.*, 2011; H.P. Loveday *et al.*, 2014; Denton, 2016). These guidelines recommend a structured approach to device selection. More importantly, patients are expected to live with their device for many months or even years (Moureau, 2019). Literature on the clinical advantages and disadvantages of VADs is plentiful. However, this remains largely technically focused rather than patient focused (Simonov, Pittiruti, Rickard *et al.* 2015, Bodenham, 2016; Voog *et al.* 2019).

1.4.6 AIMS OF THE STUDY

- To explore how patients with cancer experience living with a VAD
- To determine if there are convergent or divergent experiences depending on which device is in situ

1.5 REFLECTION: POSITION OF THE RESEARCHER

Reflexivity is integral to experiential qualitative research (Shaw, 2010). It is defined as an awareness and honesty about feelings and inner thoughts surrounding the research. Reflexive abstracts from diary entries will be detailed in subsequent chapters, however, it is important to add a statement at this point to provide the reader with an understanding of the author's professional and personal positioning. In addition, this section will provide a reason why this particular subject was chosen.

PROFESSIONAL AND PERSONAL POSITIONING OF THE AUTHOR

As a researcher and vascular access specialist, I am aware of how my own experiences and assumptions could influence this study. My current role is that of Clinical Nurse Advisor for a medical device company. I have worked in this role for over three years. My remit includes teaching, training, and educating nursing and medical staff about VAD insertion as well as the care and maintenance of these devices. I work within clinical areas across Scotland, Northern Ireland, and Northern England. Therefore, I am exposed to many practitioners, specialties and ways of working.

My background is as a registered general nurse and nurse lecturer, where I led MSc level programmes for advanced clinical practice and urgent care.

The idea for this thesis was generated whilst in a role as a vascular access nurse. This was a new and innovative extended role for nurses and involved the insertion of a variety of vascular access devices. The following section will tell the story of my leap into the world of service development and the setting up of one of the first nurse-led vascular access services in the UK.

My first nursing post was within an interventional neuroradiology department. Interventional radiology is a specialty that carries out minimally invasive surgical procedures with the use of fluoroscopy. I continued in radiology nursing and worked in the field of gastroenterology and cardiac catheterisation. In 2000, I took on the role of charge nurse within a busy interventional radiology (IR) department.

One of the procedures carried out was that of Tunnelled Central Venous Catheter (TCVC) insertion. Due to the rise in IR procedures, it soon became extremely difficult for radiology departments to accommodate the needs of venous access patients due to an increase in workload (Kelly, 2003). This increased workload was attributed to changes in technique and technological advances in the field of interventional radiology. In theatre, the service depended on the availability of skilled specialist registrars and theatre time, which was at a premium. Patients requiring venous access were not given priority, which caused cancellations and unacceptable waiting times. I was keen to find a solution to this problem and decided that the

development of a nurse-led vascular access service could improve the patient experience of the service.

I was involved in the development of a business case which resulted in funding from the Government Cancer Plan. This enabled me to set up a service for patients requiring vascular access. Initially, my remit included inserting and removing TCVCs as well as teaching and education on vascular access across the trust (Kelly, 2002). At that point, I realised there was an alternative device available that was less invasive, and with fewer potential insertion-associated complications, that would provide the same access for the patients. Subsequently, we began to insert PICCs as well as TCVCs. I became aware that I had to be able to justify decisions regarding device selection made for my patients (NMC, 2015). It became difficult to decide upon and justify which device was best for each patient. In addition, I was unable to offer any evidence-based advice to give to patients about how to 'live with' their devices. While there were guidelines available (Loveday, 2013; CDC, 2012; Hallam et. al. 2016), none of this included information on the patient experience. This lack of knowledge provided the impetus for this study.

1.6 THESIS STRUCTURE

This thesis is divided into eight chapters. Chapter One introduces the thesis and clarifies the aims of the research. It describes the context and explains the personal motivation for undertaking research in this area. Chapter Two contains the literature review and locates the study in current research. Chapter Three describes the methodology and research design and justifies that chosen methodology. Chapter Four describes how the study was undertaken. Chapter Five presents research findings. Chapter Six discusses the undertaking and findings of a patient survey, Chapter Seven discusses findings in relation to current literature and introduces a new conceptual framework to explain the study findings. Chapter Eight discusses the implications for practice and for future research. This final chapter also acknowledges the strengths and weaknesses of the study and includes a reflective discussion about the research journey undertaken.

1.7 CHAPTER CONCLUSION

This chapter has provided a background to the field of vascular access. It discussed the range of VADs available for IV therapy and the clinicians responsible for inserting them. It explained how each of these devices can be used for long-term vascular access with indications and contraindications being equal. The aim of this study, therefore, is to discover how patients with cancer experience their lives with either device. In addition, it will explore whether these experiences differ depending on the type of device is in place.

In the next chapter, a critique of contemporary literature in the area will be presented. This will identify what is missing from the current literature and provide an explanation of what this study will add. The aim of the literature review is to identify all existing relevant literature that will act as evidence for improving the understanding of patient experience with a long-term vascular access device.

CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

The purpose of this chapter is to place this study into the body of existing theoretical knowledge and research. Without a literature review, a researcher is unaware of what is already known in the area being studied, how it has been researched, and what questions that body of research has yet to answer. Subsequently, a review can act as a springboard for further original research on a topic (Potter, 2006). Therefore, the aim of this literature review is to identify all existing relevant literature that relates to the research question: How do cancer patients experience life with a vascular access device?

To begin this chapter, a justification will be provided to support the decision to undertake a narrative review. Next, the methods used in the literature search will be described, and the methods used to synthesise the studies will be explained. Then, there will be a critical discussion of the literature reviewed before, finally, the unique and original perspective of this study, along with the ways in which it will add to the evidence base, will be defined.

The most appropriate time during which to review research literature has been widely debated (Cronin, Ryan and Coughlan, 2008; Sylvester, Tate and Johnstone, 2013; Aveyard, 2014). Whilst most authors advise undertaking a literature review prior to data collection, others suggest that literature should be reviewed following that process. If the researcher has prior knowledge of the literature, this may constrain the openness of the researcher which could, in turn, result in the introduction of bias to the study. Performing a literature review after the collection of data is particularly apposite when undertaking phenomenological research (Munhall, 2013).

The initial review identified a gap in the literature that framed the subsequent research detailed in this thesis. Following data collection, a second, comprehensive review of the literature provided a context for this study.

2.2 SELECTION OF LITERATURE REVIEW APPROACH

Various types of literature reviews exist, including systematic reviews (SR), meta-analysis, integrative reviews, and narrative or traditional literature reviews. A systematic review is an exacting synthesis of all investigations that relate to one specific research question. It differs from other methods as it aims to overcome bias at every stage (Bettany-Saltikov, 2010). Meta-analysis is a quantitative, formal, epidemiological study design used to systematically assess previous research studies to derive conclusions about that body of research. The outcomes of meta-analysis can include a more accurate estimate of treatment effects or other outcomes than separate studies contributing to the combined analysis (Haidich, 2010). Integrative reviews are viewed as the most comprehensive methodological approach (Scott-Findlay and Estabrooks, 2006) as they allow the inclusion of experimental and non-experimental studies resulting in a fuller understanding of the phenomenon being analysed. Data from theoretical and empirical literature are combined in this method, ultimately creating a consistent and comprehensive panorama of complex concepts, health theories, or problems (Russell, 2005). Finally, a narrative review (NR) critiques and summarises a body of literature. From this, conclusions are drawn about the topic under investigation. The literature is comprised of relevant studies and knowledge that address the subject area (Green, Johnson, and Adams, 2006). Each of the listed methods provides a summary of evidence. They seek to identify, assess, synthesise, and interpret evidence in a way that is unbiased and balanced (Hemingway and Brereton, 2009).

The initial scoping exercise was performed at the start of the study in 2013. This identified only three qualitative studies that met the search criteria. Therefore, the contemporary qualitative research literature available was insufficient to permit a systematic review. Since 2013, and

subsequent to this study, the body of research relating to the experiences of patients with a vascular access device grew rapidly and, upon returning to the literature in 2020, it was discovered that Ryan *et al.*, (2018) had published a protocol for a SR that focused on the patient experience of central venous access devices in anti-cancer treatment. According to the Cochrane collaboration (Higgins and Green, 2011), an SR should be reassessed every two years and, generally speaking, a new review is only prudent and useful when significant fresh information is available. Therefore, to undertake an SR would have gone against the Cochrane guidance and would ultimately have led to a similar review as the one proposed by Ryan *et al* (2018). I, therefore, decided that a narrative review (NR) method would be more appropriate.

2.3 JUSTIFICATION FOR A NARRATIVE REVIEW

Conflict exists between the assumed hierarchy of evidence in secondary research. SRs with or without meta-analysis or synthesis are still viewed as superior (Evans, 2003; Sandelwoski and Barroro, 2016; Daly *et al.*, 2007; Nagyova, 2015). Conversely, the unsystematic narrative review often includes only research selected by the authors. The absence of a clear and objective approach can lead to a number of methodological flaws, such as the potential introduction of bias (Montori, Swiontkowski and Cook, 2003).

Unlike NRs, SR reviews benefit from guidelines such as PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) statement (Shamseer *et al.*, 2015). This approach emphasises the ability of SRs to enable methodological reproducibility due to the use of review teams, clear search criteria, quality checklists, and synthesis tools, resulting in outcomes that are very similar and a reduction of bias. However, although it is often claimed that the strength of an SR is the reduction of bias (Cook, Mulrow and Haynes, 1997; Viswanathan *et al.*, 2008), both SRs and NRs are equally open to bias as a result of being performed retrospectively.

Furthermore, for some review topics, the strengths of the SR might turn into weaknesses. For example, the narrow focus and prescribed methods of the SR does not allow for comprehensive coverage (Collins and Fauser, 2005).

It could be argued that NRs are misunderstood, misapplied, and unfairly dismissed as inferior to SRs (Evans, 2003; Daly *et al.*, 2007). It is possible that the quality of narrative reviews can be enhanced by borrowing from systematic review methodologies. This would include methods to reduce bias by employing an effective bibliographic research strategy and being transparent in the selection of literature for review. Systematic narrative reviews (SNRs) also have the ability to address issues that require the wider scoping (Smith and Noble, 2016), such as how patients experience living with a VAD.

To ensure a robust literature review, a systematic approach was adopted to perform a narrative literature review (Bettany-Saltikov, 2010). This was done whilst maintaining a focus on validity, rigor, credibility, and relevance of published research and findings. This approach negates the criticisms and inadequacies aimed at the traditional NR, such as difficulties in replication, lack of objectivity and completeness, failure to sufficiently extract and summarise current knowledge, and bias (Antman *et al.*, 1992). According to Coughlan, Cronin and Ryan, (2007), an SNR is an approach that can enable a comprehensive overview of the literature whilst preserving features of an SR. The decision to adopt such an approach was also based upon the ability to provide a speedy summation of knowledge of the experiences of people living with a VAD.

2.4 CONDUCTING THE NARRATIVE REVIEW

2.4.1 IDENTIFYING RELEVANT WORK: THE RESEARCH QUESTION

How do cancer patients experience life with a VAD? This is the research question that this study seeks to answer. To identify relevant work, clear inclusion and exclusion criteria were developed. The inclusion and exclusion criteria followed the Population, Exposure, Outcome (PEO) format which subsequently became Population, Exposure, Outcome, Type of study (PEOT) (Bettany-Saltikov, 2010).

2.4.1.1 INCLUSION CRITERIA

Peer-reviewed primary research is the best available evidence and thus was part of the inclusion criteria. It is important to acknowledge that as only English language publications were included in the search; this may have introduced a language bias. Due to the exclusion of non-English language sources, potentially relevant articles might have been neglected (Bettany - Saltikov, 2016).

Given that the research question was concerned with the experiences of patients, both qualitative & quantitative research designs were included as each contain information on what it is like to live with VAD. For example, quantitative studies often include free text comments, not necessarily as the focus of the study but by way of explaining the quantitative findings (Snowden *et al.*, 2011).

INCLUSION CRITERIA
POPULATION: Human studies only; Adults > 18 years old
EXPOSURE: Those who have or previously had a PICC, TIVAD, or TCVC inserted for chemotherapy
OUTCOME: Experiences, perceptions, and views towards their PICC, TIVAD, or TCVC
TYPE OF STUDY: Primary qualitative or quantitative; Papers published in peer-reviewed journals; Studies published in the English language only; Studies published between 2000-2020

Table: 2.1: INCLUSION CRITERIA

2.4.1.2 EXCLUSION CRITERIA

Papers concerning renal dialysis catheters were excluded because these are specialist devices used exclusively for dialysis purposes and in specialist areas (Phillips and Sundel, 2018). More importantly, the indications for these catheters differ from those that are the focus of this current study. The decision was made to exclude children as the findings would potentially differ from those in adult populations due to different cognitive and development stages.

EXCLUSION CRITERIA
POPULATION: Children < 18 years old
EXPOSURE: Patients with long-term renal dialysis catheters
OUTCOME: Device complications
TYPE OF STUDY: Letters; Commentaries; Reviews; Discussion papers

Table 2.2: EXCLUSION CRITERIA

Following the identification of the inclusion and exclusion criteria, the systematic search commenced.

2.4.2 SEARCH STRATEGY

To retrieve all relevant literature for the review, a comprehensive search on the subject was undertaken. The initial search was undertaken by the author in January 2014. This was repeated between December 2019 and February 2020. To plan and execute the literature search effectively, help and advice were obtained from the university librarian, who is a specialist in healthcare and social care. The EBSCO platform was selected for the search. The following databases were used for the search as they were deemed the most appropriate: CINAHL, PsycINFO, and MEDLINE. It was decided that the combination of these sites would uncover all relevant literature about the patient experience of vascular access.

2.4.3 IDENTIFYING KEYWORDS AND DESCRIPTORS

The identification of keywords was undertaken using the component parts of the research question. Medical Subject Headings MeSH® were then utilised to make the search process systematic (Table 2.2).

EXCLUSION CRITERIA	MAJOR HEADINGS (MH) AND KEYWORDS
Totally Implanted Device	(MH “Vascular Access Devices”) OR (MH “Vascular Access Devices implantable”) OR Portacath OR TIVAD OR totally implanted port
Tunelled Central Venous Catheter	(MH “catheterization, central venous”) OR Tunelled Central Venous Catheter OR TCVC OR tunelled catheter OR tunelled cuffed catheter OR Hickman catheter OR broviac catheter
Peripherally Inserted Central Catheter	(“Catheterization, peripheral central venous”) OR (MH “Peripherally Inserted Central Catheter”) OR PICC
Patient Experience	Experience OR Attitude OR Perception OR Feelings OR View OR Satisfaction

TABLE 2.3: SEARCH WORDS

Boolean operators (AND, OR, and NOT) can improve the recall and precision of a well-planned search and, therefore, the Boolean search technique was utilised. (Bramer *et al.*, 2018). Following this search strategy, term groupings were used collectively in each database. A copy of the search history can be found in Appendix One.

Once the search was complete, results were exported into the Mendeley reference management program. This tool was used to organise and save search results and avoid searching for and inserting citations into the paper.

2.4.4 SELECTING THE STUDIES TO INCLUDE IN THE REVIEW

Following the literature search, the next stage was to select the studies to include in the review. This was done in two phases: firstly, papers were selected based on the titles and abstracts only. This involved sifting through the titles and abstracts of all articles recovered from the search.

These were then systematically screened and those that met the predetermined inclusion and exclusion criteria were selected. Next, all remaining papers were read in full and those that did not meet the criteria were rejected. A hand search was then performed, which entailed the screening of reference lists of included studies to identify whether there were additional pertinent studies which had been missed. In order to ensure that all relevant literature had been found, a Google Scholar search was also carried out; additional articles were identified that met the criteria (see Table 2.4).

2.5 ASSESSING THE QUALITY OF STUDIES

It could be argued that the quality of the literature included in this review was largely irrelevant because the most important data pertained to the reported individual experience of a VAD. However, scrutinising the literature and gaining a sense of the quality of the research allowed the value and relevance of research in this particular context to be determined. In addition, the reliability of the claims made were able to be weighed accordingly.

There are many clinical appraisal tools and approaches to evidence synthesis that support the systematic appraisal of different research studies (Treloar *et al.*, 2000; the Joanna Briggs Institute, 2016; CASP, 2017). However, these tend to appraise qualitative and quantitative studies separately. The most appropriate way to combine study results derived from diverse methodological stances was considered.

The appraisal tool selected was based on Harden and Thomas's (2005) process of mixed methods appraisals (Moule *et al.*, 2003) (Appendix Two). An advantage of this approach is that it preserves the integrity of each study design and uses a critical appraisal framework to systematically appraise the quality of the methodology of included studies.

The convention of using at least two researchers for the quality assessment process is useful from a quantitative – based review process. This approach is useful to open up the data to a broader range of possible interpretations. Due to time constraints, the studies in this review were rated by the author alone. However, a transparent approach was employed. The approach employed to rate the studies was based on the detailed explanations of the mixed method appraisal tool which was produced by Hong *et al.*, (2018). This can be found in Appendix Three.

The initial stage in the process was the technical appraisal. This judgement determined the competence of the researcher in being able to conduct research that followed established norms (Morse, 2002). Criteria in this stage included aspects of the appropriateness of the research design to meet the study aims, rigor of data collection and analysis, sampling strategy, statements of findings, representation of participants' voices, outline of the researchers' potential influences, background, assumptions, justifications of the conclusion, value and transferability of the research project.

The next stage was theoretical appraisal. This stage involved a paradigmatic approach to judgement with a focus on the research paradigm used in relation to the findings presented. To identify the quality of the decisions made, the rationale behind them or the responsiveness or sensibility of the researcher to the data consideration of the other criteria was important. This involved an evaluation of the methodological coherence or congruity between paradigms that guided the research project and the methodology and methods chosen. Also considered was the analytic stance and theoretical position, investigator responsiveness, openness, and verification. (Morse *et al.*, 2002).

Each paper was rated on the category that corresponded to the method; for example, qualitative studies were only rated on the corresponding criteria. Rather than calculating an overall

numerical score, a more detailed presentation of the ratings of each criterion was used to better inform the quality of the studies. This led to the ability of considering the quality of studies by contrasting each of their results (Hong et al. 2018; Pluye *et al.*, 2011). Each study was assigned a rating of either weak, moderate, or strong. The overall score was determined by the highest rating achieved over the total categories. A detailed presentation of the ratings assigned to each criterion can be found in Table 2.4 and Table 2.6.

All studies, despite methodological flaws, lack of reporting and low ratings, were included in the review and not excluded. This is because such studies can still generate new insights (Hong et al. 2018; Pluye *et al.*, 2011).

2.5.1 THE APPROACH TO SYNTHESIS

It can be argued that it is epistemologically and ethically inappropriate to attempt to summarise the findings from qualitative studies that focus on human experiences because of the ideographic focus and the complexities of qualitative research. This makes the summarisation of research findings controversial (Light and Pillemer, 1986; Sandelowski, Barroso and Voils, 2007). Therefore, this endeavour could be viewed as an activity not analogous to and, in fact, at odds with qualitative research synthesis. Although engaging in qualitative synthesis brings qualitative research into the centre of inquiry, there remains a risk that the process might depreciate the value of qualitative research (Sandelowski and Barroso, 2007).

It is argued that synthesising qualitative research findings contravenes the assumptions and imperatives of qualitative research. Qualitative synthesis is regarded as an attempt to mainstream qualitative inquiry. However, this could actually result in weakened research findings as it badly summarises human experience through the loss of integrity and vitality (Davis, 1991). It could be argued that turning idiographic knowledge into data for analysis

represents a loss of the distinctiveness of different sources of experience, and a departure from the greater pedagogic and emancipatory aims of qualitative research.

Despite these views, qualitative research could, indeed, be endangered by a failure to synthesise findings. Given that qualitative researchers work in isolation from each other, research produced has been termed 'one-shot research' (Estabrooks, Field and Morse, 1994, p.510), which often leads to similar studies being performed and so-called reinventions of the wheel. Qualitative researchers often fail to situate their work in larger programmes of research or fields of scholarship. Glaser and Strauss (2017) warn that the continued failure to link local grounded theory into formal theories (such as qualitative meta-synthesis) would consign findings of separate studies into separate islands of knowledge.

Therefore, synthesising existing qualitative research studies can be viewed as an essential step to reach high analytic goals, and subsequently, to enhance the transferability of qualitative research. Transferability in qualitative research, unlike quantitative research, is directed towards naturalistic and idiographic generalisations, or generalisations made about particulars (Sandelowski and Baroso, 2006). It is reprehensible and incongruent with contemporary views of science not to recognise and value qualitative generalisations. Synthesis enhances the value of qualitative research and research synthesis enterprise in general; it brings qualitative research into the mainstream of inquiry that will ultimately legitimise it.

A variety of methods exist for the synthesis of qualitative research findings, including meta-ethnography, grounded theory qualitative research synthesis, ecological triangulation, framework synthesis, thematic synthesis, content analysis, content survey, narrative syntheses, thematic synthesis, meta-summary, and meta-analysis (Thomas and Harden, 2008; Tacconelli, 2010; Noblit and Hare, 2012; Glaser and Strauss, 2017). Whilst narrative synthesis focuses on describing and summarising primary data in a structured manner and translating the

studies into one another, meta-ethnography, grounded theory, thematic synthesis, meta-study, meta-narrative, and critical interpretive synthesis attempt to push beyond the initial data to a renewed interpretation of the phenomena under review (Barnett-Page and Thomas, 2009). Given that the synthesis performed in this study included both qualitative and quantitative studies, a suitable approach was needed. In the literature review process, it was discovered that the methodologies of the qualitative and quantitative studies were not as disparate as anticipated. This meant that a common approach could be used to synthesise their findings.

As well as the synthesis methods mentioned above, Sandelowski and Baroso, (2006) propose meta-summary as a new and original approach to handling a compilation of both quantitative and qualitative studies. This method differs from others in that findings are accumulated and summarised instead of being transformed. According to Sandelowski and Baroso (2006), this approach results in a 'map' of the contents of qualitative studies which reflects the logic of qualitative research. Subsequently, Sandelowski, Barroso and Voils, (2007) advance the use of qualitative meta-synthesis to a technique useful for synthesising both qualitative and quantitative descriptive findings. Although this method was an option for synthesising the data in this thesis, the author made the decision to synthesise the findings using thematic methods.

2.5.2 JUSTIFICATION FOR THEMATIC SYNTHESIS

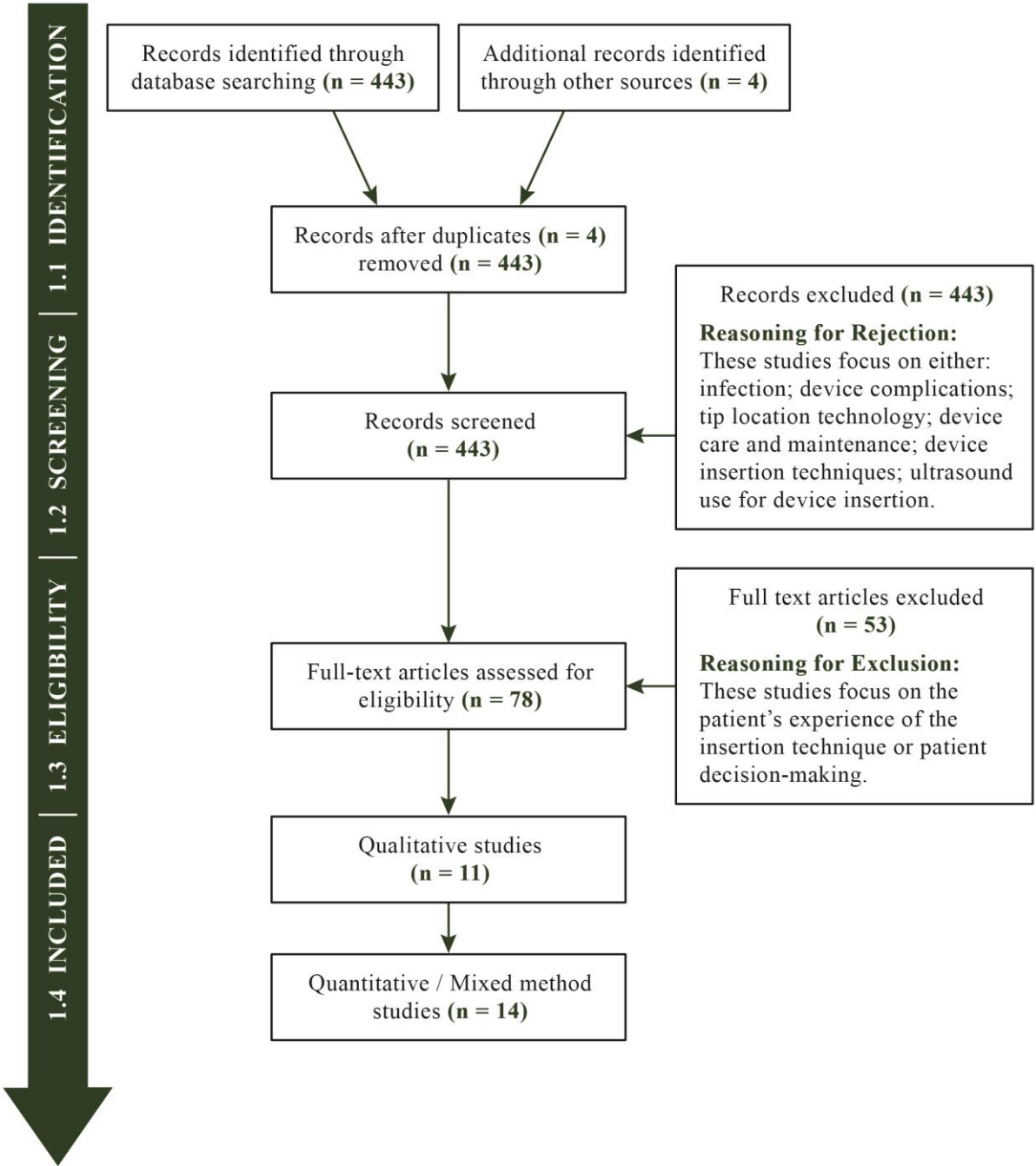
Thematic synthesis draws upon the principles of meta-synthesis in that it involves the identification of the recurrent themes described in studies (Sandelowski and Barroso, 2007). It is an approach that combines elements from meta-ethnography and grounded theory, and allows methodologically heterogeneous studies to be synthesised (Barnett-Page and Thomas, 2009). It was developed out of a need to conduct reviews that focus on questions relating to intervention need, appropriateness, and acceptability whilst not compromising on key principles developed in SRs. As in meta-ethnography, analytical themes are comparable to

third order interpretations, and the development of descriptive and analytical themes, using coding, invokes reciprocal translation. It shares with grounded theory an inductive approach and the development of categories using a constant comparative method (Glaser and Strauss, 1967). The end synthetic product has the added benefit of informing policymakers and healthcare practice.

Thematic synthesis was selected for use in this study for several reasons. Firstly, it was an appropriate method to present the author's objective of accumulating existing evidence and recognising patterns within the studies. Secondly, although thematic synthesis is typically associated with qualitative research outcomes, it is also appropriate for the synthesis of quantitative research outcomes, particularly where heterogeneity occurs in outcome measurements and variables (Thomas and Harden, 2008; Green *et al.*, 2015). Lastly, thematic analysis is a technique that is transparent, with clear outcomes.

2.5.3 ANALYTIC METHOD

The three stages of thematic synthesis were applied to the qualitative studies and repeated for the quantitative and mixed method studies. Codes were derived from the data; these were then associated with topics relating to patient experience. Next, similarities between codes were identified, and matching codes grouped into themes. These themes captured and described patterns found within the data and across the studies. The themes were then summarised, tabulated under thematic headings, and demonstrated in Table 2.8. Finally, the study findings were synthesised, and meanings interpreted in relation to the research question. This resulted in a narrative component of the analysis and a description of each theme.



2.6 LITERATURE REVIEW FINDINGS

From the literature search, a total of 25 publications were selected as appropriate for review (Table 2.2), including Oakley, Wright and Ream (2000); Gabriel (2000); Chernecky (2001); Campbell *et al.*, (2004); Goossens *et al.*, (2005); Kreis *et al.*, (2007); Molloy, Smith and Aitchison, (2008); Nagel (2008); Martins *et al.*, (2008); Johansson *et al.*, (2009); Ignatov *et al.*, (2009); Møller and Adamsen (2010); Yamada *et al.*, (2010); Goltz *et al.*, (2013); Sharp *et al.*, (2014); Alpenberg, Joelsson and Rosengren, (2015); Ritchie *et al.*, (2015); Minichsdorfer *et al.*, (2016); Burbridge and Goyal, (2016); Song and Oh, (2016); Yagi *et al.*, (2016); Parás-Bravo *et al.*, (2018); Ryan *et al.*, (2019); Park and Lee, (2020).

The quality appraisal of the studies resulted in a rating of strong for four studies (Ryan *et al.*, 2019; Kreis *et al.*, 2007; Møller and Adamsen, 2010; Nagel *et al.*, 2012). Moderate for twenty studies (Oakley, Wright and Ream, 2000; Chernecky, 2001; Campbell *et al.*, 2004; Goossens *et al.*, 2005; Martins *et al.*, 2008; Molloy, Smith and Aitchison 2008; Ignatov, *et al.*, 2009; Johansson *et al.*, 2009; Yamada *et al.*, 2010; Goltz *et al.*, 2013; Sharp *et al.*, 2014; Alpenberg, Joelsson and Rosengren, 2015; Ritchie, *et al.*, 2015; Song and Oh, 2016; Edström, Lindqvist and Rosengren, 2016; Burbridge and Goyal, 2016; Minichsdorfer, *et al.*, 2016; Yagi *et al.*, 2016; Park and Lee, 2020). One study was rated as weak (Gabriel, 2000). The main limitations in the quantitative studies was their cross - sectional nature, the lack of control for confounders and the limited use of validated data collection instruments. The strengths were related to rationale, data collection methods and analysis. The main limitations for the qualitative studies was sampling and sample size and results and findings (See tables 2.4 and 2.5).

Studies were not disregarded because of their methodological rating. The methodological reasons for assigning the ratings are discussed in section 2.5 and follow the instruction detailed in Appendix three. The results of the data extraction are presented in Table 2.6.

AUTHOR/ DATE	RATIONALE	METHODS	DATA COLLECTION & ANALYSIS	SAMPLING & SAMPLE SIZE	ETHICS	RESULTS & FINDINGS	CONCLUSION	OVERALL RATING
Gabriel (2000)	Strong	Weak	Weak	Moderate	Moderate	Weak	Weak	Weak
Oakley <i>et al.</i> (2000)	Strong	Strong	Moderate	Moderate	Strong	Moderate	Moderate	Moderate
Martins and Carvalho (2007)	Moderate	Moderate	Moderate	Moderate	Strong	Moderate	Moderate	Moderate
Molloy <i>et al.</i> (2008) MIXED	Strong	Moderate	Moderate	Moderate	Strong	Moderate	Strong	Moderate
Møller <i>et al.</i> (2010)	Strong	Strong	Moderate	Moderate	Strong	Strong	Strong	Strong
Sharp <i>et al.</i> (2014)	Strong	Moderate	Strong	Moderate	Strong	Strong	Moderate	Moderate
Aplenberg <i>et al.</i> (2015)	Strong	Moderate	Moderate	Moderate	Strong	Moderate	Moderate	Moderate
Ritchie <i>et al.</i> (2015)	Moderate	Moderate	Moderate	Weak	Moderate	Weak	Moderate	Moderate
Song and Oh (2016)	Strong	Moderate	Moderate	Moderate	Strong	Strong	Strong	Moderate
Parás-Bravo <i>et al.</i> (2017)	Strong	Strong	Strong	Moderate	Moderate	Moderate	Strong	Moderate
Ryan <i>et al.</i> (2019)	Strong	Strong	Strong	Moderate	Strong	Moderate	Strong	Strong

TABLE 2.4: QUALITY APPRAISAL OF QUALITATIVE STUDIES FOCUSING ON THE PATIENT EXPERIENCE OF VASCULAR ACCESS

AUTHOR/ DATE	RATIONALE	METHODS	DATA COLLECTION & ANALYSIS	SAMPLING & SAMPLE SIZE	ETHICS	RESULTS & FINDINGS	CONCLUSION	OVERALL RATING
Gabriel (2000)	Strong	Weak	Weak	Moderate	Moderate	Weak	Weak	Weak
Oakley <i>et al.</i> (2000)	Strong	Strong	Moderate	Moderate	Strong	Moderate	Moderate	Moderate
Martins and Carvalho (2007)	Moderate	Moderate	Moderate	Moderate	Strong	Moderate	Moderate	Moderate
Molloy <i>et al.</i> (2008) MIXED	Strong	Moderate	Moderate	Moderate	Strong	Moderate	Strong	Moderate
Møller <i>et al.</i> (2010)	Strong	Strong	Moderate	Moderate	Strong	Strong	Strong	Strong
Sharp <i>et al.</i> (2014)	Strong	Moderate	Strong	Moderate	Strong	Strong	Moderate	Moderate
Aplenberg <i>et al.</i> (2015)	Strong	Moderate	Moderate	Moderate	Strong	Moderate	Moderate	Moderate
Ritchie <i>et al.</i> (2015)	Moderate	Moderate	Moderate	Weak	Moderate	Weak	Moderate	Moderate
Song and Oh (2016)	Strong	Moderate	Moderate	Moderate	Strong	Strong	Strong	Moderate
Parás-Bravo <i>et al.</i> (2017)	Strong	Strong	Strong	Moderate	Moderate	Moderate	Strong	Moderate
Ryan <i>et al.</i> (2019)	Strong	Strong	Strong	Moderate	Strong	Moderate	Strong	Strong

TABLE 2.5: QUALITY APPRAISAL OF QUANTITATIVE STUDIES FOCUSING ON THE PATIENT EXPERIENCE OF VASCULAR ACCESS

Table 2.6: ARTICLE SELECTION A MANAGEMENT AND METHODOLOGICAL QUALITY RATING

STUDY & SETTING	POPULATION & DEMOGRAPHICS	EXPOSURE	OUTCOME	STUDY TYPE	METHODOLOGICAL QUALITY	RATING
Gabriel (2000) UK	<p>Participants: 15 participants referred for a PICC (no other details provided).</p> <p>Gender: Unknown</p> <p>Ages: Unknown</p> <p>Diagnosis: Unknown</p>	<p>Patients with a PICC requiring IV therapy on an outpatient home basis for at least 14 days.</p> <p>To identify patients' perceptions of the effect that a PICC had on their quality of life, as opposed to perceptions arising from their underlying medical condition.</p> <p>Objective: To generate a hypothesis on the perceived quality of life of recipients of PICCs.</p>	<p>All patients said that the PICC made treatment easier for them.</p> <p>All 13 patients commented on:</p> <p>The comfort of the PICC, lifestyle unaffected away from the hospital, reliability of the PICC, and reduction in peripheral cannulation.</p>	<p>Qualitative: Phenomenology & grounded theory.</p> <p>Successive patients referred for a PICC for any treatment (antibiotics, chemotherapy, blood administration).</p>	<p>Data analysis was not clearly defined.</p> <p>Lack of demographical detail.</p> <p>Questionnaires non validated – risk of researcher bias.</p> <p>No verbatim statements utilised. Not possible to gain insight into what transpired between researcher and respondent. Convenience sampling reduces generalisability.</p>	Weak
Oakley (2000) UK	<p>Participants: 10 patients being treated for cancer.</p> <p>Gender: Predominantly male</p> <p>Ages: 42 – 80 years</p> <p>Ethnicity: Predominantly Caucasian</p>	<p>Patients with a PICC being treated for cancer.</p> <p>To explore patients' and nurses' experience of a nurse-led PICC line service. Convenience sample of five community nurses, five ward nurses, and 10 cancer patients.</p>	<p>PICCs seen as beneficial to patients. No reports of restricted arm movements. Body image not a problem. Some patients could continue with everyday activities (driving and housework). Training required for nurses. This should focus on patient adaptation.</p> <p>A comparative study of patients' experiences of PICCs and TCVCs and their impact on patients' perceived body image is recommended.</p>	<p>Exploratory study. Patients were invited to participate if they were having a PICC inserted. An inclusion criterion was used.</p> <p>Patient interviews: Two face-to-face interviews.</p> <p>First: Within 24 hours of PICC insertion (involved information about insertion procedure, and sensory experience).</p> <p>Second: Conducted 3–4 weeks post device insertion (enquired about the experience of living with a PICC).</p>	<p>Title and abstract suggest that the study is exploring nurses and patients' experiences of the nurse-led service, whilst in the text, the aim was listed as 'to explore the experiences of patients with PICC lines'. Structured interviews did not allow for in-depth conversation. No opportunity for prompting or gaining a more detailed explanation of the patient responses.</p> <p>Only focused on one device – PICC. Only focused on one patient group – oncology.</p>	Moderate

STUDY & SETTING	POPULATION & DEMOGRAPHICS	EXPOSURE	OUTCOME	STUDY TYPE	METHODOLOGICAL QUALITY	RATING
Chernecky (2001) USA	<p>Participants: 24 chemotherapy patients.</p> <p>Gender: Male = 6 Female = 18</p> <p>Ages: <18 years</p>	<p>Patients with a TIVAD Receiving outpatient chemotherapy.</p> <p>To examine outpatient oncology satisfaction/dissatisfaction with VADs.</p> <p>Identify positive and negative experiences and determine their effect on quality of life.</p> <p>Convenience sample. Oncology patients.</p>	<p>Patients happy with VAD, as it improved quality of life.</p> <p>Positives: Decreased pain compared to cannulation, The need for fewer needle sticks, Quicker blood draws and lab tests.</p> <p>Negative: Monthly heparin flushes, sleep disturbances, pain.</p>	<p>Descriptive study. Participants from an outpatient oncology clinic. Two-page questionnaire.</p>	<p>Focus was only one device. Questionnaire limitations including lack of ability to probe or clarify questions and answers.</p> <p>Non-probability samples tend to be non-generalisable to the target population which is limiting to this study. As one of the first studies that considered patient satisfaction with a TIVAD, this study provided important considerations for future practice.</p>	Moderate
Campbell <i>et al.</i> (2004) UK	<p>Participants: 54 respiratory patients.</p> <p>Gender: Male = 15 Female = 39</p> <p>Ages: 5 – 63 years</p>	<p>Respiratory patients with cystic fibrosis with TIVADs requiring IV therapy.</p> <p>To obtain information which might guide vascular access specialists and patients in the choice of site for CVADs.</p>	<p>Most patients free of problems regardless of site.</p> <p>Issues with discomfort, wearing a seatbelt, cosmetic results, scarring, choice of clothing, lying in bed, or sleeping.</p>	<p>Quantitative survey-based study. Structured questionnaires sent to patients.</p>	<p>Postal questionnaires – no opportunity to discuss, probe, clarify.</p> <p>Potential lack of understanding.</p> <p>Convenience sampling reduces generalisability.</p> <p>Potential research bias related to the questionnaire design.</p>	Moderate

STUDY & SETTING	POPULATION & DEMOGRAPHICS	EXPOSURE	OUTCOME	STUDY TYPE	METHODOLOGICAL QUALITY	RATING
Goossens (2005) Belgium	<p>Participants: 98 patients with a TIVAD attending outpatient for IV therapy.</p> <p>Gender: Male = 34 Female = 60</p> <p>Gender of four patients unknown.</p> <p>Median age: 58 years</p>	<p>To collect the positive and negative experiences of patients regarding their port catheter, and to investigate the impact of the catheter on their overall quality of life.</p>	<p>Nearly half of the patients (48.49%) expressed positive experiences with VA: No more needle sticks.</p> <p>Negative: Port visibility, cancer association, temporary but</p> <p>Necessary but should be removed ASAP.</p> <p>Inconvenience during daily activities: Sleep, seat belt, bra.</p>	Quantitative Prospective study using questionnaires.	<p>Study should have been stratified for age and time since insertion. Lack of detailed responses to some questions. No opportunity to probe.</p> <p>The decision to use open-ended questions in this study allowed more comprehensive answers to the questions.</p>	Moderate
Kreis <i>et al.</i> (2006) Germany	<p>Participants: 232 patients with gynaecological or breast malignancies with a TIVAD.</p> <p>Gender: Females (100%).</p> <p>Ages: 27 – 80 years</p> <p>Median age: 56.3 years</p>	<p>TIVAD required for chemotherapy.</p> <p>To analyse patients' port related QOL.</p> <p>Patients with gynaecological or breast malignancies.</p>	<p>199 of the patients were very satisfied or quite satisfied with their TIVAD.</p> <p>It made them feel secure. However, 19 patients reported fear of port access. 80% stated they would have a port inserted again if required.</p> <p>201 patients did not feel disturbed by the device during ADL. Work was still possible for 114 patients.</p> <p>Issues reported over poor care of device outside of the hospital.</p>	Quantitative approach using questionnaires.	<p>Questionnaire was piloted and adapted in accordance with suggestions from patients.</p> <p>Small power for the analysis. The small sample size, despite stratification and randomisation, could have imbalanced the factors taking impact on QOL.</p> <p>Convenience sampling could suggest bias.</p>	Strong

STUDY & SETTING	POPULATION & DEMOGRAPHICS	EXPOSURE	OUTCOME	STUDY TYPE	METHODOLOGICAL QUALITY	RATING
Martins and Carvalho (2008) Brazil	<p>Participants: 15 participants with hematological pathologies with a TIVAD</p> <p>Gender: Male = 8 Female = 7</p> <p>Ages: 20 – 45 years</p>	<p>TIVAD required for ambulatory chemotherapy.</p> <p>To evaluate patients' perception regarding their use of a PICC or TIVAD.</p>	<p>Patients were more independent.</p> <p>60% revealed that some activities were restricted.</p> <p>57% patient dissatisfaction after TIVAD implantation.</p> <p>14% of CI revealed pre-implant problems.</p> <p>28% of CIs showed that the TIC favoured body aesthetics.</p> <p>75% revealed implantation as traumatic.</p> <p>25% remained calm during procedure.</p> <p>100% revealed chemotherapy made easier.</p>	<p>Qualitative study, Critical Incident Technique using Two-part questionnaire.</p> <p>Part one: Gender, age, period with catheter, base disease.</p> <p>Part two: Three guiding questions formulated with the CI methodological approach.</p>	<p>Interviews were not recorded; Researcher asking the questions and note taking during the interview introduces a risk of research bias and acquiescence bias. Data validity may be affected by recall. Finally, there is a risk that the author misheard, or misinterpreted, information given by the participant. It was not detailed if the interview transcripts were returned to the patient for verification and therefore this method of data collection is open to interviewee bias.</p>	Moderate
Molloy <i>et al.</i> (2008) UK	<p>Participants: Patients with MdG within an oncology centre.</p> <p>Phase One: 10 participants</p> <p>Phase Two: 62 participants</p> <p>Gender: Male = 5 Female = 5</p> <p>Ages: 42 – 76 years</p>	<p>PICCs required for delivery of chemotherapy.</p> <p>To determine which aspects of living with a PICC line caused MdG patients most difficulties.</p>	<p>Majority held favorable views of their PICC. Patients adapted to and accepted the PICC. Reduction in peripheral cannulation. Challenges with showering, bathing, hair washing, and sleeping.</p> <p>Gave patients independence. Friends and family worried about the PICC. Patients avoided crowds (avoidance of social situations). Issues with body image.</p> <p>Patients adapted well with minimal disruption to daily life. Concerns regarding coping at home, dealing with information.</p>	<p>Mixed methods two-stage descriptive study.</p> <p>Phase One: Semi-structured interviews to determine if the PICC is a benefit or burden when receiving ambulatory chemotherapy.</p> <p>Phase Two: Questionnaire survey of the MdG population.</p>	<p>The mixed method approach of semi-structured interviews followed by the questionnaire resulted in findings of specific difficulties faced by patients with PICCs.</p> <p>Limited to one very specific patient group.</p> <p>Convenience sampling reduces generalisability.</p> <p>The questionnaire used was not validated and therefore not subject to test-retest measurement.</p>	Moderate

STUDY & SETTING	POPULATION & DEMOGRAPHICS	EXPOSURE	OUTCOME	STUDY TYPE	METHODOLOGICAL QUALITY	RATING
<p>Ignatov (2008) Germany</p>	<p>Participants: 356 women with breast and gynaecological malignancies.</p> <p>Gender: All female</p> <p>Ages: 28 – 82 years</p> <p>Median age: 55 years</p>	<p>TIVADs inserted for the delivery of chemotherapy.</p> <p>To assess the factors that predict complications and patient satisfaction of TIVAD.</p>	<p>TIVADs are well accepted. Over 92% of the patients were very or quite satisfied with their TIVAD.</p> <p>Dissatisfaction was related to pain, the feeling of a foreign body under the skin, anxiety and encumbrance of daily activities, and complications rather than cosmetic results or impaired daily activities (9%).</p>	<p>Quantitative study. Questionnaire-based telephone survey.</p>	<p>Potential limitations with the use of telephone questionnaires includes a lack of rapport. The questions were structured and closed which did not allow expansion or a focus on aspects that might have been important to the patients. Potential for research bias related to the questionnaire design.</p> <p>The use of convenience sampling introduces bias also.</p>	Moderate
<p>Johanson <i>et al.</i> (2009) Sweden</p>	<p>Participants: 32 patients with acute leukaemia.</p> <p>Gender: Male = 38 Female = 26</p> <p>Median age: 68 years</p>	<p>TCVCs and CVCs inserted for chemotherapy.</p> <p>To analyse perceptions of having a CVAD.</p>	<p>The port is less restrictive in daily life than the CVC.</p> <p>More patients with a CVCs experienced restriction during hygiene and dressing compared to those with a TIVAD.</p>	<p>Prospective randomised study using two locally designed, study specific questionnaires.</p>	<p>Longitudinal study generated useful data to add to existing literature. Comparison study also gleaned further knowledge about living with each device.</p> <p>Non respondent – unsure of reasons.</p> <p>Study prematurely closed. Low number of response rates.</p> <p>Longitudinal study – deteriorating health can result in loss of follow up. No clear idea of the extent or restrictions faced by patients.</p>	Moderate

STUDY & SETTING	POPULATION & DEMOGRAPHICS	EXPOSURE	OUTCOME	STUDY TYPE	METHODOLOGICAL QUALITY	RATING
Yamada (2010) Japan	<p>Participants: 38 Terminally ill cancer patients in a palliative care unit.</p> <p>Gender: Male = 28 Females = 11</p> <p>Mean age: 71 years</p>	<p>Patients with successful PICC insertion for palliative care.</p> <p>To clarify the levels of patient-perceived comfort and convenience, in addition to procedure-related distress resulting from the use of PICCs in terminally ill cancer patients.</p>	<p>Most patients preferred a PICC.</p> <p>In this study, PICCs are viewed as comfortable and convenient.</p>	<p>Prospective, observational study.</p> <p>Clinical audit Patients questioned orally.</p> <p>Structured interview.</p>	<p>Treating physicians asked the questions – potential for under estimation of self-reported distress.</p> <p>Non-comparative study.</p>	Moderate
Møller and Adamsen (2010) Denmark	<p>Participants: 18 patients with haematological conditions.</p> <p>Gender: Male = 5 Female = 4 (intervention group)</p> <p>Male = 5 Female = 4 (control group)</p> <p>Mean age: 38.5 years mean (intervention group) 40.3 years mean (control group)</p>	<p>CVCs required for chemotherapy.</p> <p>To explore a new clinical intervention in which patients or their relatives were trained to provide CVC self-care.</p>	<p>The care of CVC has different influences in the patients' clinical psychological outcomes.</p> <p>Patients fear complications.</p> <p>Self-cares increase independence. CVCs cause psychological problems including altered body perception, sexual activity avoidance, and feeling stigmatised.</p>	<p>Qualitative, explorative non-experimental design incorporating a transverse phenomenological hermeneutic template analysis.</p> <p>Semi-structured questionnaire.</p>	<p>Randomised controlled trial, well-designed and robust methodology.</p> <p>Studies using themed questionnaire can potentially introduces bias.</p> <p>Questionnaire not validated. Study was concerned with infectious complication in addition to experience so this could have consequently favoured the clinical aspects rather than patient experience.</p>	Strong

STUDY & SETTING	POPULATION & DEMOGRAPHICS	EXPOSURE	OUTCOME	STUDY TYPE	METHODOLOGICAL QUALITY	RATING
Nagel <i>et al.</i> (2012) Germany	<p>Participants: 57 patients with an underlying malignant disease.</p> <p>Gender: Male = 42 Female = 15</p> <p>Mean age: 56.3 years</p>	<p>TIVAD required to administer chemotherapy.</p> <p>To assess the satisfaction and quality of life in patients with a TIVAD.</p>	<p>Most responding patients reported high overall satisfaction. The overall impact of the device was perceived not to be negative. The multiple stepwise regression showed that the cosmetic result was a predictor of overall satisfaction. Overall, it was found that the cosmetic result of the implantation procedure was a predictor of satisfaction and quality of life and should not be underestimated.</p>	<p>Quantitative survey-based questionnaire.</p>	<p>Risk of bias introduced with the use of non-validated questionnaires.</p> <p>Lack of follow up due to the underlying malignant disease. This means that potentially only healthy patients completed the questionnaire. This used a cross sectional design.</p> <p>Small sample size. Limited patient group, oncology only.</p>	Strong
Gotlz <i>et al.</i> (2013) Germany	<p>Participants: 50 patients with an underlying malignancy with upcoming chemotherapy.</p> <p>Gender: Male = 26 Female = 24</p> <p>Mean age: 55.8 years</p>	<p>To compare patients' satisfaction and impact on daily life after implantation of a TIVAD.</p> <p>TIVAD inserted in the chest (CP) or forearm (FP)</p>	<p>No significant difference between forearm and chest TIVADs.</p> <p>Fear of dysfunction and infection.</p> <p>CP patients described more negative perceptions when driving a car or wearing a bra.</p> <p>All patients would recommend their device.</p>	<p>Quantitative Prospective study</p> <p>Three study-specific questionnaires.</p>	<p>Lack of randomisation, potential for patient selection bias.</p> <p>Limitations with non-validated questionnaires.</p> <p>One of the few studies to consider the patients' experience of device site.</p>	Moderate

STUDY & SETTING	POPULATION & DEMOGRAPHICS	EXPOSURE	OUTCOME	STUDY TYPE	METHODOLOGICAL QUALITY	RATING
Sharp (2014) Australia	<p>Participants: 10 participants with haematological cancers, solid tumours, infections, difficult IV access attending radiology dept.</p> <p>Gender: Male = 6 Female = 4</p> <p>Ages: 45 – 80 years</p>	To understand the patient experience of PICC insertion and the impact of the device on activities of daily living including the significance of arm choice.	<p>Apprehension / adaptation / acceptance.</p> <p>Impact of treatment.</p> <p>Trust.</p> <p>Freedom.</p>	<p>Qualitative.</p> <p>Semi-structured telephone interviews.</p>	<p>Use of telephone interviews potential to hamper communication and reduce rapport.</p> <p>Interview length: short.</p> <p>Single site study.</p>	Moderate
Alpenberg, Joelsson, and Rosengren (2014) Sweden	<p>Participants: 10 patients receiving chemotherapy at an Oncology department.</p> <p>Demographical details not provided.</p>	To broaden the understanding of patients' coping related to a PICC line.	<p>PICC viewed as a tool to get well.</p> <p>Concerns about complications. Fear of infection. PICC was a symbol of disease. Escape from being pinpricked every time but disappointment at lack of use of PICC. Device affects sleep and daily hygiene. Had to perform daily chores with caution.</p> <p>Device was concealed from relatives by clothing choice.</p>	<p>Qualitative.</p> <p>Face to face, one to one interview.</p>	<p>Interviews conducted by authors – unsure if they had inserted the devices or worked on the ward.</p> <p>Potential for response bias.</p> <p>Sampling strategy unclear.</p> <p>Demographics not provided.</p>	Moderate

STUDY & SETTING	POPULATION & DEMOGRAPHICS	EXPOSURE	OUTCOME	STUDY TYPE	METHODOLOGICAL QUALITY	RATING
Ritchie <i>et al.</i> (2015) UK	<p>Participants: 9 patients receiving chemotherapy.</p> <p>Gender: Male = 4 Female = 5</p> <p>Age range: 48 – 66 years</p>	To explore patient and clinical staff attitudes to central venous access devices (CVADs).	<p>Pain and discomfort of device.</p> <p>Stigma related to device.</p> <p>Clearer information required for patients.</p>	<p>Qualitative.</p> <p>Focus groups.</p> <p>Three patients per group.</p>	<p>Focus groups may have limited the freedom to share stories of a sensitive nature.</p> <p>Potential lack of natural conversation, dominant voices, or quiet participants</p> <p>Quality of discussion depends on the skill of the moderator.</p>	Moderate
Edtsröm, Lindqvist, and Rosengren (2016) Sweden	<p>Participants: 36 oncology patients.</p> <p>Gender: Male = 7 Female = 29</p> <p>Ages: 30 – 77 years</p> <p>Mean age: 61 years</p>	To describe patients' experiences with the PICC-line during curative oncological treatment.	<p>Satisfaction with information received.</p> <p>Moderate correlation between knowledge of device workings, purpose of device, positive patient experience, and reporting fewer effects on everyday life.</p> <p>Some concerns about lack of information. Better than a peripheral pin prick. Eventually forgets it's there.</p> <p>Anxiety about infection and other complications, sleeping and interacting with others.</p> <p>Restrictions in daily life, refraining from water activities such as swimming.</p>	<p>Quantitative, cross sectional study.</p> <p>Non-randomised.</p>	<p>Questionnaire (adapted and translated from English to Swedish).</p> <p>Convenience sampling reduces generalisability.</p>	Moderate

STUDY & SETTING	POPULATION & DEMOGRAPHICS	EXPOSURE	OUTCOME	STUDY TYPE	METHODOLOGICAL QUALITY	RATING
Song and Oh (2016) South Korea	<p>Participants: 22 burns patient participants.</p> <p>Gender: Male = 15 Female = 7</p> <p>Ages: 23 – 58 years</p>	<p>To explore the subjective experience of PICC insertion procedures amongst burns patients.</p>	<p>PICCs provide a relatively safe and easy way for venous access.</p> <p>Reduced the need for painful peripheral venipunctures.</p> <p>Lots of pros and a few cons of PICCs.</p>	<p>Qualitative descriptive study.</p> <p>Four focus group interviews, five to six participants per group.</p>	<p>Focus group interviews may limit freedom of speech or limit discussion of a personal nature.</p> <p>Convenience sampling reduces generalisability. PICC lines only. Burns patients only.</p>	Moderate
Burbridge and Goyal (2016) Canada	<p>Participants: 127 patients requiring chemotherapy.</p> <p>Gender:</p> <p>Chest: Male = 10 Female = 41</p> <p>Arm: Male = 11 Female = 65</p> <p>Mean age: Chest = 55.9 years Arm = 54.2 years</p>	<p>Port inserted for chemotherapy.</p> <p>To assess the impact on quality of life and satisfaction with their venous device (chest port or arm port).</p>	<p>Some negatives of chest ports that were statistically significant in comparison to arm ports.</p> <p>Most patients felt that their port had a positive effect on their treatment, and they would have another port if required.</p>	<p>Quantitative, questionnaire based.</p>	<p>Bias associated with structured questionnaires.</p> <p>Devices placed in two different hospitals so practice may have been different.</p>	Moderate

STUDY & SETTING	POPULATION & DEMOGRAPHICS	EXPOSURE	OUTCOME	STUDY TYPE	METHODOLOGICAL QUALITY	RATING
Minchsdorfer <i>et al.</i> (2016) Austria	<p>Participants: 202 patients receiving chemotherapy.</p> <p>Gender: Male = 79 Female = 123</p> <p>Median age: 61 years</p>	<p>To evaluate the satisfaction and impairments of activities of daily life of ambulatory patients with PAC systems.</p> <p>Two tertiary patient-centred care facilities.</p>	<p>A third of the patients said that the device interfered with activities of daily living.</p> <p>The device alleviated the burden of chemotherapy administration.</p> <p>Would choose a TIVAD again.</p>	<p>A cross-sectional study, questionnaire-based study.</p> <p>Self-designed questionnaires.</p>	<p>Issues with a cross-sectional study.</p> <p>Variety of malignancies.</p> <p>Large patient sample.</p> <p>Locally designed questionnaire potential for researcher bias.</p>	Moderate
Yagi <i>et al.</i> (2016) Japan	<p>Participants: 50 patients receiving chemotherapy.</p> <p>Gender: Male = 33 Female = 17</p> <p>Ages: >70% over 60 years</p>	<p>To investigate the experiences of patients prior to and after port implantation, as well as their experiences regarding the use of their ports.</p>	<p>74% satisfied with their port.</p> <p>Those who had the device due to poor access, wished they had it inserted earlier.</p> <p>Negated the need for repeated cannulation.</p> <p>Difficulty fastening seatbelts, bathing.</p>	<p>Quantitative, questionnaire-based study.</p>	<p>Locally-designed questionnaires, no test, re-test. Potential for researcher bias.</p> <p>Convenience sampling reduces generalisability.</p>	Moderate
Paràs-Bravo <i>et al.</i> (2018) Spain	<p>Participants: 18 participants with a PICC.</p> <p>Gender: Male = 7 Female = 11</p> <p>Mean age: 58 years</p>	<p>To describe the experience of using a PICC in cancer sufferers receiving outpatient treatment.</p>	<p>Patients gradually accept the device by adapting their lifestyle.</p> <p>Advantages described.</p> <p>Lifestyle modifications required.</p>	<p>Qualitative, phenomenological study.</p> <p>Semi-structured interviews and researcher field notes.</p>	<p>Interviews performed in Spanish and presented in English which involves translation – related decisions. This could affect trustworthiness.</p>	Moderate

STUDY & SETTING	POPULATION & DEMOGRAPHICS	EXPOSURE	OUTCOME	STUDY TYPE	METHODOLOGICAL QUALITY	RATING
Ryan <i>et al.</i> (2019) UK	<p>Participants: 42 patients with cancer.</p> <p>Gender: Male = 22 Female = 20</p> <p>Mean age: 61.7 years</p>	<p>To explore patient acceptability of the three VADs.</p> <p>Patients receiving systemic anticancer therapy.</p>	<p>Attitudes towards all devices was positive.</p> <p>Patients viewed their device as part of their illness and recovery.</p> <p>Patients with external devices compared their devices favourably with PIVCs.</p> <p>Patients with TIVADs felt their devices were superior to other devices and felt a greater sense of freedom and less intrusion in the context of personal relationships.</p>	<p>Qualitative. Focus groups.</p>	<p>Some disadvantages associated with focus groups. This includes quieter individuals voices not being heard. Stronger voices dominating.</p> <p>One of the first qualitative studies to explore all devices.</p> <p>Focus groups allow for discussions to expand and follow patients' thoughts.</p> <p>Six centres in the study.</p>	Strong
Park and Lee (2020) South Korea	<p>Participants: 41 patients with cancer.</p> <p>Gender: Males = 21 Female = 20</p> <p>Mean age: 45.1 years (SD = 11.1 years; range, 18-64 years)</p>	<p>To investigate the discomforts and satisfaction that cancer patients with a CVC may experience in daily activities as an outpatient and to provide a rationale for nursing interventions.</p>	<p>More information required.</p> <p>Sufficient emotional support should be provided to the patient to minimise discomfort.</p> <p>Patient education needed to empower patient self-care.</p> <p>An understanding of the cultural aspect of South Korean patient who practice the Confucian ethics of 'unaltering one's body' and are therefore reluctant to have a CVC inserted is needed.</p>	<p>Quantitative, descriptive survey questionnaire- based study.</p> <p>Modified survey tool.</p>	<p>Single care facility only.</p> <p>Structured questionnaire, non-validated. Issues of potential researcher bias.</p> <p>Convenience sampling reduces generalisability.</p>	Moderate

2.7 RESEARCH APPROACH / METHODOLOGIES

2.7.1 POPULATION

Studies in this review originated from across the globe. Six studies were from the United Kingdom (Molloy *et al.*, 2008; Oakley, Wright and Ream, 2000; Gabriel, 2000; Campbell *et al.*, 2004; Ritchie, *et al.*, 2015; Ryan *et al.*, 2019) and four from Germany (Kreis *et al.*, 2007; Ignatov, *et al.*, 2009; Nagel *et al.*, 2012; Goltz *et al.*, 2013). Other European contributions to the review include three from Sweden (Johansson *et al.*, 2009; Alpenberg, Joelsson and Rosengren, 2015; Edström, Lindqvist and Rosengren, 2016), South Korea contributed two studies (Song and Oh, 2016; Park and Lee, 2020). One study came from each of the following countries: Japan (Yamada *et al.*, 2010), Belgium (Goossens *et al.*, 2005), Denmark (Møller and Adamsen, 2010), Austria (Minichsdorfer, *et al.*, 2016), Australia (Sharp *et al.*, 2014), Spain (Parás-Bravo *et al.*, 2018), United States of America (Chernecky, 2001), Brazil (Martin *et al.*, 2008), and Canada (Burbridge and Goyal, 2016).

The age ranges and gender of the participants can be found in Table 2.6. Gabriel, (2000) and Alpenberg, Joelsson and Rosengren, (2015) did not list any demographic information.

2.7.2 EXPOSURE

The majority of studies recruited participants who had their vascular access device inserted for the delivery of chemotherapy (Oakley, Wright and Ream, 2000; Chernecky, 2001; Goossens *et al.*, 2005; Kreis *et al.*, 2007; Martins and de Carvalho, 2008; Molloy, Smith and Aitchison, 2008; Ignatov, *et al.*, 2009; Johansson *et al.*, 2009; Møller and Adamsen, 2010; Nagel *et al.*, 2012; Goltz *et al.*, 2013; Alpenberg, Joelsson and Rosengren, 2015; Ritchie, *et al.*, 2015; Burbridge and Goyal, 2016; Edström, Lindqvist and Rosengren, 2016; Minichsdorfer, *et al.*, 2016; Yagi *et al.*, 2016; Parás-Bravo *et al.*, 2017; Ryan *et al.*, 2019; Park and Lee, 2020). However, most of these studies focus on patients with either a PICCs or TIVAD. Three studies

recruited patients who required their devices for a variety of reasons, including chemotherapy infections or difficult venous access (Gabriel, 2000; Nagel *et al.*, 2012; Sharp *et al.*, 2014); one was concerned with patients with burns (Song and Oh, 2016); and one with patients with cystic fibrosis (Campbell *et al.*, 2004).

2.7.2.1 Sampling

Eight studies employed purposeful sampling (Martins and de Carvalho, 2008; Goltz *et al.*, 2013; Sharp *et al.*, 2014; Alpenberg, Joelsson and Rosengren, 2015; Ritchie, *et al.*, 2015; Minichsdorfer, *et al.*, 2016; Parás-Bravo *et al.*, 2018; Ryan *et al.*, 2019). One was a randomised controlled study (Møller and Adamsen, 2010). The remainder of the studies employed a convenience sampling approach (Oakley, Wright and Ream, 2000; Gabriel *et al.*, 2000; Chernecky, 2001; Campbell *et al.*, 2004; Goossens *et al.*, 2005; Kreis *et al.*, 2007; Molloy, Smith and Aitchison, 2008; Johansson *et al.*, 2009; Yamada *et al.*, 2010; Nagel *et al.*, 2012; Song and Oh, 2016; Edström, Lindqvist and Rosengren, 2016; Burbridge, 2016; Yagi *et al.*, 2016; Park and Lee, 2020).

2.7.3 OUTCOME

Eleven studies focus solely on the patient experience of PICCs (Oakley, Wright and Ream, 2000; Gabriel, 2000; Molloy, Smith and Aitchison, 2008; Yamada *et al.*, 2010; Sharp *et al.*, 2014; Alpenberg, Joelsson and Rosengren, 2015; Edström, Lindqvist and Rosengren, 2016; Song and Oh, 2016; Parás-Bravo *et al.*, 2018; Park and Lee, 2020). Ten focused on TIVADs (Chernecky, 2001; Campbell *et al.*, 2004; Goossens *et al.*, 2005; Kreis *et al.*, 2007; Martins and de Carvalho, 2008; Ignatov, *et al.* 2009; Nagel *et al.*, 2012; Goltz *et al.*, 2013; Burbridge and Goyal, 2016; Minichsdorfer *et al.*, 2016; Yagi *et al.*, 2016). One study focuses on patients with a TCVC, whilst the final three studies focus on two or more of the devices (Johansson *et al.*, 2009; Ritchie *et al.*, 2015; Ryan *et al.*, 2019).

2.7 TYPE OF STUDY

Four studies were dated between the year 2000 and 2005 (Oakley, Wright and Ream, 2000; Gabriel, 2000; Chernecky, 2001; Goossens *et al.*, 2005). Six studies were dated between 2006 and 2010 (Kreis *et al.*, 2007; Martins *et al.*, 2008, Ignatov, *et al.* 2009; Johansson *et al.*, 2008; Molloy, Smith and Aitchison, 2008; Møller and Adamsen, 2010). Four studies were dated between 2011 and 2015 (Nagel *et al.*, 2012; Goltz *et al.*, 2013; Alpenberg, Joelsson and Rosengren, 2015; Ritchie *et al.*, 2015). The majority of studies in this review (nine) were published in the period between 2016 and February 2020 (Yagi *et al.*, 2016; Song and Oh, 2016; Burbridge and Goyal, 2016; Minichsdorfer *et al.*, 2016; Yagi *et al.*, 2016; Edström, Lindqvist and Rosengren, 2016; Parás-Bravo *et al.*, 2018; Ryan *et al.*, 2019; Park and Lee, 2020)

Ten of the studies were qualitative (Oakley, Wright and Ream, 2000; Gabriel, 2000; Martins *et al.*, 2008; Møller and Adamsen, 2010; Sharp *et al.*, 2014; Alpenberg, Joelsson and Rosengren, 2015; Ritchie *et al.*, 2015; Song and Oh, 2016; Parás-Bravo *et al.*, 2018; Ryan *et al.*

al., 2019), Fourteen were quantitative studies (Chernecky, 2001; Campbell *et al.*, 2004; Goossens *et al.*, 2005; Kreis *et al.*, 2007; Ignatov, *et al.* 2009; Yamada *et al.*, 2010; Nagel *et al.*, 2012; Goltz *et al.*, 2013; Johansson *et al.*, 2009; Burbridge and Goyal, 2016; Minichsdorfer *et al.*, 2016; Yagi *et al.*, 2016; Edström, Lindqvist and Rosengren, 2016; Park and Lee, 2020) and one was a mixed methods study (Molloy, Smith and Aitchison, 2008).

2.7.4.1 Data collection methods

The data collection instrument used by Chernecky, (2001) had been pilot-tested, and face and content validation were performed by two nurse researchers. Subsequently, this tool was modified and utilised in the study by Goossens *et al.*, (2005). Lastly, Burbridge and Goyal, (2016) used a validated quality of life assessment tool for data collection. However, the remaining studies utilised self-reported questionnaires and non-validated tools that had not been tested for psychometric properties or verified for internal and external validity as data collection methods (Molloy *et al.*, 2008; Gabriel, 2000; Chernecky, 2001; Campbell *et al.*, 2004; Goossens *et al.*, 2005; Kreis *et al.*, 2007; Johansson *et al.*, 2009; Ignatov, *et.al.*, 2009; Nagel *et al.*, 2012; Goltz *et al.*, 2013; Edström, Lindqvist and Rosengren, 2016; Burbridge and Goyal, 2016; Harrold, Martin and Scarlett, 2016; Minichsdorfer *et al.*, 2016; Yagi *et al.*, 2016; LeVasseur *et al.*, 2018; Park and Lee, 2020).

The majority of these tools were designed by the authors or by other healthcare professionals from the study area (Johansson *et al.*, 2004; Goossens *et al.*, 2005; Molloy, Smith and Aitchison, 2008; Kreis *et al.*, 2007; Nagel *et al.*, 2012; Goltz *et al.*, 2013; Yagi *et al.*, 2016; Edström, Lindqvist and Rosengren, 2016; Minichsdorfer, *et al.*, 2016). Some authors took steps to ensure that the tools were evaluated and adapted prior to use. Molloy, Smith and Aitchison, (2008) had their questionnaire reviewed by an expert panel who agreed that it had face and content validity in that it was representative of the interview themes. Meanwhile, Kreis *et al.*,

(2007) designed a provisional questionnaire that was evaluated by patients, which was then amended to reflect the comments and suggestions.

Semi-structured interviews were the data collection tool for the majority of qualitative studies in this review (Oakley, Wright and Ream, 2000; Gabriel, 2000; Molloy, Smith and Aitchison, 2008; Møller and Adamsen, 2010; Alpenberg, Joellson and Rosengren, 2015; Parás-Bravo *et al.*, 2018). Song and Oh, (2016), Ritchie *et al.*, (2015), and Ryan *et al.* (2019). Telephone interviews were the data collection tool used by Ignatov, *et al.*, (2009). Finally, Martins and de Carvalho (2008) used a qualitative Critical Incident Technique (CIT) to evaluate patients' perceptions of their TIVADs.

2.8 THEMATIC SYNTHESIS

The method of synthesis was thematic, as described in Section 2.5.3. It could be suggested that, by bringing these research studies together, individual findings may be decontextualized, and an assumption made that the findings are commensurable (Campbell *et al.*, 2003). However, throughout this synthesis, attempts were made to bring the study findings together whilst preserving and respecting the essential context and complexity of the original research.

The literature review identified four main themes: Improvement in treatment burden, Impact on activities of daily life, Impact on body image, and Living with apprehension and anxiety. These themes will now be discussed.

COMMON THEMES	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	
IMPROVEMENT IN TREATMENT BURDEN	X	X	X	X	X	X		X		X	X	X	X	X		X	X	X	X	X	X	X		
IMPACT ON DAILY LIFE	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
IMPACT ON BODY IMAGE		X	X	X	X	X	X		X	X	X			X	X		X	X		X	X	X	X	
LIVING WITH APPREHENSION AND ANXIETY		X	X			X	X	X	X	X			X	X	X	X	X			X	X	X	X	

FIGURE LEGEND:

1: Gabriel, (2000); 2: (Oakley, Wright, and Ream, (2000); 3: Chernecky, (2001); 4. Goossens *et al.*, (2005); 5. Kreis *et al.*, (2006); 6. Martins and de Carvalho, (2008); 7. Ignatov *et al.*, (2008), 8. Molloy, Smith, and Aitchison, (2008); 9. Johansson *et al.*, (2009); 10. Moller *et al.*, (2010); 11. Nagel *et al.*, (2012); 12. Goltz *et al.*, (2013); 14. Sharp *et al.*, (2014); 14. Alpenberg *et al.*, (2015); 15. Ritchie *et al.*, (2015); 16. Edström *et al.*, (2016); 17. Song and Ho (2016); 18. Burbridge and Goyal, (2016); 19. Minchsdorfer *et al.*, (2016); 20. Yagi *et al.*, (2016); 21. Parás-Bravo *et al.*, (2017); 22. Ryan *et al.*, (2019); 23. Park and Lee, (2020).

Table 2.7: Thematic Synthesis Matrix of Common Themes

2.8.1 IMPROVEMENT IN TREATMENT BURDEN

The majority of studies in this review concluded that patients express satisfaction with their VAD (Molloy *et al.*, 2008; Oakley, Wright and Ream, 2000; Chernecky, 2001; Ignatov, *et al.*, 2009; Nagel *et al.*, 2012; Alpenberg, Joelsson and Rosengren, 2015; Edström, Lindqvist and Rosengren, 2016; Yagi *et al.*, 2016). Patients in the study by Parás-Bravo *et al.*, (2018) regarded their PICC as a positive experience, whilst Yamada *et al.*, (2010) concluded that patients found PICCs comfortable and convenient. Concurring, patients in the studies by Kreis *et al.*, (2007); Sharp *et al.*, (2014) and Ryan *et al.*, (2019) all voiced acceptability of their VADs. In the study by Burbridge and Goyal, (2016), the conclusion was that TIVADs were positively received by patients and, echoing this, patients in the study by Song and Oh, (2016) expressed appreciation of their PICC. Despite these findings, it can be argued that, rather than acceptance and satisfaction, patients were actually tolerating their device as they were preferable to the alternatives of which they were aware or had already experienced. This argument is highlighted in a verbatim statement from a patient in the study by Edström, Lindqvist, and Rosengren, (2016) who, when discussing their device, stated: ‘*I felt like I had no alternative*’, and is further

emphasised by a patient who saw their device as a '*necessary evil*' (Ritchie *et al.*, 2015, p.410). Additionally, many studies identified that the presence of a long-term VAD reduced some of the burdens associated with treatment. It can, therefore, be argued that improvement in treatment experience may be the primary reason for acceptance and satisfaction of long-term VADs, especially when considering that, without a VAD, treatment may not be possible.

Møller and Adamsen (2010) conclude that patients view their VAD as important because the devices are the main port of treatment towards a cure. Furthermore, patients positively adjust to the placement of the catheter in the body by viewing the catheter as a function of treatment. In agreement, Molloy, Smith, and Aitchison, (2008) state that the acceptance of a PICC is closely associated with illness and cure. Equally, this finding was echoed by Nagel *et al.*, (2012) who write that 38 (90.5%) patients in their study found their TIVAD 'very much' or 'quite' simplified their course of treatment. It seems clear from reviewed literature that, in addition to vascular access being a means to administer chemotherapy, the method of vein access is crucial in relation to the patient experience.

The presence of a PICC makes treatment delivery and blood taking easier as it negates the need for skin punctures (Molloy *et al.*, 2000; Gabriel *et al.*, 2000; Chernecky, 2001; Goossens *et al.*, 2005; Sharp *et al.*, 2014; Alpenberg, Joelsson and Rosengren, 2015; Edström, Lindqvist and Rosengren, 2016; Song and Oh, 2016; Burbridge and Goyal, 2016 Yagi *et al.*, 2016; Ryan *et al.*, 2019). This finding was initially unearthed in an early qualitative study by Gabriel (2000). Gabriel (2000) suggests that patients accept vascular access devices as a necessary and useful tool for treatment delivery. Gabriel states that patients view their device as '*a solution to their difficult venous access problems*' which they perceive will be of benefit to their quality of life for the duration of their treatment Gabriel (2000, p29). Gabriel (2000) conclude that a positive aspect of the PICC is that it is a reliable form of access which removes the need for additional

venepuncture. This finding was reiterated by Chernecky (2001), who claim that almost half of the participants (n=48, 49%) in their study discussed positive experiences with their TIVAD. The experiences related to a decrease in the pain associated with venepuncture (n=7, 20%); the need for fewer venepuncture procedures (n=6, 25%); and the quicker and more effective procedure for taking blood (n=3, 12.5%). Participants in this study who had had a previous difficult experience of attempted cannulation and venepuncture (blood withdrawals) prior to their device insertion also discussed the greatest improvement in quality of life than those who did not. Agreeing, Martins and de Carvalho, (2008) conclude that the presence of a TIVAD diminishes anxiety and stress, and puts patients at ease during chemotherapy delivery. Sharp *et al.*, (2014) and Song and Oh (2016) concur and describe improvement in patient experience in vascular access because of the negation of peripheral cannulation.

More recent studies strengthen and support the fact that the reduction of peripheral cannulation improves the patient experience (Alpenberg, Joelsson and Rosengren, 2015; Edström, Lindqvist and Rosengren, (2016); Burbridge and Goyal, (2016)). These studies purport that having a VAD helped patients escape being pinpricked every time a venous-related procedure was necessary. Concurring, most subjects in the study by Burbridge and Goyal, (2016) felt that their TIVAD had been convenient for laboratory work and infusions, and that the decision to have a TIVAD inserted had a positive impact on their care. Reinforcing this, in the study by Yagi *et al.*, (2016), the second most commonly stated opinion (68%) was that multiple venepuncture procedures were no longer necessary due to the presence of their TIVAD. This is a finding once more echoed by Parás-Bravo *et al.*, (2018), who found that the greatest advantages of the PICC included the ease of access and the decrease of the numbers of punctures required. Finally, a recent study from Ryan *et al.*, (2019) agrees and concludes that long-term VADs made treatment administration less painful and easier for both the patients and the staff.

This reduction in peripheral cannulation improved the burden of treatment, which was highlighted by Minichsdorfer, *et al.*, (2016), who found that the presence of a TIVAD eased therapy administration in 96% (n=194) of patients. Patients in this study also reported a significantly higher reduction in therapy burden ($p=0.0$). Moreover, improving the treatment burden, was the finding that patients appreciate the accelerated processes in the hospital that their VAD allowed. The introduction of a PICC allows patients to receive their chemotherapy on an outpatient basis (Catherine Oakley, Wright and Ream, 2000; Kreis *et al.*, 2007; Molloy, Smith and Aitchison, 2008), which is an important finding as a reduction in hospital visits is a positive factor in patient experience.

Patients recognise the necessity to have a VAD inserted to allow treatment to be delivered safely. Therefore, to not accept a device would be to not accept treatment. Additionally, the alternative method of IV access (peripheral cannulation) is known to be less convenient, less comfortable, more difficult, and has a high failure rate (Helm *et al.*, 2015). It should not be a surprise, then, that acceptance, or tolerance, of a longer-term VAD is forthcoming, which is evident from the literature reviewed in this study. It can, therefore, be argued that the experience of multiple venepuncture procedure impacts negatively on quality of life, and the presence of a VAD has the opposite effect.

2.8.2 VASCULAR ACCESS DEVICES IMPACT ON ACTIVITIES OF DAILY LIFE

Reviewed studies predominantly conclude that a VAD impacts on the daily lives of patients. This results in patients adapting their daily activities, such as sleeping, washing and dressing, to accommodate the device (Molloy, Smith and Aitchison, 2008; Catherine Oakley, Wright and Ream, 2000; Chernecky, 2001; Martins *et al.*, 2008; Johansson *et al.*, 2009; Sharp *et al.*, 2014; Alpenberg, Joelsson and Rosengren, 2015; Ritchie *et al.*, 2015; Burbridge and Goyal, 2016; Yagi *et al.*, 2016; Minichsdorfer, *et al.*, 2016; Edström, Lindqvist and Rosengren, 2016; Parás-Bravo *et al.*, 2018; Ryan *et al.*, 2019; Park and Lee, 2020). Furthermore, social activities, exercise, and hobbies are restricted when a VAD is present (Møller and Adamsen, 2010; Sharp *et al.*, 2014; Burbridge and Goyal, 2016; Minichsdorfer, *et al.*, 2016; Edström, Lindqvist and Rosengren, 2016). These studies argue that, due to the presences of a VAD, adaption of the lifestyle of patients is necessary. The main areas affected are personal hygiene and sleeping. Adjustments and adaptations to patients' personal hygiene activities, such as showering, bathing, and hair washing, featured strongly in the literature (Oakley, Wright and Ream, (2000); Molloy, Smith and Aitchison, (2008); Johansson *et al.*, (2009); Sharp *et al.*, (2014); Edström, Lindqvist and Rosengren, (2016); and Park and Lee, (2020). Most participants in the second phase of the study by Molloy, Smith and Aitchison (2008, p.6) found that having a PICC made showering and hair washing '*a lot more difficult*'. One patient highlighted how this affected her by stating: '*If you're laying with one arm out [of the bath] you haven't got that relaxation*' (Molloy *et al.*, 2008, p.6). This statement suggests that, for this patient, having a bath was not purely for hygiene reasons but acted as a method of relaxation; a luxury which was withheld by the presence of the PICC. Concurring, Oakley, Wright, and Ream (2000) describe how participants found showering and bathing (72% and 70% respectively) problematic. Discomfort whilst in the bath was also an issue for two patients (4%) in the study by Yagi *et al.*, (2016) Johansson *et al.*, (2009) support this, and note that patients with a TCVC

felt disturbed by the device when taking a shower, taking a bath, and dressing. Edström, Lindqvist and Rosengren, 2016 concur, and describe restriction in daily hygiene routines for patients with a TIVAD; almost 80% of patients in this study reported restrictions in daily hygiene routines, such as taking a shower or a bath.

Patients make adaptations or used strategies to make the process of daily hygiene easier. This includes using plastic covers or sleeves when showering (Sharp *et al.*, 2014, Ritchie *et al.*, 2015; Ryan *et al.*, 2019). Ryan *et al.*, (2019) described how patients source various waterproof covers, whilst some patients in the study by Alpenberg, Joelsson and Rosengren, (2015) used plastic bags and tape or held their arms out of the shower to prevent water getting into the PICC. According to Alpenberg, Joelsson and Rosengren, (2015), in terms of daily hygiene, these adaptations led to additional work for the patients. However Parás-Bravo *et al.*, (2018) claims that modification of routines and the integration of the catheter into patients' personal hygiene routines is necessary to finally adapt to living with it. One example of adaptation of hygiene routines was offered by a patient in this study: '*instead of showing every day, I wait a couple of days and I am careful to try and gently wash the arm where the catheter is*' (Parás-Bravo *et al.*, 2018 p.445). Personal hygiene is a crucial part of everyday life and it is evident from the literature that the presence of a VAD has a negative impact on this.

Despite the strong evidence that VADs have a negative impact on the activities of daily life, there is still debate amongst several authors (Gabriel, 2000; Goossens *et al.*, 2005; Merizio Martins and de Carvalho, 2008; Burbridge and Goyal, 2016). Interestingly, according to the study by Burbridge and Goyal, (2016), 98% of patients claim that there is no impact on personal hygiene. In support of this, Martins and de Carvalho (2008) found that only a minority of patients in their study described bathing as problematic (CI 30%, 58%). It is important to note that the studies in which personal hygiene was unaffected were those that focused on TIVADs which are totally implanted under the skin.

Sleeping is also affected when a VAD is present (Oakley, Wright, and Ream, 2000; Chernecky, 2001; Alpenberg, Joelsson, and Rosengren, 2015; Ryan *et al.*, 2019). Oakley, Wright, and Ream, (2000) report that patients experienced difficulties with sleeping while living with a PICC. Agreeing, one participant in the study by Chernecky (2001) described an inability to sleep well due to discomfort at the insertion site. Patients highlight how the PICC affects sleeping habits and how normal sleeping positions have to be adjusted due to the presence of it (Alpenberg, Joelsson, and Rosengren, 2015). Ryan *et al.*, (2019) and Burbridge and Goyal, (2016) agree that VADs affect the sleeping habits of patients, with some having to change the way they normally sleep. One patient in the study by Ryan *et al.*, (2019) admitted that she no longer shared a room with her partner due to the presence of her VAD and the fear of her partner's movements during the night inadvertently catching her device. She stated: '*Often, I slept downstairs on the couch because I'm worried about my partner who does [big arm movements] you know, in his sleep*' Ryan *et al.*, (2019; p.4). Conversely, in the study by Martins and de Carvalho (2008), only a minority reported that sleeping (CI: 16%, 40%) was problematic.

In addition to personal hygiene regimes and sleeping, decisions about clothing selection are problematic with the presence of a VAD. Oakley, Wright, and Ream, (2000) conclude that patients experience difficulties when choosing clothing with a device in place. Furthermore, they suggest that patients with PICCs make adaptations to their choice of clothing; an example was offered of an Asian woman who was unable to wear her sari blouse due to the presence of her device. Edström, Lindqvist, and Rosengren, (2016) concur, and write that 39% of patients experience difficulties when changing clothes and dressing. The effect of clothing decisions when living with a device was also highlighted by Parás-Bravo *et al.*, (2018), who described how patients changed the way they dressed. One patient in this study admitted to no longer feeling very feminine or pretty with the catheter. Similarly, although this only affects women,

a significant finding in the study by Goltz *et al.*, (2013) was that difficulties were experienced whilst wearing a brassiere, which could be related to the chest placement site of the TIVAD. These admissions emphasise the impact that a VAD can have on the lives of patients, and how they view their personal selves following insertion of the device.

It is clear that the presence of a VAD causes disruption to other daily activities. These activities include driving, doing household chores, and childcare commitments. Ritchie *et al.*, (2015) discuss how patients focussed on strategies to minimise this disruption. The need to retain continuity of daily life also emerged as a priority for patients in the study. This finding was echoed in the study by Alpenberg, Joelsson and Rosengren, (2015), who discuss how patients adapted the way they carried out daily chores, doing so with caution as a result of their PICC. Conversely, Yagi (2016) states that all patients in their study appeared to adjust well at home, with six (60%) patients continuing to undertake household chores. The participants in the study by Yagi (2016) all had a TIVAD rather than an externally sited device, which would account for this variation.

Driving, or being a passenger in a car, is something done by most individuals as part of daily life. However, Yagi *et al.*, (2016) found that patients experience difficulties fastening seatbelts (6%). This was due to the presence of their chest-placed TIVAD which causes discomfort. In support of this, it was claimed that driving a car and wearing a seat belt both created problems for patients with chest-placed TIVADs (Goltz *et al.*, 2013).

According to the literature, the presence of a VAD places your life on hold. This was highlighted by a patient in the study by Ritchie *et al.*, (2015), who described the undesirable dependency on healthcare professionals for care and maintenance procedures which contributed to a feeling of their life being on hold. In agreement, Edström, Lindqvist and Rosengren, (2016) claim that weekly dressing changes created restrictions to daily life. Patients also limited activities or

remained indoors because of their VADs, due to worry about PICC blockages (Song and Oh, 2016), fear of device damage, or the need to maintain privacy (Møller and Adamsen, 2010).

Regarding sports and extracurricular activities, Møller and Adamsen (2010) conclude that it was the need to maintain privacy which resulted in patients initiating partial isolation; that is, refraining from activities such as going to the beach, sunbathing, and playing sports. By isolating themselves, patients did not have the fear of their device being seen by others. This finding was strengthened by Sharp *et al* (2016), who describe how one patient could not continue with his hobby of target shooting because of the potential for the PICC to be damaged during the recoil action of the firearm. Similarly, Edström, Lindqvist and Rosengren, (2016) claim that 50% of patients were faced with restrictions during exercise due to the presence of their VAD. Some patients felt uncomfortable while practising sports; such unease was related to the need of having to reflect on whether a patient could practice an activity, or if it entailed a risk to the catheter, rather than being related to the actual presence of the device (Parás-Bravo *et al.*, 2018). Additionally, Parás-Bravo *et al.*, (2018) conclude that those with a PICC in the dominant arm reported feeling apprehensive regarding the performance of daily life activities, as they fear damaging the catheter.

Despite the negative impacts of VADs on daily life, the early study by Gabriel (2000) concludes that a PICC did not affect participants' lifestyle. According to this study, the majority of participants found PICCs comfortable and their lifestyles were unaffected, with one participant out of 15, who reported the negative impact of not being able to have a bath. Equally, Martins and de Carvalho (2008) conclude that the TIVAD provides greater independence and fewer restrictions on carrying out daily activities. Similarly, Goossens *et al.* (2005) state that nearly half of the participants with a TIVAD (49%, n=48) expressed positive experiences with their VAD. Additionally, 77% (n=69) of participants in the study reported that the TIVAD had no influence on their quality of life. Molloy, Smith, and Aitchison (2008) also found that

participants' lifestyles were relatively unaffected by the device, and that participants adjusted to and accepted their PICC following a period of adaptation. Minimal difficulties were reported by most participants in the study, with 77% reporting a positive adaptation to the PICC. According to Molloy, Smith, and Aitchison (2008), patients living with a PICC can continue with their daily living activities. Finally, Oakley, Wright, and Ream (2000) lend strength to this argument, concluding that patients adjusted to life with PICCs once at home and, furthermore, they were able to continue undertaking household chores and typical everyday activities such as driving.

2.8.3 VASCULAR ACCESS DEVICES AND BODY IMAGE

Irrespective of the vascular access device, its presence results in changes to the body and impacts body image (Oakley, Wright and Ream, 2000; Chernecky, 2001; Campbell *et al.*, 2004; Molloy, Smith and Aitchison, 2008; Møller and Adamsen, 2010; Burbridge and Goyal, 2016; Ryan *et al.*, 2019; Pak and Lee, 2020). Subsequently, attempts by patients to conceal the device are common and feature strongly in the literature review findings.

The only reviewed study focusing on patients living with a TCVC was performed in Copenhagen by Møller and Adamsen (2010). Eighty-two patients from a haematology ward with a TCVC were enrolled in the study. Metaphors used by some participants in this study illustrated a high degree of dissociation with the body. One example came from a 39-year-old woman: *'I see myself as a human experiment with tubes coming out everywhere, no hair, no nails – ugly and painful – a little like an experiment'* (Møller and Adamsen, 2010, p. 431). Another example from the same study came from a 54-year-old man, who stated: *'When one looks in the mirror, one appears different from before – and although it is just an image, it remains ingrained'* (Møller and Adamsen, 2010, p. 431). These findings were echoed by Burbridge and Goyal, (2016) who found that patients experienced negative body image perceptions and viewed chest ports as too visible and ugly. Similarly, one patient in the study by Oakley, Wright, and Ream (2000, p. 212) referred to her arm in which the PICC was inserted as her *'bad arm'*. These statements highlight the negative feelings and thoughts that patients experience towards their VADs.

Some patients become disturbed by the presence of their device (Chernecky, 2001; Campbell *et al.* 2004; Martins *et al.*, 2008); this appears to be due to the cosmetic results and scarring associated with the device. Campbell *et al.* (2004) describe how cosmetic results were reported

in more than 49% of responses. Patients in this study noted that they did not like the look of the scar resulting from TIVAD insertion. In the study by Chernecky, (2000), 28 patients (66.7%) considered the port to be a disturbing foreign object. This caused negative feelings, such as: *'It disturbs me that I have something foreign in my body'* (Chernecky, 2001p. 1614). Equally, in the study by Martins and de Carvalho, (2008), three patients (50%) indicated dissatisfaction with their physical appearance and placement of their TIVAD, expressing concern about the prominence of the device and its unusual location. Conversely, Nagal *et al.*, (2012 p.200) states that 66% (28 patients) considered TIVADs to be a disturbing foreign body only *'a little'* or *'not at all'*.

Such negativity extends beyond personal feelings and patients' fear that others might have the same thoughts about their VAD. Patients with a VAD fear being stared at in public (Martins *et al.*, 2008; Møller and Adamsen, 2010), and imagine that, if people do see the device, they are too frightened to ask about it (Oakley, Wright, and Ream, 2000). Conversely, when people do enquire about the device, this appears to cause distress (Oakley, Wright, and Ream, 2000; Burbridge and Goyal, 2016). Ryan *et al.*, (2019) found that, no matter the device, patients expressed different sorts of emotion when they discussed their decision to show their device to others. Discomfort was experienced by patients with PICCs and TCVCs regarding the device appearance and how it might make others feel, this was summed up by one study participant: *'I don't like seeing a tube going into my chest, so I don't imagine other people want to see it either'* (Ryan *et al.*, 2019. p. 5).

To prevent these potentially distressing situations, patients consciously try to hide their devices from others (Oakley, Wright, and Ream, 2000; Martins *et.al*, 2008; Møller and Adamsen; 2014; Ritchie *et.al*, 2015; Burbridge and Goyal, 2016; Parás-Bravo *et al.*, 2018). To conceal and accommodate their device, patients adopt a conscious approach to choosing clothing (Oakley, Wright, and Ream, 2000; Edström, Lindqvist and Rosengren, 2016; Parás-Bravo *et al.*, 2018).

Patients become resourceful, with some designing their own protective covers, such as adapting old pair of tights to use as a protective cover for a PICC (Ryan *et al.*, 2019). Parás-Bravo *et al.*, (2018) also describe how some female patients used other types of clothing, or changed their dressing habits, to conceal the catheter. This author claims this was done '*out of shame*' (Parás-Bravo *et al.*, 2018.p.447). Martins *et al.*, (2008) supports this, their study discusses how some patients felt ashamed of their bodies and limited the type of clothing worn. These patients felt dissatisfied with their bodies and experienced sadness because they could not wear what they wished. The desire to hide the device was also a strong theme in studies by Ritchie *et al.*, (2015) and Burbridge and Goyal, (2016). Participants used words such as '*hide*', '*conceal*', or '*cover*' repeatedly. For example, '*I try to hide it [the VAD] as much as I can*' (Ritchie *et al.*, 2015, P. 410).

The presence of a VAD can be a reminder of infirmity, and represent a badge of illness (Molloy, Smith and Aitchison, 2008; Chernecky, 2001; Sharp *et al.*, 2014; Alpenberg, Joelsson and Rosengren, 2015; Burbridge and Goyal, 2016). For some patients, the PICC began to symbolise the disease and treatment progress; one patient stated: '*I think when you look at it [...] it makes you think about the sickness you are going through [...] once it came out you feel like you're starting to heal*' (Sharp *et al.*, 2014 p. 31). Alpenberg, Joelsson, and Rosengren, 2015 concur, and found that the PICC became a symbol of disease which patients looked forward to having removed. Moreover, Burbridge and Goyal, (2016) argue that 39%-47% of patients felt that the device reminded them of their disease. The visibility and presence of a TIVAD is often associated with cancer, meaning it becomes impossible to hide the fact that patients have cancer and are undergoing treatment (Chernecky, 2001; Møller and Adamsen, 2010). Møller and Adamsen (2010) found that the catheter acted as a constant visible expression and reminder of the illness, which led to feelings of repulsion and being ugly to others. Finally, patients can

remain aware of their devices '24/7'. A patient in the study by Ryan et al., (2019) explained that he came to resent his treatment because he conflated treatment and mode of delivery.

The reviewed studies suggest that a VAD results in changes in body image. Patients conceal their devices so that they do not have to visualise it. This is because they often feel it is undesirable. Patients utilise methods and strategies to hide the device from others because they feel shame or stigma about the presence of the VAD. If the device is hidden, they do not have to discuss it with others; they do not have to divulge information about their illness or treatment, and privacy can be maintained. An important finding from the study by Park and Lee (2020, p.101) highlights that many South Koreans practice traditional Confucian ethics of 'unaltering one's body' and are, therefore, reluctant to have VADs inserted. This factor should be considered for other religions or systems of belief with the same precept.

Therefore, having a VAD can have a negative impact on the body image of patients. The visibility of the device can leave patients with a constant reminder of their illness which can be disturbing. In addition, the option of keeping their illness to themselves is taken away due to the visibility of the device. To counteract this, participants attempted to conceal their devices from others. A final key finding from these studies was the anxiety and fear experienced by patients whilst living with a VAD

2.8.4 LIVING WITH APPREHENSION AND ANXIETY

The studies reviewed illustrate the fact that participants experience apprehension and anxiety prior to, and whilst living with, a VAD (Oakley, Wright, and Ream, 2000; Chernecky, 2001; Kreis *et al.*, 2007; Molloy, Smith, and Aitchison, 2008; Goltz *et al.* 2013; Sharp *et al.*, 2014; Edström, Lindqvist and Rosengren, 2016; Alpenberg, Joelsson and Rosengren, 2015; Ritchie, *et al.*, 2015; Song and Oh, 2016; Ryan *et al.*, 2019). This appears to be related to the information received regarding potential device complications prior to insertion. Molloy, Smith, and

Aitchison (2008) capture this in a statement by a patient: '[...] *is it going to turn into septicaemia or phlebitis or thrombosis because that is the actual words they used [...]* frightening names' (Molloy, Smith and Aitchison, 2008, p. 6). Having this knowledge seems to trigger anxiety before the device is actually inserted (Sharp *et al.*, 2014), which is an issue evident across all device types. Once the VAD is inserted, patients continue to feel worry and concern about potential device complications, such as infection, device blockage, spillage of chemotherapy, and catheter malfunction and dislodgement (Chernecky, 2001; Kreis *et al.*, 2007; Molloy, Smith and Aitchison, 2008; Johansson *et al.*, 2009; Goltz *et al.*, 2013; Song and Oh, 2016).

In addition to potential complications, the presence of the device itself appears to be an issue for some patients. Sharp *et al.*, (2014) claim that apprehension is a result of considering a piece of plastic was left in the body. The fact that the device's tip then terminates in the heart can also cause concern for patients, as demonstrated by small group of participants (n=3) in the study by Oakley, Wright, and Ream (2000). Similarly, location was a source of anxiety found by Sharp *et al.*, (2014); the fact that the tip of the VAD resides in central circulation, close to the heart, was perceived as frightening and resulted in concerns that such placement could lead to an adverse event (Sharp *et al.*, 2014). Furthermore, the relationship between the external part of the device being in contact with the outside world and the tip being in the central circulation caused further anxiety due to the potential for infection or sepsis (Oakley, Wright and Ream, 2000; Johansson *et al.*, 2009; Goltz *et al.* 2013; Sharp *et al.*, 2014; Alpenberg, Joelsson and Rosengren, 2015; Edström, Lindqvist, and Rosengren, 2016; Burbridge and Goyal, 2016).

All devices were associated with concerns about inadvertent removal, dislodgement, accidental damage, or device blockage (Oakley, Wright and Ream, 2000; Goltz *et al.* 2013; Sharp *et al.*, 2014; Alpenberg, Joelsson, and Rosengren, 2015; Burbridge and Goyal, 2016; Song and Oh, 2016; Parás-Bravo *et al.*, 2018; Ryan *et. al.*, 2019), which caused restrictions and anxieties

during normal arm movement (Sharp *et al.*, 2014). Patients with a TIVAD also feared dislocation of their TIVAD during sleep (Goltz *et al.* 2013). One patient in the study by Ryan, *et al.* (2019) described worry regarding hugging her husband in case the VAD got caught up, which resulted in a fear of device dislodgement. In addition to device damage, Goltz *et al.* (2013) describe patients expressing concerns and anxieties around device blockage. These findings are comparable to those of Song and Oh, (2016), who describe how patients restricted their outings due to this fear. For example, *'I couldn't go out because of a fear of it blocking'* (Song and Oh, 2016, p.1442). Finally, a fear of device damage was highlighted in the literature (Burbridge and Goyal, 2016; Parás-Bravo *et al.*, 2018). Such was this fear that some patients worried about normal everyday activities, with one patient describing feelings of unease when holding their children or practicing sports. Patients feared that acting as usual might damage the catheter: *'as I have the catheter in my dominant arm, I'm afraid it will break because I move it more [...] I try to move that arm less'* (Parás-Bravo *et al.*, 2018. p446). Likewise, Edström, Lindqvist, and Rosengren, (2016) argue that worry about the device caused patients anxiety regarding heavy lifting and, sadly, often prevented them from playing with their children (29.4%) or hugging friends and family members (19.5%).

Healthcare workers' lack of knowledge leads to anxiety whilst living with a VAD (Chernecky, 2001; Goossens *et al.*, 2005; Molloy, Smith, and Aitchison, 2008; Alpenberg, Joelsson, and Rosengren, 2015; Ritchie, *et al.*, 2015; Ryan *et al.*, 2019). Gabriel *et al.* (2000) describe how participants who had previously had a VAD in place were concerned with the care of their device being undertaken by junior medical staff. Previous experiences and knowledge had led these patients to question the techniques and skills of this group of junior practitioners. Chernecky (2001) also describes how one patient noted that experience and knowledge of staff about TIVADs in areas that were not haematological was lacking. The patient stated: *'Some hospitals won't use it for blood draws or to give fluids through, it disturbs me that I have*

something foreign in my body and I can't get blood out of it' (Chernecky, 2001, p. 1614). This was echoed by Goossens *et al.*, (2005), who also highlight a lack of experience and knowledge of staff about TIVADs. Furthermore, Alpenberg, Joelsson, and Rosengren, (2015) describe feelings of insecurity and concerns about potential complications resulting from nurses' uncertainty and doubt when handling devices, performing dressing changes, and variations in practice. Concurrently, lack of staff knowledge was a source of worry and led to delays and inconvenience according to Ryan *et al.*, (2019). Finally, Alpenberg, Joelsson, and Rosengren, (2015) describe disparity in dressing skills which made patients feel insecure; patients in this study also expressed anxiety and insecurity due to lack of aseptic conditions.

To protect themselves from perceived potential harm, patients often take a defensive stance regarding care and maintenance, regularly performing self-care (Ritchie *et al.*, 2015). However, to feel as if they are in safe hands, patients stress how important it is that nurses know how to look after the device. Patients also need to know what is going to happen to them to help reduce anxiety (Alpenberg, Joelsson and Rosengren, 2015). At present, it appears that many patients resort to either teaching staff themselves or travelling to other hospitals in order to ensure that they are in safe hands. Patients suggest that HCPs spend extra time explaining everything and provide information about who to contact if there are any concerns.

It can be argued, however, that information, if given, is not always welcomed, or retained, by patients. This is due to the timing of information giving; some patients have trouble in maintaining or retaining information that is given to them (Molloy, Smith and Aitchison, 2008). As suggested by Molloy, Smith, and Aitchison (2008), difficulty in such retention was because information about the need for PICC insertion was usually given at a time of stress, such as during the imparting of information about the return of cancer, details of prognosis, or details of chemotherapy side-effects. Subsequently, participants found it difficult to retain information they were given about the PICC. The timing of information giving was also underlined by

Oakley, Wright, and Ream (2000). In this study, five out the 10 participants (50%) discussed the importance of the timing of information, suggesting that this should be imparted at a pace suitable to each individual patient. Furthermore, the amount of information imparted was a key factor when living with a PICC. Molloy, Smith, and Aitchison (2008) agree that each patient should be considered individually before deciding upon the amount of information given. This kind of consideration would reduce the feeling of being overwhelmed with the volume and nature of information. Some participants in this study described the information given to them as *'unhelpful'*, *'excessive'*, and *'frightening'*. Conversely, of the 10 participants in the study by Oakley, Wright, and Ream (2000), nine felt reassured and less anxious following the information they received. Individualised patient needs were reflected in that some patients preferred information in a written form, while others felt more benefit from verbal communication. Two participants in the study by Oakley, Wright, and Ream (2000) suggested that the opportunity to speak with or meet another patient who had a PICC would have helped them learn about life with the device. These studies suggest that the optimal amount and type of information imparted to each patient should be decided based on individual consideration.

2.9 IDENTIFYING THE GAP IN THE LITERATURE

Based on the literature review findings, certain gaps are evident, including a focus on patient experience and meaning making. The majority of previous studies focus on patient satisfaction and quality of life rather than patient experience. Therefore, in-depth, meaningful details about how participants make sense of their experiences and their meaning-making processes have

been understudied. The approach taken for these studies focused on the ‘what’ of the experience rather than ‘how’ the experience impacted on the participant.

2.9.1 POPULATION (Sample)

The predominance of studies in this review used convenience sampling to recruit participants (Oakley, Wright and Ream, 2000; Gabriel *et al.*, 2000; Chernecky, 2001; Campbell *et al.*, 2004; Goossens *et al.*, 2005; Kreis *et al.*, 2007; Molloy, Smith and Aitchison, 2008; Johansson *et al.*, 2009; Yamada *et al.*, 2010; Nagel *et al.*, 2012; Song and Oh, 2016; Edström, Lindqvist and Rosengren, 2016; Burbridge, 2016; Yagi *et al.*, 2016; Park and Lee, 2020). The most obvious criticism of such a method is sampling bias, and that the sample is not representative of the entire population. It is highly vulnerable to selection bias and other influences beyond the control of the researcher. These factors result in a lower study credibility. The use of inclusion criteria, however, would result in the assurance that attributes of subjects that are essential for their selection to participate are considered. Inclusion criteria identify the study population in a consistent, reliable, uniform, and objective manner and, therefore, remove the influence of specific confounding variables (Garg, 2016).

Although the majority of studies originated from the United Kingdom, to date, there have been no studies conducted on the experience of living with a vascular access device within an exclusively Scottish context and including all three of the long-term VADs available. The inclusion of a study from an exclusively Scottish perspective may add to the body of research by introducing experiences from a different patient group and healthcare system.

2.9.2 EXPOSURE

Aside from the studies by Ritchie, *et al.*, (2015) and Ryan *et al.*, (2019), the remainder focus on only one or two of the vascular access devices. Additionally, only one study had a focus on the experiences of living with a TCVC (Johansson *et al.* 2009). This demonstrates a lack of

research that enables comparisons of the experiences of patients with the range of long-term VADs. Authors in the review also suggested further studies comparing the experiences of patients with different devices (Oakley, Wright, and Ream, 2000; Chernecky, 2001).

2.9.3 OUTCOMES

The reviewed studies have provided an insight into how a VAD impacts on patients' lives. However, the findings could be viewed as superficial as, apart from the Critical Incident study by (Martins *et al.*, 2008), they have not focused on participants' stories or uncovered their deeper feelings. It could be suggested that, in most research studies, when it comes to the insertion of a VAD, the body is viewed separately from the mind. By not considering how the device will impact on the patient psychologically, we are not viewing the person as a whole. Therefore, there remains a need to explore how participants make sense of their experiences of living with a VAD.

2.9.4 TYPES OF STUDIES

This review identified a mixture of qualitative and quantitative studies. Moreover, the quantitative studies did offer some insight into the experiences of living with VAD; although, the depth of that information was lacking, and the resulting information was superficial. This was often due to the data collection tool employed.

Most studies in the review utilised questionnaires as the data collection tool which introduces a degree of bias. Most utilised self-reported questionnaires and non-validated tools that had not been tested for psychometric properties or verified for internal and external validity as data collection methods (Molloy *et al.*, 2008; Gabriel, 2000; Chernecky, 2001; Campbell *et al.*, 2004; Goossens *et al.*, 2005; Kreis *et al.*, 2007; Johansson *et al.*, 2009; Ignatov, *et.al.*, 2009; Nagel *et al.*, 2012; Goltz *et al.*, 2013; Edström, Lindqvist, and Rosengren, 2016; Burbridge

and Goyal, 2016; Harrold, Martin and Scarlett, 2016; Minichsdorfer *et al.*, 2016; Yagi *et al.*, 2016; LeVasseur *et al.*, 2018; Park and Lee, 2020).

Questionnaires allow large populations to be assessed with relative ease. This leads to findings being more generalisable, particularly if the sample was collected randomly. However, one of the main limitations of this method is the possibility of respondents not having the ability to engage with the researcher fully, openly, and honestly. This is particularly true if the questions are of a sensitive nature. This can potentially manifest as social desirability bias, where responses which are more socially acceptable are given (Piedmont, 2015). Clarity is also an issue, as participants might have different interpretations of the questions. Moreover, if questionnaires are highly structured, participants might be forced into an answer that does not reflect their true views (Piedmont, 2015). Finally, the structure of the questionnaires could be perceived as reflecting the views of the researcher. While there are measures to reduce such bias, it is unclear if those measures were employed in these studies.

Song and Oh, (2016), Ritchie *et al.*, (2015), and Ryan *et al.* (2019) used focus group interviews as data collection tools. Focus groups can be convenient as they are less time consuming than some other forms of interview and allow a wider reach of participants. However, focus group limitations include challenges for control of the group and the potential for strong voices dominating quieter group members (Opdenakker, 2006). Although Smith, (2004) and Langdrige, (2007) believe that this combination is ripe for detailed exploration, some others remain sceptical about whether focus groups can be truly phenomenological (Dowling, 2007).

Telephone interviews were the data collection tool used by Ignatov, *et al.*, (2009). This type of synchronous interview has become more common in the past two decades. There are advantages to telephone interviews, including the fact that they are quick and inexpensive; they allow extended access to studies; and make it possible to recruit individuals from hard to reach population, such as mothers with young children, shift workers, and those with disabilities

(Mann and Stewart, 2000). In addition, the anonymity of the respondents is ensured, which is a particular advantage if the interview relates to sensitive information (Opdenakker, 2006). Nevertheless, the disadvantages of telephone interviews for qualitative research exist. One of the main disadvantages is that it is not possible for interviewers to observe verbal responses. Although voice and intonation can be picked up, the lack of social cues, such as body language, reduce the amount of additional information that is often gained during face-to-face interviews (Opdenakker, 2006).

2.9.5 ADDRESSING THE GAP

The lived experience of being a body in the world can never be totally captured. However, it is an issue that should not be ignored or disregarded (Smith, Flowers, and Larkin, 2009). For this reason, when considering how patients experience living with a VAD the place of the body as a central element must be considered. This stance is particularly relevant due to the alteration of the body when a VAD is inserted. A clearer understanding of how the addition of a device affects the sense of self is necessary.

To address this gap in literature, a study of embodiment through the lens of an enactive approach should be considered (Barandiaran and Egbert, 2013; Laroche, Berardi, and Brangier, 2014). According to this approach, the mind is both a living and a lived phenomenon which emerges from the coupling of the agent-world (Aguilera *et al.*, 2013). Within social psychology, there has been an awareness that individuals think, feel, and act from within their bodies. Our embodiment is a unity that we live; we do not perceive the world in parts or meaningless sensations, but as a complete pre-given, pre-reflective world (Benner, 2000). As stated by Merleau-Ponty (1962, p. 159): 'I am my body'.

This literature review highlights that the meaning attributed to the experience of living with a VAD has not been explored. Consequently, in the UK literature, evidence of how patients make

sense of this experience is lacking. While some qualitative research has been conducted, it is argued that an alternative stance should be taken to provide a richer, unique insight, and consequently, gain a deeper understanding of the experiences of patients living with these devices. Therefore, more in-depth, exploratory research is warranted to help our understanding of the experience of living with a VAD.

2.10 CHAPTER TWO CONCLUSION

Chapter Two commenced by describing methods for searching, assessing, and synthesising the literature. It continued with a rationalisation and outline of the organisation of the literature review and progressed by systematically reviewing and appraising the literature in terms of methodological quality. Following synthesis and interpretation of the study findings, conclusions were drawn. From the literature review and the background information in Chapter One, a rationale for the study was developed.

The ability of this study to fill gaps in existing knowledge has been suggested. Most importantly, the need to make sense of patients' experiences of living with each of the three VAD has been detailed. Before closing this chapter, the research question, objectives, and the scope of this study will be provided.

2.11 RESEARCH QUESTIONS AND STUDY OBJECTIVES

The primary research questions for this research study is:

- How do patients with cancer experience life with a VAD?
- Are there any convergent and divergent experiences of patients living with a long-term VAD?

The objectives of this study are to explore and interpret the lived experiences of patients with cancer with a Vascular Access Device *in situ*. The next chapter will discuss the study methodology that will be utilised in the attempt to answer the research questions.

REFLEXIVE BOX: THE LITERATURE REVIEW PROCESS

(Sept 2017) I'm going to start to update and finalise my literature review chapter now, but I feel a little confused and unsure. I finished my initial literature review before I started my study (2013). This is how I recognised that there was a gap in the literature. I'm not too sure if I should start to update my literature review as I go along or to stop at this point? I know that I have to be mindful that I want to preserve openness and I feel that, if I review new research on the topic, it might influence me when I start my analysis. I have kept myself up to date with the new literature coming out and this is increasing. I'm going to see what my supervisory team thinks.

(Oct 2017) I've had a chat with the team, I'm going to return to the literature and redo my review including studies up to the current time. I'll try and not let it influence my analysis that I am doing just now – that is so difficult!

Very frustrating, my literature review has been reviewed by my supervisors and one thinks that the new studies overlap my study and findings so questions if my study is required! I think this could be a positive because I have my findings before many of the new studies that have been published did. That means that my study findings are common. We've decided that the only way that I can demonstrate that my study was necessary to fill a gap in the literature is to go back and do a literature review up to the start of my data collection. That seems to make sense to me. Back to the drawing board!

(Jan 2018) How will I bring in the new research? I know that I'm going to have to do this. Spoke to my supervisory team and I was introduced to Concurrent Analysis. I'm going to read up on it. I've also got an IPA session coming up at Glasgow Caledonian University so I'm going to ask the group what they think.

CHAPTER THREE: METHODOLOGY

3.1 INTRODUCTION

This chapter will provide an overview of the main research paradigms adopted in social research. Following this, the justification for choosing the current study's paradigm will be offered. Next, the practical and theoretical motives for employing a qualitative research design will be explained, and a rationale for choosing Interpretive Phenomenological Analysis (IPA) principles presented. Finally, a detailed account of the sampling strategy, recruitment, data collection methods, and analysis will be provided.

Since this chapter is a personal reflection, it has been written in the first person. It is recognised that the use of personal pronouns in doctoral studies is often criticised as having the potential to result in a lack of critical thinking. Subsequently, this has been discouraged in the past (Kirkman, 2005). However, within IPA, researchers 'bring their fore-conception' (prior experiences, assumptions, preconceptions) to the encounter, and cannot help but look at any new stimulus in the light of their own prior experiences (Smith, Flowers and Larkin, 2009, p.25). This implies that, as the researcher, you are actively engaged in shaping the research. In addition, the American Psychological Association (APA) 6th edition publication guidelines suggest that, to avoid ambiguity, it is appropriate to use a personal pronoun rather than the third person when describing steps taken in research studies (Shelton, 2015, p.2). In this study, I viewed myself as an instrument of inquiry. Engagement in double hermeneutics meant that I was present and dwelling within the research. I did not stand outside of the research. For these reasons, I believe that a neutral voice would have contradicted the aims of IPA. I will commence the chapter by considering my own beliefs and values, and how these have influenced my decision to use a qualitative approach underpinned by constructivism as the worldview in the design of my study.

RESEARCHER LENS

Coming to this this research, my skills and expertise lay in clinical practice and academia. My background was that of a registered nurse with interventional radiological, cardiac catheterisation, and vascular access experience. I also had gained experience as a lecturer within higher education.

I commenced my nursing career in the early 1980s, a time when debate about theory and practice, art and science, raged. I was a still a student nurse when this all began to change. In the 1960s and 1970s, the medical approach was the focus. Public health, health promotion, health education, and disease prevention were the focus. Behavioural approaches, summarised in the ideology that problems in health were contributed to lifestyle, and placing the responsibility on individuals were evident. In the 1980s, it was recognised that there were wider issues that affected public health and that measures to address social, economic, and environmental factors were required to address these issues (Conway, 2016).

Nevertheless, I believe that nursing has evolved in its perspective of health and illness, and the importance of the wider issues related to it. It is my belief that the medical model remains dominant in Western Society. However, a profession that embraces art and science dictates that health behaviours cannot be separated from social context, which is evident in the concept of holistic care (Taylor *et al.*, 2014). Despite my view on the dominance of the medical model, I recognise the shift from a focus on individual ill health to a focus on health and whole populations.

My social, environmental, and political perspectives have an involvement in how I function in all roles. As a black woman living and working in Scotland, I am aware that my background has greatly shaped my perspectives, and these may influence aspects of my study. I have always felt that I had to shout a little louder to allow my opinion to be heard and taken seriously, and this has made me very strong-minded and determined.

There are many ways to conduct research. My research lens mirrors my real-world perspective. I view the world as a global entity that is interdependent and integrated. This world is continually progressing and embraces both art and science to facilitate advances in understanding and knowledge. I believe that this should be echoed on the field of research.

3.1.2 RESEARCH PARADIGMS

A paradigm is an understanding of reality through the lens of research (Madill and Gough, 2008). Paradigms can be defined as scientific world views or epistemological stances (Crotty, 1998; Guba and Lincoln, 2005). Philosophically, researchers make claims about what knowledge is (ontology), how we know it (epistemology), what values goes into that knowledge (axiology), how we write about it (rhetoric) and the process of studying it (methodology) (Cresswell, 2009). Paradigms can also be defined as beliefs that are shared by small research communities (Madill and Gough, 2008). Guba and Lincoln (2005) identify four main research paradigms of inquiry that exist in the social sciences: positivism, post-positivism, critical theory, and constructivism.

Positivism is concerned with defining causality between variables, and is ingrained in the principles of empiricism, objectivism, observations and control (Guba, 1990). Positivist epistemology suggests that we gain knowledge by gathering facts about the world whilst viewing it in a systematic, objective way. This is typically done by the testing of hypotheses to increasingly shape and describe universal laws of nature (Potter, 2006). Traditionally, positivist assumptions have governed claims about what warrants knowledge (Cresswell, 2009). Positivists believe that there is a simple one-to-one relationship between events in the external world and individuals' knowledge of those events (Alvesson and Sköldberg, 2009). Positivist ontology views the world as objectively real and separate from human-meaning-making. In this paradigm, the researcher takes a structured, controlled approach when designing and conducting their research, and aims to discover objective and impartial knowledge about a phenomenon which is unbiased (Giorgi, 1997).

Post-positivism is also concerned with prediction and control. However, it accepts that the level of objectivity required by positivism is not always possible. Human standpoints and

understandings are fallible, meaning that selectiveness and bias can always taint preconceptions (Cresswell, 2009). Positivism and post-positivism are rooted in epistemological stances of objectivism and rely on quantitative methodologies (Gray, 2014). Critical theory, on the other hand, suggests that reality is shaped by social, political, and cultural forces which progress into structures deemed to be real (Guba, 1990). This paradigm suggests that knowledge is interwoven with the interaction between the researcher and the experience or the object. Subsequently, researchers cannot be separated from the phenomena they are exploring (Guba, 1990).

A constructivist or interpretivist paradigm was adopted for the current research. Constructivism views knowledge not as something that is waiting to be discovered but as something which is socially constructed through people's purposive and practical interactions with the social world (Ormston *et al.*, 2013). Constructivism aims to understand subjective lived experiences as they occur in certain contexts (Gray, 2014).

Constructivists study subjective perceptions and experiences through interactions, meaning they cannot be detached observers. Indeed, it is through interactions that researchers gain an insight into how and why individuals behave in certain ways. The approach must, therefore, be interactive and flexible rather than pre-planned and structured, since interactions between people are not predictable (Cresswell, 2009). Unlike positivism, constructivism suggests that researchers construct interpretations and meanings based on the participants' interpretations and meanings (Ormston *et al.*, 2013). The researcher's own understandings and views of the concept are, consequently, explored, and are acknowledged to potentially have an impact on the research process (Langdridge, 2007).

In terms of ontology, constructivism suggests that reality is relative. Ontology and epistemology are not separated because the inquirer and the object of inquiry are interlinked

(Guba and Lincoln, 2005). Constructivism is concerned with the subjective experiences of individuals and, therefore, favours the qualitative approach. By eliciting and refining personal and social constructions of knowledge, dialectical and interpretivist methodologies enable interpretation and existential understanding. This is done through an examination of the interaction between the researcher and the participants (Guba and Lincoln, 2005).

3.1.3 JUSTIFICATION FOR THE SELECTION OF A CONSTRUCTIVIST PARADIGM

The justification for using a constructivist paradigm for my study is multifactorial. Firstly, this paradigm allows the construction of reality. It is based on the distinct methodological traditions of inquiry, which explore a social or human problem (Gray, 2014). Constructivism is interested in deep descriptions, which allow data to be understood as coming from an individual rather than being an observable phenomenon, meaning it is, therefore, suited to the study. Furthermore, the current study sought to understand human experience of living with a Vascular Access Device by means of exploration, which aligns with this paradigm's understanding of the ever-changing nature of reality. Finally, constructivism permits an accurate and refined measure of realities that are multiple. This is not the case in positivist or post-positivist paradigms. Therefore, to satisfy the objective of this study, constructivism was deemed the most appropriate paradigm. The following section will consider research designs in qualitative research.

3.2 RESEARCH DESIGNS

The theoretical underpinnings of the constructivist paradigm rely on a qualitative research design. The purpose of qualitative research is the description and interpretation of human experiences. The design enables social situations or human experiences to be more clearly understood (Guba and Lincoln, 2005). Mason (2002) agrees that qualitative research allows

insight into many dimensions of the social world in the experiences and understandings of research participants, the ways in which social processes work, and the meanings generated from them. Qualitative and quantitative research designs have advantages and disadvantages, and the selection of a design must be based on which is most appropriate for the research question. Table 3.1 offers a visual representation of the differences between the two approaches:

	Qualitative Research	Quantitative Research
Researcher	Identifies personal stance	Remains in the background
Researcher intent	To understand the meanings of individuals' experiences and describe a phenomenon	To deductively test a theory so it can be supported or refuted
Researcher intent	Minor role	Major role
Literature	Justifies problem Underpins argument and research question	Justifies problem Identifies questions and hypotheses
Data Collection	Open-ended Understanding complexity of a single phenomenon Words and images Few participants	Closed-ended Test specific variables that form hypotheses/questions Numbers Many participants
Data analysis	Themes Patterns	Numerical Descriptive Infer
Data Validation	Procedures that rely on participants, researcher, or the reader	Procedures based on external standards

Table 3.1: DIFFERENCES BETWEEN QUALITATIVE AND QUANTITATIVE RESEARCH DESIGNS

3.2.1 JUSTIFICATION FOR THE SELECTION OF A QUALITATIVE RESEARCH DESIGN

The primary aim of this study was to explore the experiences of patients living with a Vascular Access Device (VAD). I, therefore, adopted a qualitative research design. Such a design accepts that the researcher is integral to the investigation (Cresswell, 2009). Moreover, it enables the exploratory nature of the aim of the research. It is built on an inductive process which involves the researcher building concepts and theories whilst the data is collected (Hamilton *et al.*, 2006). Qualitative research encompasses several approaches which seek to understand human experiences by many means, including exploration, perceptions, motivations, and behaviours (Holloway, 2015). It is a process of understanding based on distinct methodological traditions of inquiry which explore a social or human problem. Realistically, a qualitative approach was the only research design capable of answering my research question and satisfying the objective of this study. The following section will explore the different approaches to qualitative research and will conclude with a justification of my chosen research approach.

3.3 RESEARCH APPROACHES

Approaches to qualitative research continue to evolve as styles of human interactions change (Cresswell, 2009). The decision about the most appropriate approach was based both on the research question and study aims. The major potential approaches included: ethnography, grounded theory, action research, case study, and phenomenology.

3.3.1 ETHNOGRAPHY

Ethnography is an approach in which cultural and social issues, as well as society, are the focus. Direct observation is used to study participants in their ‘real life’ environment, often over

lengthy periods of time (Sutton and Austin, 2015). The researcher seeks to describe phenomena as they are experienced and expressed by individuals within groups. The aim is to gain a holistic understanding of group behaviour and interactions (Parahoo, 2014) rather than focusing on individuals (Prus, 2007). Ethnographers allow groups to speak about views and perceptions that might not otherwise be heard. According to Prus (2007), ethnography provides a window into groups as well as an understanding of what they do and why.

Goodson and Vassar (2011) caution that this approach is time-consuming and laborious. Despite this, ethnography remains a popular research approach. However, such an approach was deemed unsuitable for my study as observation is the key method that distinguishes the ethnographer. I did not believe that observing participants with a VAD in place would uncover experiences felt on a personal level. In addition, I felt that spending time with a participant who was already facing a gruelling treatment regimen for cancer therapy within their home would have been too intrusive. These patients already face many outpatient appointments for chemotherapy and blood tests, as well as care and maintenance procedures. I, thus, felt further intrusion might be too much for the patient, and, therefore, could reduce the number of willing participants. Furthermore, this could be viewed as unethical. Finally, ethnography is interested in groups, and this study was focused on the experiences of individuals. For these reasons, ethnography was not selected as a suitable approach for this study.

3.3.2 GROUNDED THEORY

Grounded theory takes a contrasting approach to other forms of qualitative research because the aim is for the researcher to develop theory that is based (or grounded) in the data as it is gathered (Glaser and Strauss, 1967). Grounded theory uses both inductive and deductive approaches to theory development. According to Field and Morse (1985, p. 23), *'constructs and concepts are grounded in the data and hypotheses are tested as they arise from the*

research'. These authors go on to argue that the generation of theory within the field of nursing is crucial if knowledge is to be developed. Jacelon and O'Dell (2005) agree and suggest that grounded theory is an excellent method for gaining an understanding of how patients manage health problems.

Myers (2009) warns that novice researchers can become inundated with the coding level necessary for grounded theory as it can be a time-consuming, tiring, and arduous process. This is, in part, due to the concept of 'data saturation', which means that data is collected using observation, field notes, and interviews until no new data emerges. Charmaz (2006) reiterates these warnings and contends that novice researchers are at risk of blurring methodological lines and might engage in purposeful sampling. This is a technique commonly used in qualitative research to identify information-rich cases (Cresswell and Plano Clark, 2010) instead of theoretical sampling.

Despite these challenges, grounded theory remains popular in a broad range of research three decades after its introduction (Thomas and James, 2006). I considered using grounded theory as a research approach. However, if this approach was employed, I considered that I might not obtain adequate samples, which would have resulted in inadequate data. Additionally, grounded theory focuses on processes rather than the lived experience, which is the focus of my study. With these considerations in mind, and with my status as a novice researcher, I decided to avoid falling into any of the pitfalls described by Charmaz (2006), and rejected grounded theory as an approach for this study.

3.3.3 ACTION RESEARCH

Action research is a process that is not easily defined and often described as a style rather than a specific method (Myers, 2009). It is a particularly useful approach for identifying problems and developing solutions. According to Hicks and Hennessy (1997), the ultimate aim of action

research is to improve practice. Within this approach, researchers work explicitly with and for people, rather than undertaking research on them (Heron and Reason, 1997). The key elements of action research are the characteristics of the participants and its simultaneous contribution to social science and social change (Carr and Kemmis, 2005). Furthermore, a fundamental aspect of action research is participation. If the participants do not perceive a requirement for change, they may choose not to engage in the research or the change process. Therefore, willingness and commitment on the part of participants is vital. Continuous negotiations and agreements with participants must be ensured in order to reduce the potential for conflict. Finally, to reduce any feelings of risk, an ethical code of practice must be agreed with participants.

Action research is an ideal approach if change and improvement are required within a setting. However, to ensure a smooth, successful process, it must be ensured that the researcher possesses excellent interpersonal skills (Meyer, 2000). My study question did not result from a requirement for change or improvement, but rather as an attempt to uncover the thoughts and feelings of participants. Therefore, I felt that action research would be inappropriate given that it would not be able to answer my research question.

3.3.4 CASE STUDY

It could be argued that, rather than being a research method in itself, the case study approach is a way to collect and analyse data which generates material suitable for in-depth qualitative analysis (Cresswell, 2009). However, I believed that this approach merited consideration in this section. When conducting a case study, the researcher performs an in-depth exploration of a program, event, activity, or process with one or more individuals. The cases are bounded by time and activity. Researchers then use a variety of data collection procedures over a sustained period of time to collect detailed information (Cresswell, 2009). A case study has the potential

for characteristics such as an idiographic focus, as well as a focus on particular context, triangulation of data (data collection from a variety of sources of information), an exploration of the implication of time (the way things are processed over time), and generation of new theories (Willig, 2001).

Due to their in-depth, multi-sided approach, case studies can shed light on aspects of human behaviours and thinking that could not be studied in other ways (Cresswell, 2009). A case study methodology does lend itself to the idiographic approach which my study warranted. Although triangulation is considered to be a powerful tool to strengthen qualitative research designs (Jonsen and Jehn, 2009), I felt that the issue of triangulation might have been too time-consuming. Moreover, as I aimed to explore the meaning that individuals applied to their experiences, I felt that case study research would curb such comprehension. Hence, the case study approach was rejected.

3.3.5 DESCRIPTIVE QUALITATIVE RESEARCH

Qualitative description is a label used in qualitative research for studies that are descriptive in nature. This approach is particularly used when examining healthcare and nursing phenomena (Polit and Beck 2014). Qualitative description is a regularly cited research tradition and is key for research questions that focus on discovering the who, what, and where of events or experiences. The purpose is to gain insights from informants about a poorly understood phenomenon. It is also an approach that is useful when a clear description of a phenomenon is sought or information is required to develop or refine question (Elliott and Timulak, 2005; Neergaard *et al.*, 2009; Sandelowski, 2010). Descriptive research can provide an in-depth view of any topic and is a valuable method of enquiry. One key benefit is that it allows us to observe phenomenon in a natural environment. Descriptive qualitative research was an option considered, but I decided that to gain a deep insight into how participants made sense of their

experiences, an interpretive approach would be an approach more capable of achieving this. Subsequently, this approach was rejected.

3.3.6 NARRATIVE RESEARCH

This research approach focuses on the meanings created through the telling of a story. Participants are requested to share their experiences through their story telling. Subsequently, the narrative from each individual case is analysed before the analysis takes place across the group. Finally, the researcher re-tells the final story. Unlike other qualitative research in this approach there is a dynamic between the researcher and participant or storyteller. The participant remains in control of the story and establishes the link between the final draft and the understandings and interpretations of the researcher. The French philosopher Paul Ricoeur has been influential in this research approach as he proposed that the underlying relationship between human existence and time is conveyed through narrative. As this study was to explore how individuals made sense of their experience of living with a vascular access device, I wanted to ensure that issues that were important to the participant were explored in detail. A casual coherent sequence of events composed from a story might not have allowed this. This is because sense-making is not always coherent, sequential or casually linked. Rather it is contradictory and non-linear. Narrative inquiry was hence rejected as a theoretical model for this study.

3.3.7 DISCOURSE ANALYSIS

This methodology is predominantly used by psychologists to unearth meanings and constructions of social reality expressed by language. Discursive psychology and Foucauldian discourse analysis are two types of the discourse analytic method. Discursive psychology was introduced by Potter and Wetherell, 2010) and disputes cognitivism. Foucauldian discourse analysis was influenced by the post-structuralist, Foucault (Willig *et al.*, 2011).

Although these methods can complement each other, Willig, (2001) suggests that they cannot answer the same research questions. Discursive psychology is concerned with how people use language to deal with their social environment and reach interpersonal objectives. Whereas Foucauldian discourse analysis considers the description of an individual's discursive worlds and the exploration and theorising of their experiences (Willig *et al.*, 2011).

Both types of discourse analysis were rejected as a methodology for this study as the aim was to uncover how individuals made sense of their experience of living with a vascular access device. The focus was not on the power of language to create such processes.

3.4 INTERPRETIVE PHENOMENOLOGICAL ANALYSIS (IPA)

The principles of Interpretive Phenomenological Analysis provided the methodology for this study. IPA is phenomenological in principle and is strongly connected to the interpretive, hermeneutic tradition (Smith, Flowers and Larkin, 2009). It involves the detailed examination of the participants' 'lifeworld' and their experiences of the phenomenon under investigation, as well as how they make sense of their experiences and the meanings they attach to them (Smith, 2009). Subsequently, IPA encourages a rich, nuanced insight into the experiences of participants, which is what I sought to achieve in this study.

3.4.1 THEORETICAL UNDERPINNINGS OF IPA

IPA was initially used as a distinctive research method in psychology in the mid-1990s. At that time, Smith (1996) argued for an approach to psychology that would permit researchers to capture both qualitative and experiential dimensions while continuing a dialogue with conventional psychology (Shinebourne, 2011). IPA has been criticised for having a weak theoretical base (Finlay, 2011). However, according to Smith, Flowers and Larkin (2009), the strength of IPA is in its meticulous description of the interpretative analysis process. The key

theoretical perspectives that IPA draw from are phenomenology, interpretation (hermeneutics), and ideography (Smith, 2009). These inform its epistemological framework and research methodology.

3.4.1.1 PHENOMENOLOGY

Phenomenology is a broad discipline which has been described as both a philosophical movement and an approach to human science research (Earle, 2010). It is a method of inquiry based on the premise that reality consists of events as understood and perceived in the human consciousness without recourse to theory, deduction, or assumptions from other disciplines, such as the natural sciences. Phenomenology attempts to understand people's perceptions, understandings, and interpretations of a situation or phenomenon, and is described by Speziale and Carpenter (2011) as the analysis of the notion of being.

The phenomenological movement began in the first decade of the twentieth century. It started as a response to a feeling of crisis in the natural sciences and has subsequently grown into a powerful research method (Taylor, 2013). Many conflicting approaches to phenomenology have emerged over time (Cohen and Omery in Morse, 1994; Lopez and Willis, 2004). The two main approaches in the literature are descriptive (eidetic) phenomenology and interpretive (hermeneutic) phenomenology (Morse, 1994). The most influential philosophers who formed the various schools of phenomenological thought and made lasting contributions to the field are Husserl, Heidegger, Gadamer, Sartre, and Merleau-Ponty (Taylor, 2013).

Husserl is considered the father of phenomenology (Polit, 2014; Holloway, 2015). Husserl, previously a mathematician, has been described as both a phenomenologist and a transcendental philosopher (Earle, 2010). His philosophical ideas about how science should be conducted led to a descriptive phenomenological approach (Duranti, 2006). Husserl was interested in epistemological questions such as '*how do we know this man?*' or '*what it is like to be human?*' The goal of his

phenomenology was describing and making sense of the lived world. It was concerned with getting “*back to the things themselves*” and with descriptions of an event by those who had experienced that event (Husserl, 2000 p.168).

A key component of Husserl’s phenomenology is the eidetic reduction or notion of bracketing, also known as epochè. Bracketing involves the researcher holding all prior beliefs and opinions about the phenomenon under study in abeyance (Natanson, 1973; Hollway and Wheeler, 2010; Polit, 2014). This process should mimic the bracketing in mathematics, meaning all presuppositions are sectioned off so that the data can be viewed in a form as clear and pure as possible. This method is a principal component of phenomenological reduction. Husserl believed we can bracket or cease from positioning the existence of the world around us. This approach results in an epistemological stance in which the researcher describes the phenomena from the participant’s view.

The notion of bracketing has been widely criticised as being positivist in nature (Crotty, 1998), while some existential phenomenologists who followed Husserl have taken issue with the concept (LeVasseur, 2003). Koch (1995), for example, believes it is not possible to separate description from one’s own interpretation. Hamill and Sinclair (2010) agree that it may be impossible to suspend presuppositions fully. Concurring, Gadamer rejected the concept of bracketing and questioned whether researchers’ preconceptions could absolutely be set aside by the adoption of an open attitude (Gadamer, 1976). Gadamer acknowledged that individuals are historical beings who bring life experiences and prejudices with them. These shape the meaning, interpretation, and understanding of fresh experiences. It is my personal belief that to completely suspend prior beliefs or interpretations is something that would be difficult to achieve and to demonstrate. As a vascular access specialist with prior knowledge and preconceptions, rather than attempting to suspend my beliefs, I believe that to acknowledge

these and to be open about them throughout the research is more achievable than attempting to suspend them.

Despite these factors, descriptive phenomenology has become a popular approach in the nursing discipline (Beitz and Goldberg, 2005; Kornhaber *et al.*, 2014; Thelin, Lundgren and Hermansson, 2014). It offers a discerning means of understanding nursing phenomena which are related to the lived experience. Earle, (2010) warns, however, that, in nursing research, the boundaries between phenomenology as a research method and as a philosophical movement remain blurred. Since the primary phenomenological writings were published in German, it has been difficult to determine whether the translations of technical vocabulary have been undertaken and interpreted precisely. During the process of translation, it is thought that some of the meanings of the original texts might have been distorted (Temple and Young, 2004). Much philosophical writing is notoriously incomprehensible. This could be due to the fact that, since Roman times, Western philosophy has been bi- or multilingual, imposing a foreign stratum of concepts and words adopted by the philosopher for self-expression. Since the seventeenth century, philosophers have written in Greek, Latin, Arabic, English, and French. These works have tended to be dialogic and colloquial. According to Ree (2001), the bonding of hieratic and demotic styles by dressing new concepts in common words and idioms adds to the challenge of translation. Subsequently, it is well known that many researchers fail to fully understand the philosophy which underpins the method (Crotty, 1998; Converse, 2012). This is relatable to me as, during research for my master's dissertation, I took a phenomenological approach. It is only since reading more about the philosophy underpinning phenomenology that I realised my lack of deep understanding. It has taken a great deal of effort and extensive engagement with literature to gain a good understanding of this philosophy.

Debate continues around how much researchers should struggle with obscure German text, and Koch (1995) suggests that having an understanding of the arguments that surround the philosophical underpinnings of the methodology is adequate. In agreement, Converse (2012) suggests that nurse researchers, in particular, who use phenomenology need to understand the underpinning philosophy enough to produce a research design that is philosophically congruent. However, it could be argued that this is necessary for any research approach. Finally, it is claimed that there is no clear description or direction offered for researchers who wish to follow this research method, which has resulted in researchers looking to philosophers such as Gadamer or Heidegger for direction (Sadala and De Camargo Ferreira Adorno, 2002).

Heidegger (1962) modified and built on the work of Husserl. His ideas inform the interpretive or hermeneutic research tradition (Cohen and Omery, 1994). As well as being critical of 'bracketing', Heidegger believed that the nature of being was missing from Husserl's theory. He posited that individuals could not abstract themselves from the world and their everyday experiences. Heidegger's phenomenology was criticised by many, including Gadamer (1976), whose main critique surrounds the concept of intersubjectivity and the question of whether it was possible to reach a place in which multiple subjectivities resulted in objectivity.

Heideggerian phenomenology suggests that human experience occurs in a world of language, culture, people, and relationships. This means that a researcher and participants are unable to detach themselves from these factors (Tuffour, 2017a). Therefore, enquiry commences with the perspective of the researcher due to their prior experience (Smith, Flowers and Larkin, 2009). The researcher must understand the phenomena to subsequently be able to guide the study and provide interpretations of experiences. My prior experience is what drove this study and, therefore, my knowledge is necessary to guide its enquiry. I do not believe that there can be a detachment of myself from the experience of the participants. I believe this is necessary for the meaning-making process being explored.

German philosopher Hans-Georg Gadamer was influenced by the work of Heidegger. Gadamer added a further two concepts into the phenomenological philosophy: prejudgement and universality (Moran, 2000; Earle, 2010). His work, *Truth and Method*, explains that prejudgement refers to the set of prejudices that are possessed by people who see universality as a connection between the expressions of people and their understandings (Moran, 2000; Earle, 2010). According to Gadamer, the preconceptions of the researcher and participants will always fuse. Since the researcher and participants have their own preconceptions and prejudices, it is essential to embrace these differences if we are to understand how people experience phenomena (Gadamer, 1976). This process allows the researcher to interchange their own understandings and preconceptions with the lived experience of the participants (Smith, Flowers and Larkin, 2009). This is referred to as a fusion of horizons, and relates to the convergence of the vantage points of the participant with the researcher's knowledge and understanding of the phenomenon (Laverty, 2008). I understand that my prior understanding, experiences, and knowledge of vascular access has a limit. However, this knowledge and understanding, in combination with the experiences of the participants, will lead to new understanding of the phenomenon.

Sartre extended some aspects of existential phenomenology and introduced the notion of 'nothingness'. This highlighted the importance of the absence of things with those present in facilitating understanding of the world (Moran, 2000). Sartre built on Heidegger's interpretation of worldliness of human experience by incorporating the significance of contextualised human relationships (Smith, Flowers and Larkin, 2009).

Along with Husserl, Heidegger, and Sartre, Merleau-Ponty was one of the four major phenomenological philosophers who illuminated phenomenology as both a singular and pluralist endeavour, existing on a continuum (Tuffour, 2017). Merleau-Ponty (1962) focused his work on subjectivity, embodiment, and our relationship with the world. He saw the body

as shaping the fundamental character of our knowing about the world (Smith, Flowers and Larkin, 2009). At the centre of Merleau-Ponty's philosophy was an argument about the pivotal role perception plays in understanding and engaging with the world. The use of concepts such as *the lived, own body* and *of lived space* emphasise, from a first person perspective, the co-penetration that exists between the subject and the world (Moya, 2014). Merleau-Ponty argued that it was necessary to acknowledge the role of human existence in shaping the elementary principles of knowing the world (Tuffour, 2017a).

Merleau-Ponty viewed the body as having two sides: an object side, which is able to be touched, and a subject side that sees and touches (Crossley, 1996). Even though the lived experience of being a body in the world can never be totally captured, this experience is one that should not be ignored or disregarded (Smith, Flowers and Larkin, 2009). For this reason, in IPA, the place of the body as a central element in experience must be considered. Such a stance is particularly relevant in this study due to the alteration of the body that the patients face during their treatment journey (Molloy, Smith and Aitchison, 2008; Møller and Adamsen, 2010). Most importantly, body, language, and speech are intimately connected or, in fact, inseparable. Therefore, I felt it necessary to interpret the spoken words of the participants to make sense of their experience.

It is, therefore, acknowledged that researchers have preconceptions that should be set aside in order not to influence the research process. However, this can be achieved by acknowledging those preconceptions as well as discussing them and their implications for the study (Crotty, 2011). It must be recognised that researchers bring their own background and experiences to their research. Therefore, they should 'position' themselves in the research, and acknowledge that their interpretations come from their cultural and historical experiences. In Chapter One, I discussed my background as well as my experience and knowledge of vascular access. However, rather than attempting to suspend my preconceptions, prejudices, and beliefs

completely, as would be necessary in descriptive phenomenology, I acknowledge them and will present my reflexive accounts throughout this thesis.

3.4.1.2 HERMENEUTICS

Interpretive phenomenological philosophers present alternative focuses and agree that there is no knowledge outside of interpretation. Central to the methodology of IPA is the work of Heidegger (1962), which incorporates hermeneutics with phenomenology. Heidegger proposed hermeneutics of everydayness, which encompasses an understanding of day-to-day practices. The fundamental aspects of our existence disguise their structure behind common sense. Within hermeneutics, pre-existing subjective experiences and prejudices should not be eliminated or suspended, but instead should be acknowledged and exert an influence on the understanding of phenomena. According to Sensuse and Ramadhan (2012) and Kinsella (2006), a hermeneutic approach seeks:

1. Understanding rather than explanation
2. Acknowledgment of the situated location of interpretation
3. Recognition of the role of language and historicity in interpretation
4. A view of inquiry as conversation
5. Comfort with ambiguity.

The term ‘double hermeneutics’ begins with the participant attempting to make sense of their personal and social world (Smith, 2004). Researchers encourage participants to tell their story in their own words but, in addition, through their own ‘fore-conception’, the researcher becomes a point of access to the interpretation of the participant’s experience (Smith, Flowers and Larkin, 2009). Researchers have the challenge of critically and reflexively evaluating the ways in which their pre-conceptions and understandings might influence research, since their fore-structure might present an obstacle to interpretation (Smith, 2007). IPA researchers must attempt to identify their basic understanding of a particular phenomenon whilst prioritising the

new object instead of the researcher’s preconceptions (Smith, 2007). It must be remembered, however, that IPA is a partnership; the researcher’s interpretation is, therefore, both valid and key (Smith, Flowers and Larkin, 2009).

The hermeneutic circle, or loop, is central to hermeneutic understanding. It signifies a methodological process of understanding. Coming to understand a complete text and its related parts are interdependent activities (Natanson, 1966). Therefore, construing the meaning of the whole enables making sense of the parts, while grasping the meaning of the parts depends upon having some sense of the whole (Kinsella, 2006). Any alteration in the understanding of a single pole, either the whole or a part, can generate an alteration in understanding at the other pole. This moves us into an interpretive or hermeneutic loop. The concept of the hermeneutic loop operates at these two levels: the part and the whole. This can be understood to describe a number of relationships. Smith, Flowers and Larkin (2009) suggests an example which can be seen in Table 3.2.

Table 3.2: DEFINING INTERDEPENDENT RELATIONSHIPS

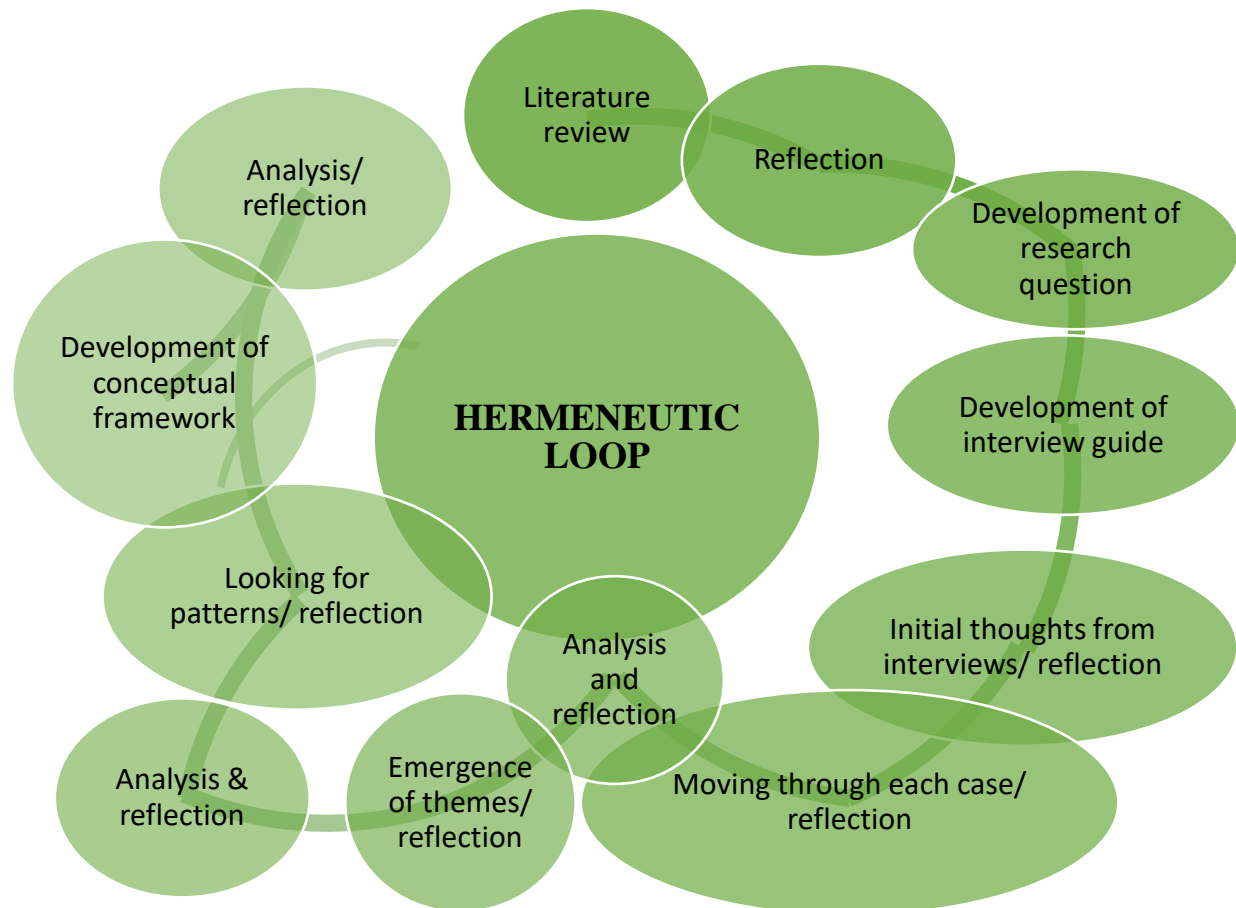
The part	The whole
The single word	The sentence in which the word is embedded
The single extract	The complete text
The particular text	The complete oeuvre
The interview	The research project
The single episode	The complete life

(Smith, Flowers and Larkin, 2009, page 28)

The dialogue between the researcher and the text is ongoing throughout the whole research process. Whilst engaging with on-going reflexive analysis, original understandings are shaped and prejudices are uncovered. It was the use of my reflexive diary and discussions during supervisory sessions that

allowed me to consider and challenge my own thinking and prejudices. My personal, continuing journey through the hermeneutic loop is presented in Figure 3.1, demonstrating my constant engagement in the process. The figure demonstrates each stage of the research process with reflection intertwined at every stage.

Figure 3.1 MY HERMENEUTIC LOOP



Smith, Flowers and Larkin (2009) assert that hermeneutic interpretation may never conclude and could go on indefinitely. It is recognised that a chosen stopping point may not be the absolute end, and that further interpretation may be possible; however, this is neither practical nor desirable. According to Smith (2007), a time comes when the interpretation is ‘good enough’ to commit to writing. Therefore, the findings and interpretations of this thesis are presented as my ‘stopping point’, while it is recognised that further interpretation might be possible.

3.4.1.3 IDIOGRAPHY

The third theoretical underpinning of IPA is idiography. IPA is interested in how individual participants make sense of their personal experience of a particular phenomenon within a given context (Smith, Flowers and Larkin, 2009). It is concerned with achieving an in-depth, finely-tuned analysis. Smith (2007) argues that individuals can offer an exclusive perception of their experience. Therefore, in IPA, a single case can become the unit for a study, particularly if one has an especially rich or fascinating case (Shinebourne and Smith, 2009). As well as solo case studies, small groups of cases can be examined. The aim of the IPA researcher is to discover as much as possible about each participant's experiences before moving onto the next participant's experience. Living with a VAD is always part of a more complex situation for patients, since they rely on these devices for receiving often lifesaving treatments. Therefore, each person's subjective experience is unique and will hold different meanings. IPA was, thus, felt to be ideally suited to my study due to its inclusion of the unique and idiographic characteristics of the participants.

3.5 HIERARCHY OF EVIDENCE-FOR- PRACTICE

According to Daly *et al.*, (2007) there are four levels of a qualitative hierarchy of evidence-for-practice (Figure 3.2). It is suggested that the least likely study to produce good evidence-for-practice are single case studies. Next are descriptive studies which might provide useful lists of quotations but do not offer an exhaustive analysis. More weight is attributed to conceptual studies that analyse all data according to conceptual themes but might be limited by a lack of diversity in the sample. Studies that are generalizable and utilise conceptual frameworks to derive an appropriately diversified sample with analysis accounting for all data are deemed to provide the best evidence-for-practice (Daly *et al.*, 2007).

Qualitative research now appears more regularly in both qualitative research publication venues as well as venues that once rejected qualitative research as unscientific. As qualitative research becomes more prominent, concerns about the value of qualitative research become more evident. These concerns focus on issues of validity, quality and rigor (Maxwell, 1992; Emden and Sandelowski, 1998, 1999). The premise that qualitative research findings are not generalisable and are derived from small, subjective, and non-representative samples and subjective procedures the findings are supposedly not valid or reliable (Sandelowski and Barroso, 2007).

The issue of generalisability of qualitative research is complex however and could be viewed as controversial. Studies which are conceived and conducted with an established theoretical framework and which follows on from previous cognate research involving clear, specific and appropriate methods are likely to generate the most robust data. However, it is possible that such studies were not designed to obtain generalisable information.

Unlike the nomothetic or formal generalisations which is the aim of quantitative research and drawn from statistically representative samples and applied to populations, the goal of

qualitative research is ideographic or case-bound generalisations. Idiographic generalisations are drawn from informationally representative cases (Sandelowski, 1996, 1997) and can reach issues related to human experiences which is not always possible with quantitative research. Additionally, the ability to develop, refine and validate culturally sensitive instruments and participant – centred interventions are viewed as distinctive capabilities of qualitative research. Finally, it has been argued that qualitative research actually augments the practical significance of, or even salvages quantitative research (Fountain and Griffiths, 1999; Barroso and Sandelowski, 2001; Cohen, Kahn and Steeves, 2002).

As described in section 3.5, qualitative research studies such as IPA are conducted on small sample sizes. The detailed case-by-case analysis of individual transcripts takes time, and the aim of the study is to say something in detail about the perceptions and understandings of this particular group rather than prematurely make more general claims. IPA is not opposed to more general claims for larger populations; however, it is committed to the painstaking analysis of cases rather than jumping to generalisations. This is described as an idiographic mode of inquiry as opposed to the nomothetic approach which predominates in psychology (Smith *et al.*, 1995). Therefore, it could be suggested that IPA research sits at the higher end of the hierarchy of evidence-for-practice.

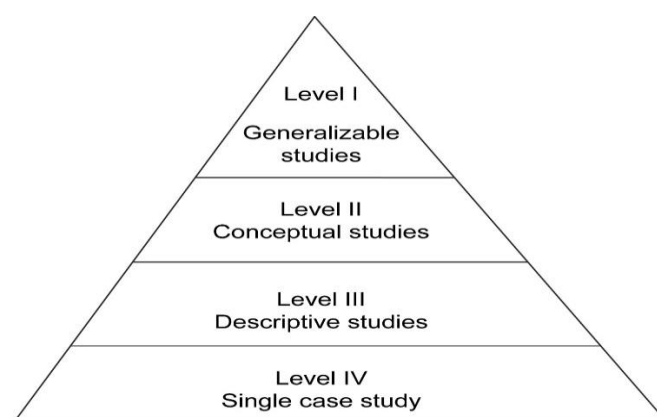


FIGURE:3.2 A HIERARCHY OF EVIDENCE-FOR-PRACTICE IN QUALITATIVE RESEARCH, STUDY TYPES AND LEVELS

3.6 SAMPLING

Typically, phenomenological studies involve a small number of participants (Polit and Beck, 2014). Sandelowski (1995) explains that an adequate sample size in qualitative research is one that permits the deep, case-orientated analysis that is a hallmark of all qualitative inquiry. Results obtained with a small sample size can result in a new and richly textured understanding of experience. Therefore, if the information from each participant has meaning and depth, a homogenous sample of fewer than ten cases may suffice.

Smith (2007) suggests that the sampling strategy of IPA should be focused on homogeneity. This is intended to create a detailed account of particular people in a certain context. In addition, a purposeful sample should be employed (Smith, Flowers and Larkin, 2009). This method involves deliberately targeting individuals who are in a position to contribute relevant information that is of interest of the study. Consequently, researchers must be clear and concise in their parameters when choosing from a particular population. This is often hampered due to issues such as time constraints and population characteristics. Resourcing of the study can also place limitations on what sampling is feasible (Kvale, 1996). For example, geographical limitations on a sample can be a result of the interviewer only being able to travel within a limited area. This requires researchers to be flexible when devising their inclusion criteria (Smith, Flowers and Larkin, 2009).

An IPA sample should be small. This is to allow for a manageable, in-depth analysis. The primary concern of IPA is with a detailed account of individual experience. To achieve this, the focus is on quality rather than quantity. Due to the complexity of most human phenomena, IPA studies benefit from a focus that is concentrated on a limited amount of cases (Smith, Flowers and Larkin, 2009). Smith, Flowers and Larkin (2009) suggest that, for a professional doctoral study, a sample of up to ten is sufficient, whilst for a PhD study, this number can vary

depending on the research question. The general suggestion is that less is more, since a smaller sample size allows for the idiographic focus of IPA (Smith, Flowers and Larkin, 2009; Callary, Rathwell and Young, 2015; Phillips, Montague and Archer, 2016). Small sample sizes have often been viewed as a limitation in research. However, in IPA, these samples mean that, during interpretation of data, a richer, more in-depth analysis is possible. This is due to the extensive time that is freed to concentrate on each account.

3.7 DATA COLLECTION

Various methods of data collection are available for qualitative studies, including questionnaires, surveys, observations, ethnographies, case studies, focus groups, and diaries. However, the primary tool of data collection in phenomenology is the interview (Biggerstaff and Thompson, 2008; Smith, Flowers and Larkin, 2009; Robinson, 2014). Interviewing is a process in which an interviewer and interviewee produce knowledge. According to Brinkmann and Kvale (2015), this knowledge is contextual, linguistic, narrative, and pragmatic. The qualitative research interview seeks to describe the meanings of the central themes in the life world of the respondents (Kvale, 1996), as well as to understand the world from their point of view (Brinkmann and Kvale, 2015). According to Burgess (1984), a qualitative interview is a conversation with a purpose. Nieswiadomy (2012) furthers this by stating that interviews can be used to obtain factual data about people in addition to allowing the measurement of their opinions, attitudes, and beliefs about particular topics.

The most commonly used types of interviews in IPA are face-to-face, semi-structured interviews (Smith, Flowers and Larkin, 2009). In a semi-structured interview, the interviewee is afforded enough time to develop an account of the issues under investigation (Creswell, 2003). Participants should be allowed time to tell their stories and afforded space to think, speak, and be heard (Smith, Flowers and Larkin, 2009). Thus, the suggested length of a semi-

structured interview is 60 to 90 minutes. The generation of a large amount of rich data is the aim of the semi-structured interview. This requires the researcher to have good interview skills (Robinson, 2014). In semi-structured interviews, the researcher sets out the topics to be covered. Such interviews are often used as they provide an ability to be prepared for periods of difficulties, for example, periods of silence. A semi-structured interview allows the interviewer to remain engaged and attentive with the use of a guide (Flick, 2007; Baker and Edwards, 2012).

3.8 DATA ANALYSIS

IPA does not prescribe a single ‘method’ for working with data; rather, it allows flexibility in matters of analytic development (Smith, Flowers and Larkin, 2009). However, the focus of IPA is to direct the analytic attention of the researcher toward the individual and how they make sense of their experiences (Smith, Flowers and Larkin, 2009). IPA is characterised by some common processes and principles, and has been described as an iterative and inductive cycle (Smith, 2007). Analysis proceeds case by case. After each case has been considered individually, the analyst moves to a group level analysis (Smith, Flowers and Larkin, 2009). The six steps of analysis, which start with one case, are detailed below.

3.8.1 STEP ONE: READING AND RE-READING

In order to gain an initial feel for the case, and to familiarise oneself with the transcript, the researcher reads and re-reads the transcript multiple times. This enables a deep level of immersion in the data (Guba and Lincoln, 2005).

3.8.2 STEP TWO: INITIAL NOTE - TAKING

In this stage, preliminary comments are made in the right-hand margin of the transcript. These are mostly exploratory comments which reflect initial thoughts about the claims, concerns, and understandings of each participant. The comments include:

- Descriptive comments that focus on what the participant found significant
- Linguistic comments that focus on the language used by the participant, such as pauses, use of pronouns, repetition, and metaphors
- Conceptual comments which focus on a more interrogative and conceptual level.

3.8.3 STEP THREE: DEVELOPMENT OF EMERGENT THEMES

This is achieved by working with the initial notes, as well as the original interview, and is one manifestation of the hermeneutic cycle. This stage involves working with a set of parts (meaningful extracts from the interviews) in relation to the whole interview. The whole interview is understood from these parts. Emergent themes are noted on the left-hand side of the transcript.

3.8.4 STEP FOUR: CONNECTIONS ACROSS EMERGENT THEMES

Convergent and divergent points across themes are mapped, which leads to the formation of subordinate themes. This process can be aided by strategies such as abstraction, polarization, contextualisation, numeration, and function (Smith, Flowers and Larkin, 2009).

Abstraction is an uncomplicated method of identifying patterns between emergent themes and developing a superordinate theme. To achieve this, like is put with like, and a new name is applied to the cluster. The higher level of superordinate theme is a result of putting the themes together.

Polarization examines transcripts for the oppositional relationships between emergent themes. It focuses on differences rather than similarities. This oppositional relationship can then offer a higher-level method of organising the data (Smith, Flowers and Larkin, 2009).

Contextualization involves identifying the contextual or narrative elements in an analysis. Constellations of emergent themes, which relate to a specific narrative moment or key life event, often shape a participant's narrative. These could be distributed throughout the transcript. Highlighting and reorganising the emergent themes in terms of the temporal moments where they are located is another method of merging patterns (Smith, Flowers and Larkin, 2009).

Although it would usually be considered quantitative, numeration can be thought of as patterning within the emergent themes. Numeration reflects the frequency in which emergent themes appear within the transcripts. As interview styles in IPA are typically open-ended or unstructured, the frequencies in which emergent themes occur could indicate their relative importance and relevance to the participant (Smith, Flowers and Larkin, 2009).

The specific function of the emergent themes in the transcripts can be examined. The interaction of meanings exemplified by organising themes by negative and positive presentations might be interpreted outside of what the participant expresses in terms of their meaning, and instead as a different way of presenting the self within the interview. This type of analysis might seem to move away from the thinking of the participants to a deeper interaction with the data. In this method, the function of language use is deeply intertwined with the thoughts and meanings of the participants (Smith, Flowers and Larkin, 2009).

3.8.5 STEP FIVE: MOVING ONTO THE NEXT CASE

Before moving onto the next case, the researcher must set aside all themes developed from the first case. The process is started again with fresh eyes. This step is important as it preserves the idiographic nature of IPA.

3.8.6 STEP SIX: LOOKING FOR PATTERNS ACROSS CASES

Finally, after each case has been analysed completely, the researcher looks for similarities and patterns across the group. It is at this point that themes can be re-labelled. Subordinate themes are further structured in a more abstract level. This results in superordinate themes.

3.9 ENSURING RIGOR

Qualitative methods are now seen as valuable within healthcare. However, the question of how rigor can be enhanced or ensured in these methods continues to be asked. In fact, some question whether qualitative research findings can ever be valid and reliable (Noble and Smith, 2013). Assessment of the quality of qualitative research is challenging, and the best ways to ensure quality in IPA studies have been debated (Hefferon and Ollis, 2006; Noble and Smith, 2015). According to Smith, Flowers and Larkin (2009), IPA can be assessed for quality according to Yardley's four principles (2000):

- *Sensitivity to context* is demonstrated by the inclusion of relevant literature, consideration of ethical issues, and description of the socio-cultural context in which the study is conducted.
- *Commitment* is shown through the collection and analysis of data. This includes showing attentiveness to participants during data collection in addition to the care with which each case is analysed. *Rigor* is demonstrated by a thorough research process, which includes details of sampling and the level of homogeneity.
- *Transparency* relates to the precision with which the steps of the research process are described and is evidenced by data collection and presentation. All decisions made in the research process should be kept as an audit trail. A method to achieve this is through the use of a reflexive account. *Coherence* is proven in the lucidity of the arguments presented during the research process. This begins at the stage of literature review, and then proceeds through the research question, presentation of findings, and the discussion.

- *Impact and importance* are achieved if the findings from a study influence a wider discipline, field, or professional domain.

3.10 JUSTIFICATION FOR THE CHOICE OF IPA

The subject of this study and research question stemmed from my experience and knowledge of vascular access and are influenced by my own set of values and beliefs. Since IPA is both phenomenological and constructionist, it is in keeping with my epistemological position. IPA is a forward-looking approach that is flexible and versatile in design; it is ideal for understanding people's experiences. As the topic of the lived experience of vascular access was understudied and poorly understood, an inductive approach was deemed the most appropriate. This was because such an approach would allow an in-depth exploration of participants' perspectives.

The experience of having a VAD inserted, as well as its subsequent impact, could be considered complex and unique for each individual. The idiographic nature of IPA sits well with the aim of my study as its intention is to reveal something about each individual participant's experience, and to uncover factors that are common to the participant group. The aim of IPA is not to form premature generalisations, but rather prescribes a different way of establishing those generalisations (Swartz and Swartz, 1982). This occurs following painstaking analysis of each individual case (Smith and Shinebourne, 2012). It is acknowledged that interpretations are bounded by the participants' capacity to articulate their experiences and thoughts (Brocki and Wearden, 2006). Therefore, an idiographic approach was deemed necessary. Additionally, I believed that the linking of cognition and language would lead to a rich insight from participants' viewpoints and would allow comprehension of how they made sense of their experience.

IPA involves the detailed examination of the participants' 'lifeworld', their experiences of the phenomenon, how they make sense of their experiences, and the meanings they attach to them (Smith, 2009). By utilising this approach, I felt I would be able to reflect and analyse more deeply, since IPA encourages a rich and nuanced insight into the experiences of participants.

3.10.1 CRITICISMS OF IPA

Having provided a rationale for the selection of IPA as the method for this study, it is pertinent to consider its limitations and to discuss some of the criticisms and challenges directed against it (Crotty, 1998; Caelli, 2001; Converse, 2012; Paley, 1997, Paley, 2016; Tuffour, 2017). I will first introduce the philosophical objections to IPA. To take this further, I will then summarise key objections raised by Paley (1996, 2002a, 2002b, 2008, 2013, 2016). Finally, I will show how I have ensured that this thesis has nevertheless engaged with this critique to present the next best alternative: an 'as good as possible' version of the use of IPA principles, with reference to a range of quality beacons agreed by those actually undertaking research into meaning.

Conducting phenomenological research is challenging, due in part to the difficulties posed by its complex underpinning philosophy and the subsequent methodological options that exist (Crotty, 1998; Caelli, 2001; Converse, 2012). As previously discussed in this chapter, it has been suggested that the misreading of the foundational philosophical texts by nurse phenomenologists undermines the credibility of findings and exposes serious weaknesses (Paley, 1996b, 1996a; Horrocks, 2002). This can result in poor quality research according to Caelli (2001) and Paley (1997; 2016).

Such criticisms have been most strongly voiced by British nursing philosopher John Paley. His body of work consists of philosophical criticism of nursing research (Paley, 1996, 2002a, 2008, 2013), culminating in 2016 with his book *Phenomenology as Qualitative Research: A Critical*

Analysis of Meaning Attribution (Paley, 2016). In it he suggested that IPA has no clear method and uses Giorgi's (2000) modified Husserlian approach and van Manen's hermeneutic phenomenology as examples of very different interpretations to make his point. He argues that the interpretive stage of IPA never actually arises from the participants own words, as suggested by Smith, Larkin and Flowers (2009), but is instead guided by the researchers fore-conceptions. Hefferon and Gil-Rodriguez (2011) concur and suggest that IPA studies are often mostly descriptive and not sufficiently interpretive. Tuffour (2017) expands on this and states that even in the presence of solid philosophical foundations, many IPA studies are still conducted poorly. More recently, Gyollai (2019) has joined the debate and argues that bracketing the researcher's fore-conceptions during the initial phases of IPA is merely an illusion.

These criticisms are all true to a degree, and all have value in pointing out that high quality research demands high levels of rigour and quality appraisal, including consistency with the relevant underpinning philosophy. This is as true for IPA as it is for Grounded Theory or Randomised Controlled Trials (RCTs). In each case the underpinning philosophy should be thoroughly and critically understood, and in each case, ontology, epistemology and methodology need to be mutually coherent such that the researcher can easily explain the strengths and limitations of their own studies with reference to the relevant paradigm (Snowden and Kelly, 2020). If one accepts that quality resides in internal consistency between philosophy and methodology, then any study simply needs to maintain logical consistency with its founding premises to say something coherent.

Whilst Paley remains frustrated with poor research, the solutions aren't always philosophical or methodological. Doing research is a practical endeavour with an ethical purpose, as in nursing studies. This is an *axiological* aspect of nurse research that does not feature in Paley's work and this is where it matters that Paley is *not a nurse or a researcher*. Paley (1997) is highly critical of Husserlian phenomenology and argues that '*the idea that it is possible to identify the essence of phenomena... must be judged unintelligible*' (Paley, 1997, P.192). This is logically true, but it is highly questionable if identifying *the* essence of anything is actually the aim of researchers in the real world. Certainly in the social sciences, truth is relative (Calderwood, 2017), and so there may be considerable (axiological) value in trying to articulate *an* essence of phenomena. In other words, no such purist versions of objectivity or subjectivity exist in the real world. In constructing his own caricature of IPA, Paley (2016) has built his own straw man; an unachievable, perfect method that nobody would recognise.

Likewise, he is keen to show that nurses' interpretation of Cartesian dualism was based on a version of dualism that didn't exist, certainly within Descartes original ideas (Paley, 2000, 2002b). However, to then go on to claim that '*the only knowledge that is important is that which can be observed or measured*' does not logically follow. Rather, this is simply a statement of personal preference for a positivist ontology. Paley abhors sloppy research, and few would argue with this. However, to attack research because it is not explicitly measuring something says nothing of importance about the value of qualitative research at all, let alone phenomenology. Paley ultimately sets the bar too high for anyone to succeed, and if taken seriously, would perhaps stop people asking difficult questions.

Unsurprisingly, several authors have in turn challenged Paley's critiques (Deary *et al.*, 2002; Hussey, 2009; Leget, 2008; Newsom, 2008, Nolan, 2009; Pesut, 2008; Giorgi, 2017). He has been criticised as having only a superficial understanding of the basic concepts of phenomenology himself, such as lived experience, phenomenological meaning and the phenomenological notion of empathy (Deary *et al.*, 2002). He also ignores and dismisses the significance of the various different forms of IPA (Giorgi, 2017), and as already alluded, restricts his attacks to a specific form of IPA that only he believes in. Probably most significantly, and in some ways also explaining his extreme standpoint, Paley has also been accused of not contributing to the empirical literature. Rather, he aims his criticism at those who '*dare to collect data with the aim of pushing forward the boundaries of science*' (Deary *et al.*, 2002). He does not put his own head above the parapet.

In pointing out assumptions and sloppy thinking in the nursing literature Paley has identified many of the pitfalls for others to avoid in qualitative research, in particular IPA. Nevertheless, he is wrong to devalue IPA itself. IPA has helped reveal some of the most important findings in nursing, creating rich interpretations of 'what it is like' to be, for example, in pain (Smith and Osborn, 2015), depressed (Pauley and McPherson, 2010), or a medical student trying to understand the experience of disease (Carel, 2011). Tuffour (2017) has suggested that one of the great virtues of qualitative methodologies like IPA are that they facilitate creativity and originality. This is not possible in the purely positivist paradigm that Paley espouses.

Throughout this thesis I have made a conscious and transparent effort to ensure that the way the different methods used throughout have been clear. For IPA principles, I have adhered to the guidance provided by Smith, Flowers and Larkin (2009) and have hopefully articulated the

participants' voice clearly through the judicious use of primary quotes. The interpretation of their narratives has been comprehensive, but most importantly explicit; done in front of the reader. By doing so, I have limited the potential for falling into some of the traps that Paley (2016) suggests exist in IPA research.

REFLEXIVE BOX: METHODOLOGY

Now that I've decided what my research question is, I know that I am going to have to use a qualitative approach. I think that because I used thematic analysis when I did my MSc. I'm trying to stay safe and do the same thing. But now I'm thinking that I need to do something different. I really what to do a really in - depth study, I want to delve deep and find out what the patient with VADs really think and feel and how and if their lives are affected by having a device inserted.

I purchased the IPA book by Smith, Flowers and Larkin, (2009) by mistake!! This is a revelation. I really like the way that this book is written and explained. It fits in perfectly with what I want to achieve in my study. I have now read loads of IPA articles and literature that explained the approach., I discovered that such an approach would be perfect to help answer my research question. I liked the structured yet flexible approach of IPA and, because of my previous knowledge and expertise in vascular access, I thought that the interpretive aspect and construction of the patient experience suited my research question and study aim.

(Aug 2016) I don't really understand phenomenology as much as I need to (truthfully)!! It sort of scares me! Loads of words that I don't understand, and it is really, really difficult to focus on some of the papers and books that I have. But... I can read, and if other people are able to learn about it then so am I. It might take a while but that is why this thesis takes so long. I quite like YouTube, it easier to listen than to read sometimes. I know that I am going to have to use lots of different sorts of resources to help me. I'll need my supervisors too and I can't be afraid to ask questions.

3.11 CHAPTER THREE SUMMARY

To summarise, the research approach I selected for my study was qualitative using Interpretive Phenomenological Analysis (IPA) principles (Smith, Flowers and Larkin, 2009). The identification of ontology at the beginning of the research process was vital as it guided the choice of IPA. My study aim was to obtain information from patients about their experience of

living with a long-term VAD. My belief is that reality is constructed based on people's individual experiences, and, therefore, the position I took was one of constructivism. My epistemological position was to view knowledge as constructed through investigation. Qualitative research was decided on as a paradigm early on in my research. Next, I had to consider which qualitative research approach would be appropriate. I had considered grounded theory, which was dismissed for reasons previously discussed. After being introduced to IPA, reading about and considering the approach, I decided that this would be an ideal methodology for my study. IPA was consistent with my research aims as it is orientated toward exploring and understanding how people make sense of their major life experiences (Smith, 2009). The following chapter will detail the methods employed in this study.

REFLEXIVE BOX: A PERSONAL REFLECTION

I know that I built some assumptions during my role as a vascular access specialist. One of these assumptions was that patients would favour a device that was implanted rather than one that exited from the arm or chest. That seemed obvious to me. I also thought that, if a device as always visible, patients would be constantly reminded of their illness and would maybe remain in a sickness role. My experience of inserting and removing Vascular Access Devices had led me to believe that patients viewed their devices as an important, or even vital, part of their treatment. Despite these assumptions, I had never spoken or questioned anyone about their individual experiences of living with a Vascular Access Device and I didn't know how they made sense of life with a VAD. I welcomed the opportunity to invite people to talk to me about their experiences so that they could be explored and understood.

Unfortunately, I have had some horrible news ... my sister has been diagnosed with cancer. She is getting a Hickman line inserted so that she can get chemotherapy – I'm terrified and really so sad. I'm wondering if this might influence my thoughts about my study. I am going to support her, and I have already spoken to her about her device and treatment. I feel confident that my personal thoughts, feelings, and experiences won't adversely influence the next stages of my study.

CHAPTER FOUR: METHODS

4.1 INTRODUCTION

The purpose of this chapter is to set out the methods used within this study. Throughout the chapter, a coherent and logical account of the processes taken during this phase of the study will be provided. The chapter will commence by discussing ethical implications related to the study. Next it will detail the methods used to collect and interpret the data. Finally, the steps taken to ensure trustworthiness during these processes will be made explicit.

4.2 ETHICAL IMPLICATIONS

Ethical implications and the psychological consequences for the participants was considered during all stages of my research. I ensured that all essential principles were adhered to at all stages and that the study was considered from the standpoint of the participants. This was to ensure that foreseeable threats to participants psychological wellbeing, health, values and dignity were eliminated (Higginbottom, 2005). Additionally, I ensured that the rights of the patients were safeguarded at every stage (Beauchamp and Childress, 2001).

The ethical standards that governed my study were the British Psychological Society's 'Ethical Principles for Conducting Research with Human Participants (Vanclay, Baines and Taylor, 2013). The main areas of which include:

- Obtaining consent
- Deception
- Debriefing
- Withdrawal from the investigation
- Confidentiality
- Participant protection

- Giving advice

As suggested by Higginbottom, (2005) I did not view ethical issues as separate from the research process. Rather, I ensure they were permeated through the whole research process. Therefore, ethical implications that were relevant to this study are addressed in detail within this chapter and as they arise throughout the whole thesis. This results in the presence of ‘ethical footprints’ throughout the study (Higginbottom, 2005, p4).

4.2.1 ETHICAL APPROVAL

The research protocol for my study was submitted for independent review and approval from the University of the West of Scotland ethics committee. My study was granted ethical approval in 2015 (Appendix four). I next applied for ethical approval from the National Health Service Ethics Committee and the NHS Research Ethics Service. My application was also approved, granted in 2015, and given the REC reference number 15/WS/0108 (Appendix five). It was only following approval from these two bodies that I commenced my study.

The following section will explore the key ethical issues of research governance relevant to the study, and which include consent and risk to participants, as well as confidentiality, anonymity, and data handling (Scottish Executive Health Department, 2006). Firstly, I will describe how study participants were selected and recruited.

4.3 SELECTION, SAMPLING, AND RECRUITMENT

I had to ensure that individuals were selected based on their knowledge, experience, and ability to articulate an experience of living with a Vascular Access Device (VAD). This provided my justification for participants being selected through the non-probability technique of purposeful sampling (Newington and Metcalfe, 2014). This method involves deliberately recruiting the type of person who would be suitable to participate. This meant people who could describe and reflect on their experiences of living with a long-term VAD. As there are three device options for long term vascular access (peripherally inserted central catheter, tunnelled cuffed catheter, or totally implanted port), it was decided that patients with any of these devices would be included. In line with the hermeneutic philosophy of IPA (Smith, Flowers and Larkin, 2009), these patients form a homogenous group who closely share their embodied horizons of understanding (Gadamer, 1976). Including participants with each of the devices also allowed for a comparison to be made about patient experiences of the different device types.

The study population was drawn from the West of Scotland Cancer Centre (WoSCC) and the Vascular Access Service in Glasgow. This was because both departments have a large population of patients requiring treatment through a long-term VAD. I decided to purposefully sample patients with cancer given that they would have experience of living with either device for a long period of time. A period of chemotherapy typically lasts between three and four months, and many patients go on to have further treatments through their devices. This results in longer-term device use (Hallam *et al.*, 2016). I decided to include patients who had a device in place for at least three weeks, believing that this period would be adequate for them to have gained enough of an experience to result in a meaningful phenomenon. At the time of my study, the WoSCC had employed a research nurse who was recruiting for another study. I was offered the assistance of this nurse to recruit for my study. After meeting with her and discussing the

study, I agreed that, due to the potential vulnerability of this patient group and her relationship with them, she would be in the perfect position to approach potential patients about my study and their possible participation.

4.3.1 INCLUSION AND EXCLUSION CRITERIA

To ensure that suitable patients were recruited, I developed inclusion and exclusion criteria (Higginbottom, 2004). The assistance of a research nurse during the recruitment was an additional reason for ensuring that participant selection was explicit (Table 4.1). I decided that all genders would be eligible to take part in the study. I chose not to include people who were under the age of sixteen in the study. I believed that children may experience different issues from adults, and, therefore, a separate study that focused specifically on children with VADs would be more beneficial.

As it was necessary for patients to voluntarily consent to the study, recruiting those with the capacity to provide consent was an essential criterion. I further decided that I would exclude patients who were unable to communicate in English. While there is a large population of people in Glasgow who do not speak English, I do not have the language skills necessary to communicate with a linguistically diverse population. I was aware that some participants might have been able to communicate using their second language for a period of time; however, according to Nicassio et al. (1986), interviews that involve emotional or sensitive topics can result in impoverished accounts if conducted in a second language, due to the additional effort required. The use of an interpreter was considered, but I felt that demands on the time of interpreters are usually at a premium, and that they may have more pressing situations to manage, such as conveying bad news or explaining diagnoses. I felt that taking interpreters away from this aspect of their roles, for up to two hours, was not ideal.

Inclusion Criteria

- Patients with a PICC, TCVC, or TIVAD receiving chemotherapy for cancer
- Patients who have had one of the three VADs in situ for *at least* three weeks
- Patients aged 16 or over
- Patients with the capacity to provide informed consent.

Exclusion Criteria

- Patients without the mental capacity to provide informed consent
- Patients unable to speak or understand the English language
- Patients aged below 16 years of age
- Patients deemed by the research nurse or PI not to be well enough to be interviewed.

Table 4.1: INCLUSION / EXCLUSION CRITERIA

4.3.2 ACCESS TO PARTICIPANTS

I negotiated access to both study sites via the NHS Research and Development Services. I met with the lead nurses for both sites, discussed my study, and invited questions and comments. Following a period of consideration, I was granted access to both sites.

4.3.2.1 RECRUITMENT AND INFORMATION

Potential participants were initially approached by the WoSCC research nurse, who provided details of the study and invited them to participate. If they expressed interest, they were provided with written information about the study (Appendix six). They were provided with my telephone number and e-mail address and were asked to contact me directly if they decided to participate or required additional information. Potential participants from the Vascular Access Service were identified by one of the vascular access nurses while making appointments

for device removal. This reason for planning potential interviews to coincide with device removal was in order to synchronise with an already planned visit to the hospital; the interview would, therefore, not have resulted in an additional visit for the patient. The potential participants were given at least 72 hours to decide to participate or to decline.

If I was contacted, potential participants were informed of the research aims, and how their involvement might benefit future patients who require a long-term VAD. In addition, it was explained that their participation in the study could provide vital information to healthcare professionals, and that patient care and understanding about vascular access might be improved as a result of the study. Story-telling, such as that which takes place in research interviews, has also been linked to a therapeutic effect for participants (Holloway and Freshwater, 2007). However, it is important to note that there was no intention to provide therapy during the research interviews.

Once participants decided to take part, a time and place for the interview was agreed. To maintain a balance of power, I ensured that the final decision of where and when to hold the interview lay with the participants. This approach ensured that a degree of control remained with the participant (Newington and Metcalfe, 2014; Polit, 2014). All participants agreed to be interviewed during a visit to the day unit whilst receiving their intravenous chemotherapy, or during their appointment to have their device removed. These were environments that the participants had all attended previously and were, therefore, familiar to them. Smith, Flowers and Larkin (2009) suggest that using a setting that is familiar to the participants will result in them feeling more comfortable.

The majority of interviews (seven) took place in the chemotherapy day bed unit. This unit is made up separate bays with either recliner chairs or beds. These are separated by screens. Two interviews took place in individual side rooms within the chemotherapy day unit. One interview

was performed in an interview room with the Vascular Access Service department and the final interview took place in an individual bay within a four bedded ward area in the cancer centre.

4.3.2.2 CONSENT

Consent should be informed, in writing, and only requested once potential participants have received written information about the research study and agreed to participate (Grady, 2015). Information about the benefits of the study to both participants and the wider community should be provided. Any potential risks should be discussed along with the relevant processes and procedures (Saks and Allsop, 2007). In qualitative research, consent should be viewed as a process and not a one-off event. This is due to the inability to predict the course of an interview or observation (Saks and Allsop, 2007). The requirement to balance harm and benefit in all data collection procedures remains central to the multifaceted issue of ethical research behaviours. Subsequently, it is paramount that the requirement to collect data does not override the rights of the participant.

Written, informed consent was gathered prior to the data collection (Appendix seven). At least 72 hours was given for potential participants to consider the written information provided and decide if they wished to be involved. Participants were advised that they could withdraw from the study at any point. It was detailed on the information sheet that any data collected up until the point of withdrawal would still be utilised; however, participants were told that they would not be identifiable during the study write up. Participants were advised that if they chose to withdraw from the study, there would be no recrimination.

4.3.2.3 CONFIDENTIALITY, ANONYMITY, AND PREVENTING RISK

The preservation of confidentiality and anonymity are vital aspects of any research study. This means there is a requirement for researchers to provide assurances of how these factors are respected. Anonymity relates to circumstances in which the participants remain unknown to the researcher, whereas confidentiality is concerned with keeping information shared during research unidentifiable to the specific participant (Newell and Burnard, 2011).

Within an interview setting, the researcher knows to whom they are talking; therefore, participants are not anonymous. This is where appropriate handling of the data becomes crucial for preserving the privacy of participants (Kaiser, 2009). Data was collected and presented in a way that avoided participants being identified; thus, ensuring confidentiality. Pseudonyms were allocated to each participant within the interview data and their real identities were not revealed. Furthermore, if participants used colloquialisms, care was taken to avoid the inadvertent identification of those participants through the use of verbatim quotes. Participants were assured that they would not be identified in the final report, and that all data collected would be destroyed at the end of the study.

All patients in my study were recruited from an oncology department and, therefore, had a VAD in place to receive chemotherapy. These patients had a diagnosis of cancer and, thus, could be considered a vulnerable group requiring special consideration (Elmir *et al.*, 2011). According to Alderson (2010), qualitative research might appear to be a simple process of talking to people, which itself cannot cause harm. However, while interviews should not place participants at any risk of physical distress, there is always a chance that talking may cause emotional distress (Richards, Helen and Schwartz, 2002). Probing can also put participants under pressure to reveal intimate personal details. In this study, I was aware that some issues related to having a long-term device might be emotional for participants. As a nurse, it would

have felt natural for me to comfort a person if they became distressed. However, I had to remember that I was there as a researcher who would only be present during the interview period and not beyond. Subsequently, I consciously attempted to not to become too emotionally attached and involved. As all interviews were one-to-one, I was able to observe changes in the participants via verbal and non-verbal cues, and to respond to these sensitively. Moreover, as the interviews took place in the hospital setting, I ensured that there was an identified nurse available to support the patient if they became upset or distressed. Fortunately, no issues of this type were encountered, and all interviews went smoothly.

4.4 DATA HANDLING

Appropriate data storage was necessary to further preserve confidentiality. According to Kaiser (2009), all data, be it hard copy, paper, or in electronic format, must be stored securely. Tape recordings and paper copies of the transcripts were stored in a locked metal cabinet. Electronic files were held on a secure computer. All methods of retrieving or transferring the data on that machine were password protected. Files were backed up on a data stick and stored within the same locked metal cabinet. This was compliant with the NHS and University of the West of Scotland data protection codes of conduct at that time. As well as providing confidentiality of content, this protected the data from damage. In accordance with the Data Protection Act (Information Commissioner's Office, 2018), study data will be held for the duration of the research study and thereafter destroyed as confidential waste.

4.5 DATA COLLECTION METHOD

Given the study's philosophical stance of hermeneutic phenomenology, gaining an understanding of the experiences of patients living with a VAD required a method that would facilitate an exchange of dialogue between myself and the participants.

I wanted the participants to be able to talk freely about their experiences and share them in detail. Therefore, face-to-face, one-to-one, semi-structured interviews were selected as the data collection method in this study. As a data collection method, interviews are congruent with the ontological stance of social constructivism. Within the interview setting, participants were afforded enough time to develop accounts of the issues important to them (Creswell, 2003). According to Smith, Flowers and Larkin (2009), participants should be allowed time to tell their stories as well as being given space to think, speak, and be heard. Open-ended questions are used, along with prompts, to allow this level of conversation. I decided to utilise an interview schedule to facilitate a comfortable interaction with participants (Appendix eight). Smith, Flowers and Larkin (2009) suggest that using a schedule enables participants to provide a detailed account of the experience under investigation. I decided to ask six main questions followed by a final question: 'Is there anything else that you would like to add that you think is important?' All six main questions had prompts attached, which resulted in a total of 12 questions. According to Smith, Flowers and Larkin (2009), a schedule with between six and ten open questions will generate a conversation of between 45 and 90 minutes depending on the research topic. I decided to use prompts as I wanted to ensure that I kept the interview active and to stimulate conversation. I did not believe that my prompts would structure the interviews, nor prevent the participants from taking the interviews off in their own directions.

To obtain the necessary data, I had to ensure that the questions asked were open and expansive (Smith, Flowers and Larkin, 2009). I commenced the interviews with a broad question: *‘Can you describe, in as much detail as possible, what it is like to live with a Vascular Access Device?’*

The purpose of this broad question was to prompt the participant to recount a descriptive episode or experience. Brinkmann and Kvale (2015) suggest that this initial freedom to share an experience allows participants to quickly become comfortable. I found that this was the case in most of the interviews. When the time was right, and I felt that the participants had eased into the interview, I invited them to become more analytical. This was when probing questions were used. Participants were invited to expand on their answers and delve deeper into their thoughts and feelings. This also involved continuing to ask open rather than closed questions to prevent leading the participants toward answers. My research supervisor had suggested a technique to keep me on track which I found useful: before I arrived for the interview, I drew a rough diagram which noted each of the questions or topics that I wanted to cover. These topics had been generated from the findings of the literature review detailed in Chapter Two (see Figure 4.1).

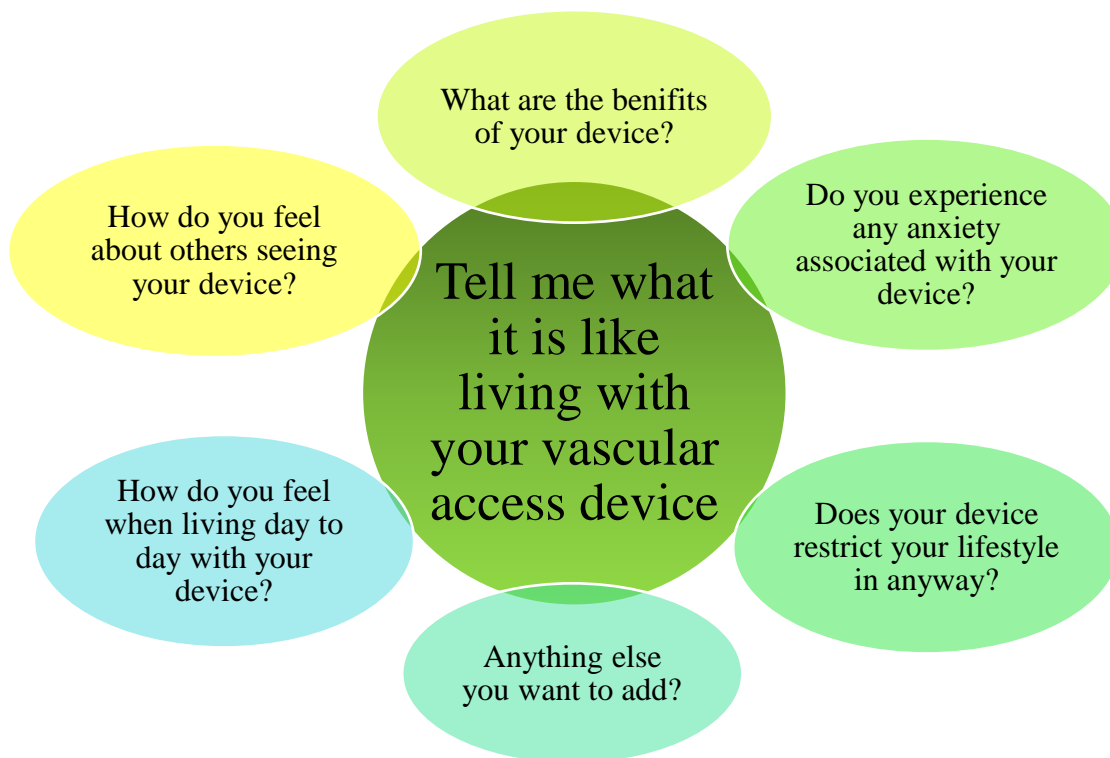


Figure 4.1: INTERVIEW PROMPTS

After I asked the main broad question and heard the participant’s story, I worked my way around my notes and covered all questions in addition to probes. This ensured that I covered all questions without having to refer to a full interview schedule and involved just a quick glance down as I moved through the interview questions.

4.5.1 PILOT INTERVIEWS

Prior to starting my study, I had taken the advice of my supervisor and performed two interviews to test my interview technique. According to van Teijlingen and Hundley (2013), conducting pilot interviews does not guarantee success in the main study. However, this process can increase the likelihood of success. This is mainly due to the ability to refine instruments and tools. Two patients were identified and approached, and they agreed to participate in the practice interviews. Ethical considerations were applied. One patient had a PICC in situ, while the other a TIVAD. Both interviews took place in an interview room within

the hospital unit. The purpose of the interviews was to test my own ability to conduct a meaningful interview, as well as to iron out any problems encountered. They also gave me an opportunity to test the audio equipment, which had been an area of concern for me. I conducted these interviews using the interview schedule. I found this process extremely useful as it increased my confidence in my interview technique while also offering some valuable lessons about listening to and prompting participants. It should be noted that data collected from these interviews were not included in the analysis.

REFLEXIVE BOX: PILOT INTERVIEWS

This is the first time that I'll be using interviews as a data collection method and I'm feeling a bit anxious and apprehensive about it and my abilities as an interviewer. I've taken the advice of one of my supervisors and devised a very loose interview schedule.

I've now done two pilot interviews. They went really well 😊, and I feel a bit more confident now. The periods of silence were a little odd to start off with, but I held off as much as I comfortably could and encouraged the participants to continue to talk and open up more. This was quite awkward to begin with but after a while I could cope with it and it got a little easier.

I really like the interview schedule, but I've refined and updated it a couple of times to make it easier and more fluid. I feel that my confidence in interviewing has increased a lot because of these pilot interviews. The pilot interviews also mean that I've now had a chance to test my audio equipment, which I was really worried about. Feeling ready to go!

4.6 RECORDING INTERVIEWS

All interviews were digitally recorded with the permission of the participants. Digitally recording research interviews is considered best practice and adds to the rigor of the data collection process (Bailey, 2008). However, it is suggested that participants may experience anxieties over the recording of face-to-face interviews (Nieswiadomy, 2012). This was overcome by using a small, discreet recorder. Participants were told when it was switched on, which was always done during general conversation prior to the start of the interview. This allowed for a less obvious commencement of the recording and helped keep anxieties at bay. Prior to each interview, I checked the functioning of the digital recorder and ensured I was always in possession of extra batteries. I decided not to take notes during the interview

as I wanted to make sure I could concentrate, listen, and respond without distraction. I also believed that this would make the participants feel less self-conscious and would lead to a freer-flowing interview.

4.7 INTERVIEW PROCESS

The interviews took place in the day ward of the WoSCC, and in the interview room of the Vascular Access Service. Privacy was assured as much as possible during the interview process. However, there were some challenges encountered within the day ward.

REFLEXIVE BOX: INTERVIEWS

There seemed to be quite a lot of little interruptions during my last interview, with either nurses popping in to see my participant, or with other staff coming to speak to them (to offer tea or coffee, or for other reasons). This was really frustrating! I think I dealt with the challenges OK though. I tried to remain professional and not show my frustration. I had to (or the patient had to) stop the conversation when appropriate, and I made sure the participant was always ready and happy to continue with the interview. I did sometimes feel that I was 'in the way', which might have affected the quality of some of my interviews. I think it could have flowed more smoothly obviously. I knew that, sometimes, the conversation was involving discussions about interventions carried out by nursing staff, and I did wonder if the possibility of being overheard by those nurses might have prevented more open and honest discussions from the patients. Overall, the patients did seem comfortable and at ease, during the interviews. I don't think I could have done anything to prevent this apart from next time consider doing interviews in patients homes instead. Something to think about.

Interviews lasted between 30 and 70 minutes. I believe my position as a novice interviewer may have played a part in some of the interviews being short. The study group may also have influenced the length of the interviews. Although most of the patients were 'well', three patients were either slightly breathless or not feeling at their best. The patients were all advised that the interviews could be stopped but all were keen to continue. In addition, the setting and intermittent interruptions experienced may have prevented a more relaxed environment that, in turn, might have led to more dialogue.

Despite the relative shortness of some of the interviews, the richness and depth of the arising data met the aims of the research. Immediately following each interview, I completed an entry

in my reflexive diary. I noted my thoughts on how the interviews went, any challenges I faced, and any additional feelings I had that might have affected the conversation.

REFLEXIVE BOX: INTERVIEW CHALLENGES

Despite having performed the pilot interviews, it still took time to develop my skills in prompting participants to describe their experiences in detail and depth. I think that this depends on each participant. Some were very eager to tell me their story, while others appeared less comfortable in sharing their story with me. This resulted in some interviews running more smoothly than others. I recognise the need to keep a balance between being firm and determined in my line of enquiry and responding to the participants' resistance in an ethical and sensitive way. Two of the interviews were really short and I feel that they were not as in-depth as I would have liked.

Alfred

The interview with Alfred was difficult, he frequently gave one-word answers and I found it difficult to get a conversation flowing during the conversation. I remember thinking that the environment was particularly noisy even though he was in an individual treatment area. It was a particularly busy day and there seemed to be a lot going on during the interview. I felt that he might have been distracted by this. I'm a bit concerned that the interview contains loads of very short answers to questions, few prompts, and it is not deep or rich in content. I'm annoyed at myself because I'm wondering if it is my interview skills that are lacking. I remember feeling a bit embarrassed and awkward during this interview. Maybe I was having a bad day and wasn't patient enough to give him time to elaborate. I can feel my confidence dipping a little. Maybe I need to make sure that the rest of my interviews are done in quiet areas so that there are fewer interruptions. Something I really need to think about.

Norman

Norman phoned me in the morning to say that he wanted to do his interview that day. I had considered cancelling this interview because I had heard that he had been admitted to the ward area the previous evening. He was keen to go ahead, so I felt I could not let him down. I had to do the interview in a four-bedded bay that was separated with screens. During the interview, I felt confident and felt that the interview went well. I was aware throughout that Norman was quite breathless through.

After the interview: I feel I did not probe this participant as much as I could have. I think I was trying to save him from harm because of his breathlessness. Maybe I should have cancelled this interview? Did I do the right thing? Because he had called me and asked me to go ahead with the interview, and because the staff said he was well enough, this justified my decision to go ahead.

REFLEXIVE BOX: ISSUE WITH ANONYMITY

I've just finished my second interview. As I expected, I felt nervous before I went into the room. I'd spoken to the patient, Mary -Rose on the telephone when we spoke about the study

and organised the interview. When I approached her bedside, she looked at me in surprise and said ...‘I know you’. At first, I didn’t recognise her. She went on to tell me that she’d met my sister at an outpatient appointment, and that they’d chatted. My sister has been diagnosed with cancer is being treated here. It then turned out that they had their TCVCs inserted on the same day. I was with my sister during that appointment; and I remember her talking away to someone. It must have been Mary-Rose. She asked me how my sister was, and we ended up having a bit of a general conversation. While we were talking, I kept thinking if I should be as friendly toward her because I now thought of her in a different way (a friend of the family??). It was strange. I reassured myself that because I ‘knew’ her and that she knew something personal about me that I wouldn’t let that interfere with my interview or with her openness to tell me about her thoughts and feelings. To be honest, I didn’t really know her much at all! Once I started the interview, I managed to become a researcher again rather than a ‘friend’, and I really think the interview was very open, deep informative.

4.8 DATA ANALYSIS

IPA does not prescribe a single ‘method’ for working with data, rather it allows flexibility in matters of analytic development (Smith, Flowers and Larkin, 2009). However, the focus of IPA is to direct the analytic attention of the researcher towards individuals and how they make sense of their experiences (Smith, Flowers and Larkin, 2009). IPA is characterised by some common processes and principles and, as detailed in Chapter Three, has been described as an iterative and inductive cycle (Smith, 2007).

Before analysis began, I had to transcribe the interviews. I made the decision to do this manually. I accepted that transcribing would be time-consuming, with an estimated time ratio of five hours of transcribing to one hour of audio data. It is advantageous that I can touch type, which made the transcription of interviews slightly less arduous. An example of a full transcript can be found in Appendix nine. Following transcription, analysis began. I chose to manually analyse the data rather than using any of the software available. Using software to analyse the data might have been faster and more convenient (Hilal & Alabri, 2013); however, while efficient, this approach might have interfered with the phenomenological process. The analysis would not have been solely between me and the participant. I needed to analyse my data in a

way that would interfere with the research process as little as possible. Analysis of the data for this study began by drawing on the strategies outlined by Smith, Flowers and Larkin (2009).

4.8.1 STEP ONE: READING AND RE-READING

Analysis of transcripts took place following each interview, and the interview schedule did not change for subsequent participant interviews. In order to gain an initial feel for the cases, I listened to each audio recording repeatedly. This helped me obtain an understanding and feeling for the ideas and statements offered by each participant (Haase and Myers, 1988). It also enabled a deeper level of immersion in the data (Guba and Lincoln, 2005). I, then, went back to the transcripts and read them on numerous occasions. On re-reading, I noticed new aspects that I had missed on previous readings and found new meanings for certain statements. Furthermore, I identified times when I could have probed deeper, leading questions I asked, and cues I had missed. I made reflexive notes throughout this process as it was important to try to acknowledge the thoughts and feelings I had during the interview, and to engage fully and purely with the data. At this stage, I entered a phase of active engagement with the data.

4.8.2 STEP TWO: INITIAL NOTE-TAKING

This element of the analysis proved to be the most time-consuming and detailed. Initially, a separate word document was created for each transcript. Next, following guidance from Smith, Flowers and Larkin (2009), a three column table was created (Table 4.3.) .

- Left-hand column: Detailed the emergent themes
- Middle column: Contained the interview along with page and line numbers
- Right-hand column: Used for my initial notes. (exploratory and mostly descriptive comments reflecting initial thoughts about the claims, concerns, and understandings of each participant)

During this period, I tried to remain open-minded and to note anything of interest. This stage became exploratory. Notes taken were broken down into three discrete types:

- Descriptive comments that focused on what the participant had said (in normal text).
- Linguistic comments that focused on the language used by the participant (in italics).
- Conceptual comments which focused on a more interrogative and conceptual level (underlined).

REFLEXIVE BOX: ANALYSIS

It is difficult to put into writing my thoughts about the respondents' stories. I find this a bit challenging. I know what I want to say but can't express it in writing. I am writing down everything I think is relevant that comes into my mind. I'm taking a note of any questions raised from participants' responses in case these prove relevant. The more transcripts I read, the easier it is to make notes without becoming too critical of my process. It's hard not to be critical or doubtful of myself.

I went to an IPA workshop at Caledonian University. This was brilliant and made me feel really confident in the analysis that I had done. I went straight back to my scripts after this and did a bit more analysis. I was surprised at how much more I saw within the scripts that I hadn't seen before. Feeling really good about my analysis now. Just need to think about how to write it all up!

This stage resulted in the production of a vast amount of new data in the form of notes and comments - see Table 4.2. I looked at the language used and abstract concepts arising from the data to help me make sense of the patterns of meaning from the interviews.

Table 4.2 INITIAL NOTE-TAKING AND EMERGENT THEMES

Emergent Themes	Original Transcript	Exploratory comments
Vivid memories of unpleasant vascular access attempts/Feeling of violation	She found a vein and as soon as she started putting the fluid in it just popped out and um at that point I just said ah, listen you can use my right arm because um you know you're not just going to have any luck on my left [laughing] and I feel like, like you're stabbing me to death [laughs].	More failure <u>over and over again – not the first time and probably not the last.</u> <u>Ruminative thinking.</u> <u>Desperate measures – risk of cannulating when lymphoedema is present.</u> <u>Taking control – gave permission to use her other arm.</u>
Multiple cannulation failures		<i>'listen' – needed to get her voice heard.</i> <u>Was this a nervous laugh? It was inappropriate. This was a distressing situation.</u>
A distressing situation		<i>Stabbing to death – an act of violence – violation.</i>
Taking control	And um I gave them permission for my right arm um and the nurse that was doing it um said that yeah there is a protocol in place for, um for that when you can't find anything on the left then you go to the other arm or vice versa, whatever.	<u>Eventually taking control of situation to stop the violation.</u> Shows an understanding of the policies and procedures in place.
Being involved		Awareness of procedures followed by staff. Took advice and again <i>seemed to be involved in the decision-making process. 'we decided'.</i> <i>Involvement in the decision-making process.</i> Choice limited due to lymphoedema and challenging access.
Feeling relieved	Anyway, they went into the right arm and blood came out first time.	

4.8.3 STEP THREE: DEVELOPING EMERGENT THEMES

Following on from note-taking, I looked for emergent themes. To do this, I began to work with the notes, which had become part of the data, as well as the original interview. This was one manifestation of the hermeneutic cycle. I was now working with a set of parts rather than the whole interview; I had broken up the narrative flow of the interview. I was also aware that the analysis now included much of myself in addition to the experiences of the participant. This was in line with the constructive philosophy adopted for this study. The resulting analysis was going to be a product of both of our collaborative efforts (Smith, Flowers and Larkin, 2009). During this stage of data analysis, I attempted to make sense of the statements and stories participants had shared with me. I considered the words and descriptions they used to describe their experiences. This type of interpretation involved empathy, as I was trying to understand what the experience was like from the participants' point of view. In order to turn notes into themes, a concise, pithy statement was attached to any comments that appeared to be of particular importance. The themes that emerged reflected both the participants' original words and my interpretation of them. An example can be found in Table 4.2.

4.8.4 STEP FOUR: SEARCHING FOR CONNECTIONS ACROSS EMERGENT THEMES

Following the development of emergent themes, I began to map out how these themes might fit together. I drew together emergent themes and produced a structure that allowed me to highlight all of the important and interesting aspects of the participants' accounts.

I did this, initially, by printing out my list of themes. These were then cut so that they were on individual pieces of paper. Using a large table, I moved the pieces around and grouped together themes that seemed to relate to each other. Themes that were parallel, or had similar

understandings, were grouped together. This process worked well for me as the visual and tactile approach seemed to bring me closer to the data.

Abstraction was also used to help identify patterns between emergent themes and to form superordinate themes. A superordinate theme is the term given to a cluster formed by putting like themes with like. The superordinate theme, therefore, emerges at a higher-level, as a result of putting the themes together. An example of subordinate themes from Ruby’s account is presented below in Table 4.3

Superordinate theme: SELF UNDER ATTACK	Key phrases	Page / Line
Emergent themes		
Pinholes in my arm	It took nine... three people two goes each, how many is that two, four, six (pause) six pin holes in my arm	(Ruby: Page: 2, Line 36)
Violation	Like you’re stabbing me to death	(Ruby: Page: 2, Line 44)
Being attacked	Every vein in my arm was collapsing Being attacked by a needle	(Ruby: Page: 3, Line 53) (Ruby: Page: 5, Line 109)

Table 4.3: ORGANISATION OF SUPERORDINATE AND SUBORDINATE THEMES FROM THE EMERGENT THEMES (Example Ruby)

4.8.5 STEP FIVE: MOVING TO THE NEXT CASE

This process was repeated for each interview in each group. It was important that I treated each transcript individually in order to ensure that I maintained the idiographic commitment of IPA (Smith, Flowers and Larkin, 2009). I must admit that, at this stage, I found it difficult to ‘bracket out’ the findings that had emerged from previous transcripts; it was challenging to put those other stories out of my mind completely. Throughout the process of analysis, I continued to make diary entries detailing the feelings and thoughts that emerged for me while working through the transcripts. My diary writing aided the reflexive process and allowed previously held beliefs and biases to be acknowledged and considered. This was in keeping with hermeneutic practice (Smith, Flowers and Larkin, 2009).

4.8.6 STEP SIX: LOOKING FOR PATTERNS ACROSS CASES

At this stage, I cut and pasted all themes from the whole corpus onto one page. I then started to find connections between them. I used recurrence to identify superordinate themes. If a theme was present in at least a third or a half of the participant interviews, it was considered a superordinate theme. While it is not the only indicator of importance, the frequency in which emergent themes appear throughout the text can be viewed as an indicator of their relative importance to the participants.

I produced a master table for each of the device groups (PICC, TCVC, and TIVAD). An example from the TCVC group can be found in Table 4.4. Next, I repeated the process of looking for connections across each of the master tables and produced another table which captured the main themes related to living with a long-term VAD (Table 4.5). Finally, I developed new superordinate and subordinate themes that captured the experiences of the participants (Table 4.6).

SUPERORDINATE THEME: THE SELF UNDER PHYSICAL ATTACK

Ruby: 'like you're stabbing me to death' 2:44

Ruby: 'Being attacked by a needle' 3:83

Mary-Rose: 'I had horrible side effects with the cannula, spasms in my arm, it felt like it was on fire and it lasted for days' 5:109

Yasmin: 'I'm going to have to get stabbed all the time' 7:129

SUPERORDINATE THEME: BEING RESCUED

Norman: 'This was a new opportunity to get something better' 1:32

Norman: 'This is a wonderful thing' 2:59

Amaya: 'Since I got this [TIVAD] it's been brilliant' 1:10

Amaya: 'It makes life so much easier' 1:26

Mary-Rose: 'It's been a life saver' 3:86

Ruby: 'It's part of me now' 4:77

SUPERORDINATE THEME: FEELING ILL-INFORMED

Ruby: 'I do think I should have been given some sort of leaflet, pamphlet' 8:186

Yasmin: 'If I could change something, I would get more information' 9:172

Mary-Rose: 'When I got home, I thought, how am I going to deal with this thing hanging out there?' 2:57

SUPERORDINATE THEME: THE NEED TO CONCEAL

Ruby: 'It could be totally concealed; you would have no idea I had anything on me' 6:120

Mary-Rose: 'I don't want anything to be seen. I don't want to be a patient; I mean I don't want people to know' 4:106

Yasmin: 'I tried to keep it hidden most of the time' 5:80

Ruby: 'You can be walking around, and no one would know that you were having chemicals pumped into your system' 5:111

Mary-Rose: 'Maybe I'm alarming them' 4:123

TABLE 4.4: MASTER TABLE OF THEMES: LIVING WITH A VASCULAR ACCESS DEVICE

SUPERORDINATE THEME ONE: THE SELF UNDER ATTACK

Ruby: 'like you're stabbing me to death' 2:44

Ruby: 'Being attacked by a needle' 3:83

Mary-Rose: 'I had horrible side effects with the cannula, spasms in my arm, it felt like it was on fire and it lasted for days' 5:109

Yasmin: 'I'm going to have to get stabbed all the time' 7:129

Tina: 'Every time when you've got to get that injection it gets harder and harder' 5:153

Amaya: 'I dreaded having a cannula' 1:9

Tina: 'You sat there with your hands in boiling water, praying that it would work. You felt like you were at their mercy' 1:69

Sam: 'Getting blood from me by the GP or phlebotomist in here was quite an ordeal' 1:6

Norman: 'Laterally it got to the stage where they had to try about 3 or 4 times before they got a vein' 1:30

Yasmin: 'I thought I was dying' 2:60

SUPERORDINATE THEME TWO: BEING RESCUED

Mary-Rose: 'It's been a life saver' 3:67

Mary-Rose: 'I don't have to worry about my arms being really painful which it was' 3:83

Ruby: 'At least with the TCVC it was just the once. They didn't have to think about (pause) going through the ... looking for (veins) being attacked by a needle' 1:28

Mary-Rose: 'It makes life easier' 2:25

Sam: 'You know they are going to get blood without an issue' 3:72

SUPERORDINATE THEME THREE: SELF PROTECTION

Ruby: 'It could be totally concealed; you would have no idea I had anything on me' 6:120

Mary-Rose: 'I don't want anything to be seen. I don't want to be a patient; I mean I don't want people to know' 4:106

Yasmin: 'I tried to keep it hidden most of the time' 5:80

Ruby: 'You can be walking around, and no one would know that you were having chemicals pumped into your system' 5:111

Mary-Rose: 'Maybe I'm alarming them' 4:123

Alfred: 'If I was on holiday and sitting by the pool or that, then it would probably be more of an issue' 2:41

Sam: 'Being able to go into the water and stuff like that. Just really from that point of view, how people might perceive it' 2:44

Sam: 'My daughter freaks out when she sees it' 2:45

SUPERORDINATE THEME FOUR: FEAR OF RETURN TO ATTACK

John: 'You can't touch it unless you're qualified' 2:57

John: 'There was about six attempts to get blood' 3:75

Sam: 'Not everyone is trained to use them' 2:59

Norman: 'She doesn't want to force it, understandably, because there is no form of back up there [district]' 2:60

Garud: 'The staff in here are more familiar with PICC lines than the district nurses are' 2:59

Tina: 'You shouldn't be caught in the middle like that' 4:124

Amaya: 'In another hospital they won't access it at all' 2:41

Amaya: 'They point blank refused to use it' 2:47

Sam: 'My GP has to do it through a cannula or a conventional syringe' 2:60

Ruby: 'I'd rather keep it in because I don't want anyone to stab me again' 10:222

Table 4.5: SUPERORDINATE AND SUBORDINATE THEMES THAT CAPTURED THE EXPERIENCES OF THE PARTICIPANTS

Table 4.5 captured the most important aspects of the participants' stories. I had moved from the part (the fragmentation of the patient's experience) to a new whole; a re-organisation of the data and expressed in superordinate themes. This process represents another manifestation of the hermeneutic cycle (Smith, Flowers and Larkin, 2009). Denscombe (2010) suggests that analysis of qualitative data should be rigorous and well-detailed. In small scale studies, according to Denscombe (2010), the researcher is the crucial 'measurement device'. Furthermore, since data analysis is a process of interpretation, it is closely linked to the researcher. This could lead to findings being taken out of context. This was considered; I, therefore, ensured that the statements of the participants were as voiced, and that interpretation was grounded in those statements.

After this interpretation, I moved on from looking at the text at a micro level and attempted to interpret participants' stories and statements at an elevated level. However, this is a skill that I discovered builds with time. On reflection, my interpretation might have been slightly cautious which, according to Smith, Flowers and Larkin (2009), is a common issue for novice researchers.

REFLEXIVE BOX: THE ANALYSIS PROCES

I decided to transcribe all of the accounts myself. I don't regret this, but it is so time-consuming and all-encompassing. This has kept me very close to the detail of the interviews and I think I am managing to examine each transcript in depth. I am trying to approach each transcript as if it was the first, but I'm finding it impossible not to immediately recognise connections and similarities between them. The interpretive / hermeneutic part of this analysis is really lengthy. I am returning to the transcripts over and over again and, even when I'm not working on my transcripts, I find myself thinking about phrases used by participants and trying to find alternative interpretations.

I've got far too many themes! I have to decide which of these are the most relevant and significant and remove the ones which don't add to the experience. This is really hard to do. Forming themes and sub themes is proving to be even more difficult. This was something that I am going back and forth with and changing all the time.

4.9 ENSURING RIGOR AND VALIDITY IN MY STUDY

Qualitative studies are valuable within healthcare. However, the demonstration of rigor within such studies can be challenging. In fact, some question whether qualitative research findings can ever be valid and reliable (Noble and Smith, 2013). Additionally, qualitative research is sometimes criticised for lacking scientific rigor due to a lack of justification for the adopted methods, or a poor demonstration of transparency in analytical procedures and findings. This can lead findings to be viewed as simply an assemblage of personal opinions which are subject to researcher bias (Rolfe, 2006). While the demonstration of rigor and quality in qualitative research can be challenging, such a demonstration is a fundamental part of enhancing the credibility and trustworthiness of studies (Noble and Smith, 2013). Therefore, it is necessary to discuss how rigor and quality were ensured in the current study.

I was aware of three specific guidelines or frameworks that considered quality and rigor in qualitative research (Elliott, 1999; Yardley, 2000; Smith, 2011). All of these guidelines were similar in content. I chose to follow the guidance offered by Yardley (2000), as detailed in Chapter Three, since these guidelines are clear and concise. Yardley's guidelines include issues of sensitivity to context, commitment and rigor, transparency and coherence, and impact and importance. The following section will describe how these issues were considered and demonstrated during my study.

4.9.1 SENSITIVITY TO CONTEXT

I used a variety of techniques to ensure sensitivity to context during my study. One of the key considerations were ethical issues related to the study. All participants were undergoing a period of chemotherapy treatment for cancer. Therefore, I had to acknowledge that this might not be an easy population to target as they were already dealing with many issues in relation to their health. I worked closely with the oncology research nurse and staff within the Vascular

Access Service to enhance the recruitment process. It was important to have the input and knowledge of participants' journeys because I did not want to overburden people who might have been recruited to more than one research study.

To ensure sensitivity during data collection, I utilised details and information gleaned from attendance at an IPA workshop that had a focus on interviewing. My practice interviews also added to my technique.

I remained aware that I had to switch from my natural nursing demeanour to that of a researcher during the interviews. However, at all times, I attempted to put participants at ease and show empathy during the disclosure of information. I had decided that I would not continue with an interview if a participant became very distressed. Despite some open and honest conversations, none of the participants became distressed during the interviews.

4.9.2 COMMITMENT AND RIGOR

According to Smith, Flowers and Larkin (2009), in IPA, commitment is synonymous with sensitivity to context. It relates to the degree of attentiveness given to each participant during the collection of data as well as the detail in which analysis is performed. In this study, a purposeful sampling technique was utilised, and the sample was homogenous. This was a suitable sampling technique for this study and one that allowed the possibility of answering the research question. I attempted to improve my interview technique as the study continued, which demonstrated commitment and an attempt to make the study as rigorous as possible.

IPA is interpretive and not descriptive. I, therefore, attempted to grasp the meaning that each participant attached to their experience. I allowed the data to speak and, in parallel, allowed the research participants to speak (Smith, Flowers and Larkin, 2009). I was aware that this did

not mean that my work would be seen as the ‘truth’. Instead, the process generated a richer explanation of my findings (Gibbs, 2007). When developing the themes - both sub- and superordinate - I ensured that these were supported by participants’ accounts. This was another element which ensured rigor in my study.

4.9.3 TRANSPARENCY AND COHERENCE

Every step of the research process has been described in this thesis. It was crucial for me to be transparent and to describe the steps taken in the development of the super and subordinate themes. This was because I had fragmented the interview and developed a new meaning from the participants statements. I ensured that this key stage of the analysis was conducted.

Subsequently, I recorded notes within my reflexive diary and within reflexive boxes throughout this thesis. I believe that I have maintained coherence throughout my study. This began with designing the literature search strategy and literature review, as well as in the selection of the research approach. The analysis of data and write up of the findings demonstrate that the study followed the steps of IPA in a coherent manner. The maintenance of a reflexive diary further demonstrates my openness and transparency throughout the whole process.

4.9.4 IMPACT AND IMPORTANCE

The findings of this study will offer a unique insight into how people make sense of life with a VAD. Literature on the clinical advantages and disadvantages of CVADs is plentiful. However, it remains largely technically focused (Simonov, Pittiruti, Rickard et al. 2015, Bodenham, 2016; Voog et al 2019). This study will, therefore, add to the limited research base focused on the patient experience of vascular access. I have already begun to consider post-doctoral work which will influence wider disciplines in the field. These will be discussed in Chapter Seven. The comparison of experiences of people living with each of the three devices

available will hopefully provide vital information for future patients, as well as to the HCPs who insert these devices. This should lead to a more informed and sensitive approach to the counselling of patients who require a device for treatment.

4.9.5 REFLEXIVITY

Reflexivity is an explicit evaluation of the self. From its etymological roots, we are aware that the term 're-flexivity' relates to looking again or turning your gaze to the self (Shaw, 2010). This means that reflexivity involves reflecting your thinking back to yourself. It suggests an interpretivist ontology that understands people and the world as connected and involved in a dialogic relationship that constructs many versions of reality (Shaw, 2010). As discussed in Chapter Three, Gadamer's notion of horizons, and Heidegger's being-in-the-world, provide backing for the need to adopt a reflexive approach in qualitative research. During all aspects of this study, I made myself aware of my feelings as well as my expectations of the research. By ensuring this, I began to fully appreciate the nature of the investigation and how it related to me on both a personal and professional level.

During my data collection, the use of each participant's presentation of self allowed me to readjust my fore-understanding, which helped me to make sense of the phenomenon afresh. I was aware of, and acknowledged, my dual roles as a researcher and a clinician, and was successful in juggling the two. I was empathetic when necessary whilst engaging in conversations with participants, allowing them to be open and honest. If the participant wanted to question me about clinical issues, I politely reminded them that I was there in a researcher role and then made sure that any queries of this sort were directed to the appropriate person. This proved easier than I thought because I was not a staff member at the site of recruitment. I did not wear a uniform and, therefore, I presented myself as a researcher and not a clinician. I believe I managed to build rapport with the participants, which aided trust between us and

enhanced the quality of the interviews. While engaging in reflexivity will not remove bias, it is a way to display existing issues and so facilitate a more precise interpretation of participants' accounts (Clancy, 2013).

4.9.6 MEMBER CHECKING

Respondent validation is a method of 'checking' research findings which involves cross checking interim research findings with respondents. However, I decided not to return to the participants as I was aware that many of them had a terminal diagnosis and were receiving palliative treatment. I did not want to risk attempting to contact participants who had deteriorated health-wise as I appreciated that they had already given up much of their precious time and felt it unnecessary to further impose on them. Additionally, while member checking has long been accepted as the gold standard in qualitative research, it is no longer considered the highpoint for expressing rigour in Heideggerian phenomenology because it contradicts many of the underpinning philosophies (McConnell-Henry, Chapman and Francis, 2011). Indeed, employing experts to confirm findings has also been suggested as being in conflict with the values of interpretivism (McConnell-Henry, Chapman and Francis, 2011). However, as a novice researcher, I chose to share two of my transcript interpretations with my research supervisors. This was a form of peer checking and, rather than looking for confirmation of my interpretations and findings, I did this to ensure I had produced an accurate reflection of the accounts (Lingis, 2014).

4.9.7 REFLEXIVE DIARY

My reflexive diary was completed following each interview. Each entry included my thoughts and feelings about that interview, particularly if any prejudgements had been apparent. I noted the range of emotions and thoughts that came to me during the interview process. Throughout the study, I made notes of when my own pre-assumptions came to the forefront. I was aware of my own pre-

conceptions from the start of the study and throughout the development of the research question, literature review, selection of methodology, data collection, and, particularly, during data analysis and findings. Examples of these can be found throughout the thesis.

4.10 CHAPTER SUMMARY

Details of the research methods employed in this research study have been provided along with a justification for my selection of data collection method, participants, and data analysis. Ethical considerations and the ways in which the risk to participants was minimised have also been detailed. Details of how quality was assured have been provided along with a discussion of reflexivity. The following chapter will present the findings developed from the analysis of the participants' accounts.

CHAPTER FIVE: FINDINGS

5.1 INTRODUCTION

In Chapter Four, I described the methods used in this study. In addition, a detailed explanation of the analysis was presented. In this chapter, findings from the analysis of the three patient groups' accounts will be presented. Firstly, this chapter details the findings in which emergent themes were consistent across the groups; secondly, where themes differ. My interpretation of the accounts captures the meaning of the phenomenon for each individual participant and, therefore, is true to the idiographic focus of IPA (Smith, Flowers and Larkin, 2009). In the first section, extracts will present the core of the most recurrent or powerful statements of any given theme. The findings in this chapter are supported by my detailed account of how each theme was constructed (see Chapter Four). This provided a clear audit trail of the steps involved and the decisions I made as I analysed the data and developed each theme. This chapter will commence with details about the study participants. The findings will then be presented in the following sections:

Section One: The lived experience of participants with a Vascular Access Device. This section will explore the convergent themes discovered across the groups.

Section Two: The lived experience of participants with a PICC, TCVC, or TIVAD. This section will explore the divergent themes discovered across the groups.

SECTION ONE

5.1.2 PRESENTATION OF FINDINGS

The words of the participants will be presented in quotation marks followed by the participant's pseudonym, and the type of device they had inserted. Minor changes were made to the verbatim statements to improve readability. Repetitions were only retained if they added to the meaning

of statements, such as to emphasise a point. Ellipses were used to indicate missing words. Words were only removed if they were redundant and did not add to the meaning of the statement. If words or phrases were added to provide an explanation to the reader, these were presented within square brackets. To indicate that there was dialogue before or after the statement, ellipses have been used. To personalise interviews and protect participants' anonymity, all identifying material was removed and pseudonyms assigned.

5.1.3 PARTICIPANT INFORMATION

Eleven patients living with Vascular Access Devices were interviewed (Table 5.1)

Name (Pseudonym)	Age	Gender	Device	Reason for device	Length of time living with device	Device inserted by
Norman	76 years	Male	PICC	Chemotherapy for colorectal cancer	18 months	Nurse
Tina	80 years	Female	PICC	Chemotherapy for colorectal cancer and liver metastases	10 weeks	Nurse
Garud	59 years	Male	PICC	Chemotherapy for colorectal cancer	Four months	Nurse
Alfred	66 years	Male	PICC	Chemotherapy for colorectal cancer	Four weeks	Nurse
Sam	84 years	Male	PICC	Chemotherapy for colorectal cancer	Six weeks	Nurse
Ruby	55 years	Female	TCVC	Chemotherapy for anal cancer	Eight weeks	Nurse
Mary Rose	63 years	Female	TCVC	Chemotherapy for colorectal cancer	Nine weeks	Interventional radiologist
Yasmin	19 years	Female	TCVC	Chemotherapy for non-Hodgkin's Lymphoma	Six months	Interventional radiologist
Anton	47 years	Male	TIVAD	Chemotherapy for colorectal cancer	18 months	Interventional radiologist
Amaya	51 years	Female	TIVAD	Chemotherapy for metastatic colorectal cancer	Five months	Interventional radiologist
John	80 years	Male	TIVAD	Chemotherapy for lung cancer	Four months	Interventional radiologist

Table 5.1: PARTICIPANT INFORMATION

5.2 STUDY FINDINGS

This section presents four superordinate themes that emerged from the data: 1) The self under attack; 2) Being rescued / being robbed; 3) Protection of others / Protection of self; and 4) Bewilderment and dismay at lack of staff competence. In addition to the superordinate themes, minor related themes have been added. These have been described as subordinate themes and

are outlined in Figure 5.1. Two of the superordinate themes have subordinate themes. The other two do not have subordinate themes as they are very specific and were able to stand alone.

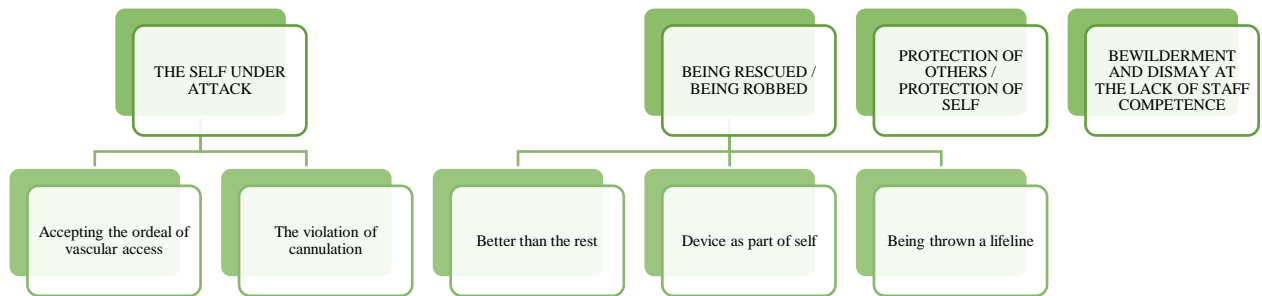


Figure 5.1: SUPERORDINATE AND SUBORDINATE THEMES

The following section will discuss each of the superordinate and subordinate themes in order.

The first superordinate theme to be discussed will be: the self under attack.

5.2.1 SUPERORDINATE THEME ONE: THE SELF UNDER ATTACK

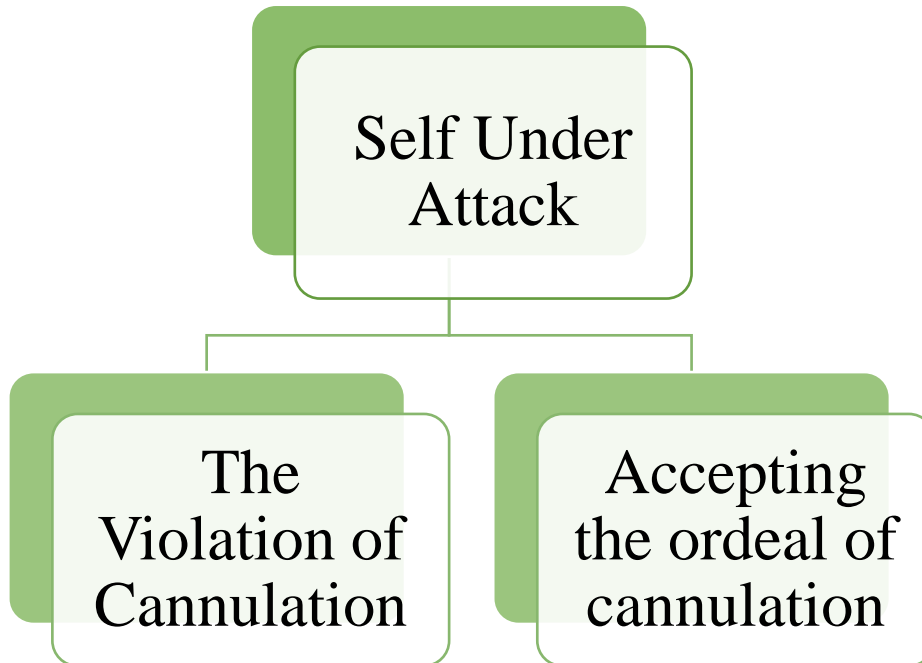


FIGURE 5.2 THE SELF UNDER ATTACK

The focus of this study was the experience of living with a long-term Vascular Access Device. The opening broad question was ‘*Describe in your own words and in as much detail as possible how it feels to live with a vascular access device?*’ This question transported participants to the period prior to having their device inserted. It triggered accounts of their experiences of vascular access and treatment delivery via the peripheral veins of the hand. Participants had to look to the past before discussing the present, suggesting that these experiences, although embodied in the past, continued to form a meaningful part of their experience of vascular access.

These accounts appeared to be intrinsically related to the journey toward acceptance of their long-term devices. For the majority of the participants, prior to long-term Vascular Access Device insertion, treatment was being delivered via peripheral cannulas. This involved

regularly accessing veins in the hand or arm. The cannula was removed following treatment, and reinserted when treatment was required again. Participants returned for treatment on a regular basis, and the act of accessing a vein for treatment appeared to become a traumatic part of the visit.

Eight of the participants in this study recalled the painful procedure of peripheral vascular access. All participants with a TCVC and PICC provided vivid descriptions of painful bodily sensations encountered during challenging peripheral cannulation. One of the patients with a TIVAD (Amaya) also described this experience. The remaining three male participants did not take themselves back to their peripheral venous access experience in great depth during the interviews, and instead focused on their long-term device.

This subordinate theme relates to the description of the act of peripheral venous cannulation as you would an act of violation.

5.2.1.1 SUBORDINATE THEME: THE VIOLATION OF VASCULAR ACCESS

The first account is from Ruby, who had a TCVC inserted for chemotherapy. Ruby had previously had a mastectomy and lymph node clearance, which meant that only her left arm could be used for blood sampling and vascular access. This was to reduce the potential risk of lymphedema.

'The right-hand side of my body is not used for taking the samples or anything particularly my right hand, my right arm. So, while I was going through the first part of the treatment... I knew we were going to have problems because every time I needed to have blood samples it took two or three people to get the vein to take the blood. After two or three of those, we couldn't find any veins in my arm. Every time she found a vein, it just collapsed. It took three people two goes each, how many is that, two, four, six, six pinholes in my arm...' (Ruby, TCVC).

Ruby recalled this episode so clearly; she could replay it in her mind and remember each person as well as the number of times each had attempted to cannulate her. She described the punctures as ‘*pinholes*’, indicating that physical holes were left on her body. Interpretation of the word ‘*pinholes*’ conjures up the image of a pin cushion. This could suggest that Ruby no longer felt like a human being with feelings, but instead felt like an object. Counting the punctures highlights the extremity of the ordeal. It suggests that each puncture mattered, and that they didn’t go away each time someone tried to access her veins. Ruby’s subsequent experience of vascular access may have been shaped by this vivid, traumatic episode.

‘... at that point I just said, listen, you can use my right arm because you know you’re not going to have any luck on my left and I feel like, like you’re stabbing me to death’
(Ruby, TCVC)

The extent of Ruby’s distress was further captured when the procedure of peripheral cannulation was described using a simile suggestive of death and violence. This was evidenced by her use of the word ‘stabbing’. Discussing the positive aspects of her TCVC, Ruby said:

‘At least with the TCVC it was just once, they didn’t have to think about going through the [skin] being attacked by a needle’ (Ruby, TCVC)

This extract emphasises an enforced passivity. Using the word ‘*attacked*’ throws up visions of a violent act and portrays Ruby as a victim. Ruby seemed to no longer have power or control over herself or what was happening to her. In the following powerful extract, she took this one step further by describing a time when she experienced multiple attempts to get a cannula inserted:

'She found a vein and, as soon as she started putting the fluid in, it just popped out and at that point I just said, listen you can use my right arm [ipsilateral to lymph node clearance]. It felt like they were stabbing me to death.' (Ruby, TCVC)

This suggests that this experience affected Ruby deeply and was felt to be traumatic. Ruby appeared to have suffered so much so that she felt like it was the end. This quote portrays a scene that was long and drawn out, with many attempts (or stabs) to obtain vascular access. This account is, again, suggestive of a lack of personal control over the situation. Ruby seemed to be reduced to an individual who is helpless, passive, and powerless. Yasmin used similar words when she discussed what would happen once her device was removed:

'I'm going to have to get stabbed all the time' (Yasmin, TCVC)

Yasmin was not talking about the cannulation procedure as a medical procedure, but rather as an unpleasant, repeated attack. She furthered this by talking about the lasting effects of the 'stabblings':

'I didn't like it, I've got scars from my cannulas and they hurt as well' (Yasmin, TCVC).

The physical scars, pain, and restrictions associated with cannulation were a negative experience for Yasmin, which resulted in her aligning the cannula with a weapon, something that caused her physical harm. A similar account from Mary Rose also highlighted the distress faced during attempts at peripheral cannulation:

'I had horrible side-effects with the cannula, spasms in my arm, it felt like it was on fire. That was the reason why they decided on the Hickman ;TCVC] line to try and [stop] the symptoms of what happened, and it did' (Mary Rose, TCVC).

And later:

'Even taking bloods and things, sometimes they would have difficulties in finding a good vein to get bloods out of and that's all uncomfortable, it all adds to the distress of all of this' (Mary Rose, TCVC).

These statements suggest that, on top of everything else Mary Rose was going through, the cannulation procedure was one more thing to deal with. She used the word '*uncomfortable*', although she then went on to say '*distress*'. It appears that, in the second quotation, Mary Rose played down the pain she endured; a pain that seemed to be a result of the repetitive process of peripheral cannulation, the repeated piercing of skin integrity. Mary Rose described what she went through and likened the feeling of being cannulated to being '*on fire*'. Use of this simile suggested great pain that was not sharp and fast but instead drawn out and long-lasting. It also conjured up images of torture. Mary Rose knew that this was not a one-off, nor was it something she could refuse. This was the only way for her to receive chemotherapy treatment and, therefore, she had to endure it, no matter how distressing. Having to endure the painful cannulation procedure appeared to leave Mary Rose facing a profoundly diminishing sense of personal control and agency.

Like the findings from the TCVC group, all participants with a PICC discussed their experience of vascular access prior to getting their PICC inserted. The act of putting the needle into Tina's vein proved to be invasive, intrusive, and surrounded in meaning. This was highlighted in an extract where she discussed the commencement of chemotherapy, which she remembered vividly:

'And when the needle goes in, I could feel my heart pounding. You realise that your life will never be the same again ... watching this thing going into your arm' (Tina, PICC).

This account describes the physical effect that the procedure of cannulation had on Tina. The piercing of the skin's integrity appeared to affect her, and her body reacted physically. Her

'pounding heart' suggests the beginning of a vasovagal episode, which is common in those with needle phobias (Han *et al.*, 2009). Her body seemed to have responded with panic or a 'fight or flight' reaction in anticipation of the impending needle puncture. Tina's description of the cannula as *'this thing'* suggests that it is something unpleasant and unwanted. She described how the act of piercing her skin and inserting the needle triggered the beginning of her treatment and, from that moment, her life would never be the same. Tina continued to share painful memories of previous cannulation attempts:

'It was horrible ... see that heating your hands up in the boiling water, and my veins were great, I've got good veins. They never have difficulties. Only once did they have difficulties and the nurse insisted on doing it here [points to an area beside her thumb]' (Tina, PICC).

Tina switched from the past to the present tense, saying *'my veins were great; I've got good veins'*. Initially, it could be assumed that Tina was referring to herself now. However, her account made it apparent that she was referring to a time in the past; a time when her veins were good and venous access was not as difficult. In the past, Tina identified as having *'great'* veins. This is in contradiction to how her veins are now. Describing how the nurse had to move to an area that was not typically used for venous access (near her thumb) suggested that her other veins were no longer viable. However, Tina did not identify as someone whose veins had become inadequate or dysfunctional. There is a sense that part of who she is was still represented by the healthy person in her image. Tina appeared to be struggling to adjust to her new self; a self that is now defined by her difficult and challenging veins.

Tina's use of the word *'horrible'* highlighted the trauma experienced and suggested something that is unpleasant or disgusting. Despite Tina stating that she had good veins, she still found the procedure of cannulation painful. She also spoke repeatedly about the process used to try to improve her veins. Warm water is often used to increase vein size; however, Tina described

this water as *'boiling'*. Traumatic or episodic memories are prone to distortion. It appears that Tina's recollection of her experience may have been altered. Her hands would not have been placed in boiling water, but her trauma may have grown over time and the pain she had felt may have been so horrendous that it felt like her skin was burning. This was an act Tina had retained in her mind. She returned to the memory of her hands in water later in the interview:

'They never had trouble getting veins for me, however, it still didn't make it any more pleasant because you just sat there with your hands in the water praying that it would work' (Tina, PICC).

Tina again repeated that she had good veins and that she didn't previously have issues with venous access. It appeared that the experience of having to place her hands in water was ingrained in her mind. This act seemed to be the issue that was making venous access unpleasant, rather than the cannulation procedure itself. The bucket of water seems to symbolise a traumatic time which had left a particularly vivid memory. This could be likened to a form of classical conditioning (Skinner, 2009). Tina had learned to associate the procedure of cannulation (an unconditioned stimulus) with the bucket of water (a conditioned stimulus). The bucket of water then appeared to exert a similar fear response to the cannulation procedure, which was an unpleasant experience. Tina also highlighted that over time, the procedure of venous access via peripheral veins became more challenging:

'Every time when you've to get that injection and it gets harder and not everyone does it painlessly, and it's not painless, it's not a painless procedure' (Tina, PICC).

The repetition of the words *'painless'* and *'painlessly'* emphasise the trauma that remained in Tina's memory. The statement also highlighted that, during the time taken to perform venous access successfully, there was nothing Tina could do to distract herself. She could not disengage from the situation but seemed to be on the outside looking in. She had no choice but

to watch the situation unfold for what (to her) seemed to be hours. Her sense of agency and control of self at this time appeared to be reduced. Tina described how the act of cannulation felt to her:

'I felt like I was being ... it was more of an invasion, whereas this (PICC) is part of me, it seems less invasive although it probably is more invasive because it's going right into you. I don't think about it. Whereas before it was like a big procedure every time. It was dramatic and, as you became less well, it became more invasive. As you became more tired you go oh, no ...' (Tina, PICC).

Tina stated that when the needle was in the small peripheral vein, she remained aware of it. She described the PICC as *'part of her'*. Tina appeared able to have a sense of ownership and agency with the PICC which was not apparent when she discussed the cannula, reflecting a limitation of self-control. As time goes on, the feeling of a lack of self-control became *'tiring'* for Tina. She began to give in, lie down and take whatever was being done to her rather than attempting to question or fight it. Tina summarised her experience of a vascular access procedure that was challenging:

'You felt as if you were at their mercy' (Tina, PICC).

This extract highlights the lack of control Tina felt over the situation; she had no defence and probably felt helpless. When attempting to regain self-control, Tina described how she tried to dissuade the nurse from accessing an area she found unacceptable and painful:

'...the nurse insisted on doing it here [points to an area near her thumb]. And I said 'Stop! That's very painful'. And she said 'That's the way'....' (Tina, PICC).

Tina had no control over what was happening to her during this encounter. Instead, she had to endure the pain that accompanied the cannulation attempt. This attempt failed, and the nurse continued to insert the device into her chosen area. Tina had lost the battle to take control of what was happening to her body. Tina believed that this had negative consequences for her:

'See that thumb, seven months, seven months or eight, it was longer, sore, and she never got it in. Months and months that thumb was sore. You know how you use your thumb quite a lot, it was like having arthritis in it.' (Tina, PICC).

This episode led to further restriction for Tina. Her body was further damaged and resulted in a self that was inadequate. Tina went on to say how she would react if this was to happen again:

'Now, I would totally say no. I know some people go for that, have it done there, but it doesn't work for me, it's too painful' (Tina, PICC).

On reflection, Tina realised she had never taken control and had allowed things to be done to her rather than being involved. She had lost control of her 'self'. Eventually she began to see herself as her own person and stated that she would be more assertive in the future.

5.2.1.2 SUBORDINATE THEME: ACCEPTING THE ORDEALS OF VASCULAR ACCESS

Participants discussed the staff who had inserted their peripheral cannulas and there was a degree of empathy for healthcare professionals. Participants felt that moving to a long-term device would not only be beneficial to them, but also to the healthcare professionals. Sam appeared to have knowledge about guidelines and procedures related to peripheral cannulation. He knew the number of attempts that an individual could have before they had to summon help from another practitioner. Sam reflected on this in his account:

'Whereas I kind of got used to it, I could see the people who were actually trying to get the blood from me get stressed from it, and they would maybe try twice and then go on to somebody else because they are not allowed to just carry on doing it. So, from their point of view, I thought it was helping them as well. Normally they would get it, I mean there was never a time when they couldn't not get bloods, but sometimes it took a long time' (Sam, TIVAD).

In this scenario, the process of getting blood involved healthcare professionals having two attempts each until a successful outcome was reached. This highlights how this procedure could

have become daunting and traumatic for participants, and why anything which mitigated this experience would be welcomed. The pain of cannulation was also discussed by Sam, who spoke about the difficulties he faced having blood taken:

'Getting blood from me by the GP or phlebotomist in here was quite an ordeal' (Sam, TIVAD).

An ordeal is an unpleasant, prolonged experience. Using this word suggests that Sam had undergone long, drawn-out cannulation attempts. It appeared that, as treatment via peripheral veins continued, the process, and success, of cannulation became more challenging:

'I was getting bloods done every day and the veins were getting more and more difficult to get bloods from... I thought it was something that I had to endure... lately it got to the stage where they had to try about three or four times before they got a vein, so it was getting really quite ah, ah, not exactly distressing but yeah it was quite...' (Norman, PICC).

Norman found it difficult to find words and hesitated when he came to discuss his feelings about the cannulation procedure. He tried to explain his experience and used the words '*not exactly distressing*', which could suggest that the experience was close to being distressing. As an older male who might not be used to expressing feelings, Norman's hesitation may have indicated an attempt to control his emotions. However, his statement suggests that cannulation was, in fact, a distressing experience for him. The word 'endure' suggests that he was suffering something painful or difficult. The fact that he was being cannulated multiple times makes this understandable. Venous access was essential for treatment to be delivered, participants are, therefore, likely to have felt they had no option but to deal with its negative effects. Sam discussed similar difficulties with practitioners attempting to access his veins. Unlike Tina, Sam stated that his veins were not very good when he started his treatment. Consequently, there was an anticipation that venous access via a peripheral cannula was going to be problematic:

'My veins have never been that great ... everyone was having a lot of trouble getting samples from me' (Sam, TIVAD).

Before having her TIVAD inserted, Amaya also experienced challenging peripheral venous access:

'Obviously your veins are starting to collapse. It was fine at first and then it was getting harder to get the veins' (Amaya, TIVAD).

And later:

'I dreaded getting a cannula in because it was sore trying to get a vein. Obviously, it was hard for the girls to get a vein, and then they started to move up a wee bit higher' (Amaya, TIVAD).

The word '*obviously*' was used twice by Amaya. This suggests that she wanted to make her experience normal and something that was expected to happen. This seemed a mechanism for Amaya to accept what had happened to her during her peripheral access experience.

The word '*dread*' signifies something unpleasant that causes anxiety and fear. For Amaya, these feelings were directly related to the anticipation of pain associated with the procedure. This was not a one-off procedure; from this statement, it appears that nurses had to make numerous attempts before they gained access. Amaya felt empathy for the nurses, recognising that it was not an easy situation for them either. Amaya's descriptions were vivid and detailed, and included physical and physiological impacts of the procedure. Interpretation of the statements suggests that there was a high degree of distress associated with the repeated peripheral cannulation which Amaya faced prior to having a long-term device inserted. These extracts suggest a sense of personal loss, and a profound diminishing of personal control and

agency. Like Tina from the PICC group, Amaya recalled the strategy of using water prior to attempts at cannulation:

'Look there's someone with their hands in water. I don't have any of that. Sometimes I sit and see people, maybe like I was, trying to find veins and I sympathise, it's horrible, it's sore and that was the part of coming in knowing that they had to access your vein' (Amaya, TIVAD).

Amaya was transported back to a time in her treatment when she was in the same position as other patients. She appeared to feel relieved and happy that she no longer had to go through the procedure, and seemed to feel empathy for those patients who did. Her use of the words *'horrible and sore'* tell us that this was an unpleasant, physically challenging procedure.

'There's no pain. All you feel is the pressure. There is not any pain at all when they are accessing it. You can tell if they are putting it in wrong but it's not sore and if they're hitting the centre, you can tell' (Amaya, TIVAD).

The presence of the TIVAD meant that Amaya no longer had to suffer the pain associated with peripheral cannulation. The *'pain'* was replaced by *'pressure'*, which was more acceptable.

5.2.3 SUPERORDINATE THEME TWO: BEING RESCUED / BEING ROBBED

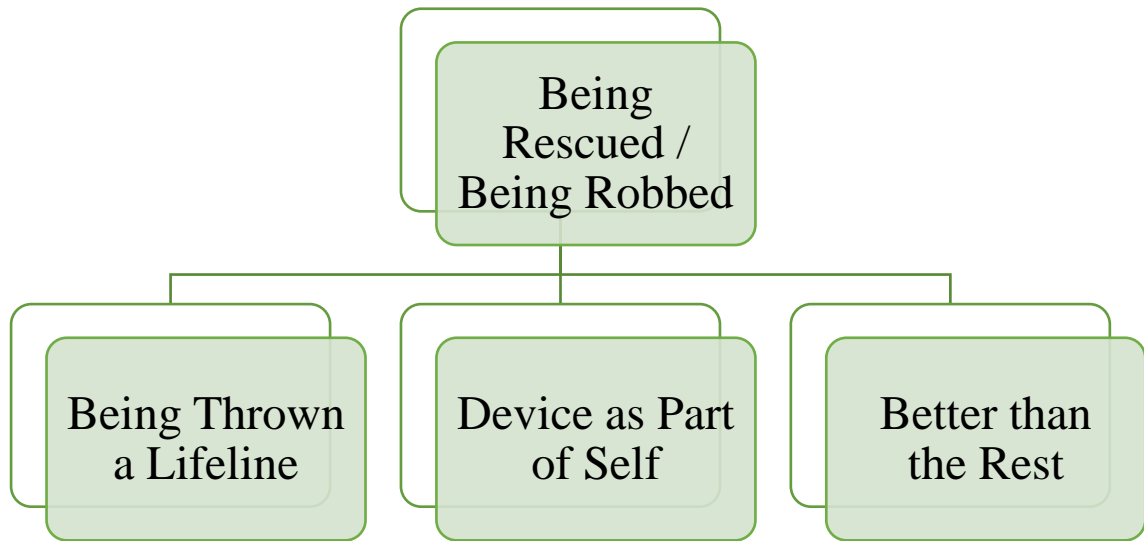


FIGURE: 5.3: BEING RESCUED / BEING ROBBED

Participants described the eventual insertion of the long-term device in words that reflected being rescued. Before the presence of their device, most participants were experiencing regular, difficult, and painful peripheral cannulation to receive treatment. The first subordinate theme is *‘being thrown a lifeline’*.

5.2.3.1 SUBORDINATE THEME: BEING THROWN A LIFELINE

Having a long-term Vascular Access Device inserted rescued participants from peripheral cannulation and was likened to being thrown a lifeline. This was captured in an account from Ruby:

‘At that point, I took advice on what to do for taking bloods or putting things into me, and we decided we might look at the PICC, but that wasn’t suitable because every vein in my arm was collapsing. The next most suitable way for my blood to come out, or for

things to go in, would be the Hickman (TCVC) which goes in just below your neck. That was the perfect one for me' (Ruby, TCVC).

And later, when recalling having previous treatment through a cannula:

'I remember that from the last time I had cancer. It gets in the way, again it gets caught on things and it does pop out – it pops out and that vein collapses and you have to move onto another one. So, at least with the Hickman, it was just in once. They didn't have to think about going through [the veins]' (Ruby, TCVC).

Ruby had reached the point where blood sampling and treatment administration were no longer possible through the veins in her arms. Thanks to this, the option of the TCVC was 'perfect'. This choice of word suggests something that is faultless, flawless, and exemplary, and contrasts with how Ruby had described her memory of peripheral cannulation. Due to the introduction of the TVCV, Ruby was rescued from the attacks she experienced when undergoing peripheral cannulation.

Ruby mentioned that her device entered a vein her body just below her neck. Stating this might be reflective of the fact that, due to previous problems with using her hands and arms for venous access, those veins were no longer able to be used. Her body had been changed as a result of vascular access. Her hand and arm veins were no longer effective, and she was an altered self. The healthcare professionals had to move to another area of Mary Rose's body, where venous access was possible.

'I've had no problems. What I like about it is that they can take all of the bloods. Everything can be done through this, there's no looking for veins. No difficulties taking blood from veins. No collapsing veins or anything, so this has been amazing' (Mary Rose, TCVC).

The insertion of the TCVC was perceived as something that enhanced Mary Rose's experience of vascular access. Her problems, as she described them, were over. She mentioned her veins on several occasions; the veins must be looked for, although, once they are located, it is still difficult to get blood from them until finally, they collapse. This seemed to be a cycle Mary Rose had experienced previously. The veins in Mary Rose's body were no longer viable. It was as if her body had finally let her down. Now that she had the TCVC, this scenario was negated. After listing the many benefits of her TCVC, Mary Rose ended this extract by saying it is 'amazing' - an emphatically positive word. She went on to say:

'I feel quite relieved that they're just attaching me to this, and I have no worries. I don't have to worry about my arms being really painful which it was, it felt like it was on fire and it lasted for days. I have absolutely none of those side-effects, so the TCVC, to me, has been a lifesaver as far as going in and having treatment through this. I don't feel anything. I just sit back and relax. I don't feel anything at all. If I need bloods, out it comes from that. I would highly recommend it' (Mary Rose, TCVC).

This account suggests relief and a release from the worries, pain, and trauma previously experienced. It appears that the previous treatment experiences that Mary Rose faced were affecting her quality of life. The use of the word 'lifesaver' suggested that she may have felt that the pain associated with the cannulation procedures was 'killing' her. A lifesaver is something that is timely and effective and occurs at a time of need or distress. This account highlights the distress Mary Rose may have been experiencing when having her peripheral veins cannulated. The insertion of a long-term device negated this distress, and Mary Rose was able to get back to living her life. Mary Rose described how the benefits of the TCVC far outweighed those of a peripheral cannula:

'Everything is straight forward with it. I'm just so used to it and I just know that I'm not going to have any more carry on with my arms ... It's the best way to have your treatment through this, rather than having injections' (Mary Rose, TCVC).

Yasmin offered a similar account, comparing the TCVC and peripheral cannula. In this statement, Yasmin explained that, initially, her sleep was affected due to the need to access her peripheral veins early in the morning:

'I remember the first couple of days when I didn't have my line (TCVC). They'd come in at seven in the morning and wake you up. I'd be like ... I'm not going back to sleep now because you've just stuck a needle in my arm. So that's good, good, just give them your line and that's it, go back to sleep' (Yasmin, TCVC).

And later:

'It was so much easier because they'd come in at six in the morning and I'd just go There you go [hand them the line]. That's a good thing as well, you don't need to get stabbed' (Yasmin, TCVC).

Having her sleep disturbed for a painful procedure was not a pleasant experience. Yasmin later described the alternative as a simple, quick and non-traumatic scenario of simply handing her line over, having blood taken painlessly, and being able to go back to sleep.

Norman described how he felt when being told that he was going to have a PICC inserted:

'I thought because I'd been quite a long time in the (other hospital), and because I'd had quite a lot of stuff going on with cannulas and all that, I thought this was a great idea. This was something that It's so easy to work' (Norman, PICC).

Norman saw the PICC as a good prospect or, in his words, '*an opportunity to get something better*'. He viewed it as an improvement on the cannula, and was so grateful that he appeared to put his PICC on a pedestal:

'It's really a wonderful thing and it's so non-intrusive that you just carry on with your life and ... you know, it's actually a really medically helpful device' (Norman, PICC).

The word '*wonderful*' suggests something delightful and marvellous. Norman was pleased to have the PICC and found it special. He described it as '*non-intrusive*', suggesting that, in contrast, the cannula was intrusive. The PICC does not interfere with anything, a fact which appeared to allow him to '*carry on with his life*'. This suggests that whilst having treatment through a peripheral cannula had put his life on hold. Sam compared treatment through the PICC to treatment through a peripheral cannula:

'It's very nice, rather than having to spend five or ten minutes trying to get the blood samples from me. You've got a high degree of confidence that the thing is going to go. The nurses get what they need' (Sam, TIVAD).

Rather than just thinking about the benefits for themselves, several extracts suggest that participants also considered the benefits that a reduction in repeated, lengthy cannulations had on the staff. It is interesting that, in his account, Sam stated that the nurses '*get what they need*'. This suggests that he was on the outside and was neither part of the procedure nor the reason for the blood samples. Sam appeared to have removed himself from the situation. This also suggests that Sam had lost confidence in the peripheral cannulation procedure; a confidence which was restored when he had the PICC inserted. Tina also described an increased degree of confidence in her PICC over the cannula:

'I would say after about the second treatment you get a wee bit of confidence in it'
(Tina, PICC).

Tina was not confident to begin with; this may have been because she didn't want to raise her hopes. She may have worried that she would have to return to peripheral cannulation procedures if anything went wrong with the PICC. Eventually, Tina accepted that her PICC was working well, and came to trust and believe in it.

'I just think that it's something that improves the whole process of taking bloods umm, giving transfusions' (Norman, PICC).

Norman talked about the '*whole process*', suggesting a long, drawn-out episode, one that will now be reduced. Norman had been rescued from his previous experience of difficult venous access. Participants all felt that a longer-term VAD would be a better option all round.

'Coming from the other treatment [cannulation], it's so much more straightforward. Like, the nurse came in the morning. She cleaned it and changed it all and I'm set up for the day and don't have that bucket of water. Although, I didn't have a lot of bother with my veins, it wasn't pleasant. I can sit here and read a book' (Tina, PICC).

Tina recalled the process she went through prior to having her PICC. The bucket of water possibly now symbolises something negative and unpleasant. The insertion of a PICC has proved to be a positive intervention as she no longer had to deal with '*the bucket of water*'. Tina appeared to be more relaxed. Although, still attending hospital to receive intravenous chemotherapy, Tina can now sit and read her book. This may demonstrate that her situation had become more normalised; she no longer had the stress and worry of peripheral venous access. Sam linked the repeated cannulation process to that of an ordeal which he would now no longer have to endure:

'From my point of view, if it meant not having three or four goes at getting blood from me every single time I went, then, yes, I did welcome it, because it was a constant ordeal' (Sam, TIVAD).

The words used in this account emphasised the effects of repeated cannulation 'every single time' and a 'constant ordeal'. The multiple punctures that accompanied cannulation impacted negatively on Sam. It was not a one-off incident, but something that happened again and again, and seemed to be never-ending.

Participants tended to see the procedure of peripheral cannulation as more invasive than that of PICC insertion. This is perhaps because PICC insertion generally occurred only once. Conversely, cannulation happened on a regular basis. This was captured in two extracts from Tina:

'It's a lot less intrusive, it's intrusive getting it done but using it is much less intrusive. It's a one-off' (Tina, PICC).

'... It's, like, gentler, less aggressive. I felt as if I was being ... it was more of an invasion, whereas this seems less invasive. Although, it probably is more invasive because it's going right into you' (Tina, PICC).

This comparison seemed to be confusing for Tina. She knew that the insertion procedure for the PICC was more invasive and so was confused about why she found the cannulation procedure more invasive. She justified this because a PICC insertion only happened once. Although, it was a more invasive procedure to have it inserted, once it is in place, that is it. It appeared that the previous repeated need to reinsert a needle into Tina's body caused her distress. The frequent cannulation procedure represented a continuous and sustained attack on the body which was negated by the presence of her PICC. In agreement, Garud discussed how he felt about getting a PICC:

'It's much easier than getting a cannula stuck in your arm every time you need to get blood taken' (Garud, PICC).

The words used by Garud suggest a procedure that is not gentle or easy. Using the word '*stuck*' makes one think of a procedure which is not performed with care and attention; it sounds more like an act that is fast and possibly violent. Garud welcomed his PICC as it meant he would no longer have to go through this intervention. Tina used an interesting analogy to explain how she felt about the difference between her experiences of getting treatment through her PICC compared to the peripheral cannula:

'Whereas, it's [treatment through the PICC] like, it's almost like getting petrol topped up. You just come in, put your arm out and it's a lot less intrusive' (Tina, PICC).

Comparing the two procedures through the use of this analogy suggests convenience and a process that is almost automatic. The effortlessness, smoothness and ease of '*getting petrol topped up*' suggest that this was how Tina experienced having treatment via her PICC. The ease of treatment through the long-term devices meant that participants eventually became accustomed to them.

5.2.3.2 SUBORDINATE THEME: DEVICE AS PART OF SELF

Patients with a Vascular Access Device seemed to eventually embody the device and even, at times, become unaware of it. John captured this in the following extract:

'You go to sleep at night, you're scared to turn in the bed. In fact, I turned last night, and I was playing with it. You forget you've got it and if you feel it itch at night then you remember – oh, I've got a tube in here' (John, TIVAD).

John switched his use of pronouns during this extract. He spoke as though he was talking about somebody else rather than himself. There are also some contraindications in what he says. Despite this, John appeared to have accepted his device as an extension of his natural self. It was not until he was made aware of it (as it itched) that he remembered it was there. The implantation of the TIVAD underneath the skin may have assisted in this embodiment. Anton described similar feelings towards his TIVAD:

'Not for one second does it cross my mind' (Anton, TIVAD).

This account emphasises that Anton was unaware of his device and could continue his life with no thoughts about his TIVAD. There was no time that Anton thought about the device that was situated under the skin of his chest. Participants in the TCVC group also appeared to embody their devices. They described feeling as though the device was now part of their body, often forgetting it was there. This was captured in this extract from Yasmin:

'I do forget that it's there, just because – you don't notice it. You don't feel it once it's already there – you just get on with it. You just forget about it' (Yasmin, TCVC).

The repetitive, emphatic language within this quote highlights that Yasmin had embodied her device. When she didn't notice or feel it, she could forget about it. Yasmin said she could now 'get on with it'. This could relate to getting on with life or with her treatment. It seems from this comment that the TCVC did not have a disruptive effect on Yasmin, and that she was able

to put the fact that she had a device hanging from her chest to the back of her mind. One story that Yasmin recalled captures this well:

'I was out with my boyfriend's family and I was wearing my wig. I don't wear my wig very often, so they'd never seen me with it before and his Grandad was like... 'Oh, what's this you've got?' He was talking about my line and I was like, I thought he was talking about my wig. 'What my wig?' He said 'No, that thing on your chest', and I was like, 'It's my line' [TCVC]. I forgot it was there' (Yasmin, TCVC).

This quotation further highlights the fact that Yasmin is not thinking about her device. Her mind is on her wig with no regard to her device at all. Ruby also embodied her TCVC and described how she felt that the device had become part of her as well as how she often forgot that it was there:

'Occasionally, when I got dressed to do something or go somewhere, and I would look down and I would be like OH! I don't even see it. It's like ... it's not there, you know?' (Ruby, TCVC).

And later:

'It settled beautifully and now it's I don't feel it's there at all, it's almost like it's not.... It's part of me now' (Ruby, TCVC).

Adding the words *'at all'* emphasises that Ruby is no longer aware of her TCVC. There appeared to have been a period until it *'settled'*. This period was a time of adaptation and may have been the time the device takes to embed itself into the body tissue. The TCVC is equipped with a Dacron® cuff. Three weeks after insertion, adhesions form around the cuff which stabilise the device. This adheres the device to the body and may be a reason why patients with a TCVC experience it as being a part of them. The use of the word *'beautifully'* suggests that

Ruby views her TCVC as something precious and special. She appeared to be satisfied with her TCVC.

Mary Rose also discussed how, after a period of time, she was no longer aware of her TCVC. However, she recounts a situation that disturbed her as she forgot it was visible:

'I've forgotten sometimes, and I've gone to try a top on in the changing room and I've come out and the girls are there, and I've tried a top on and I'm aware of them. I've thought maybe I shouldn't have tried it on or maybe I'm alarming them.... I've thought about that' (Mary Rose, TCVC).

Mary Rose had done something normal that she probably does on a regular basis. However, she had forgotten that her TCVC would be visible to others whilst shopping and trying on clothes. It is unclear whether the girls in the changing room saw the device or if they felt disturbed by it. Mary Rose began to think that this was something she should not have done, and that she would think twice about doing this again while her device was in place. The situation appeared to prey heavily on her mind; she continued to think about. Forgetting that the TCVC is there and then being faced with its reality can have a negative effect. This is seen in another extract from Mary Rose:

'Going for a shower, sometimes I forget, then I go... this blooming thing is hanging there and..... [Doesn't finish the sentence]' (Mary Rose, TCVC).

This was a difficult situation for Mary Rose to explain. She hesitated at times and was deep in thought. It was as if she had not reflected on her thoughts about the device, and so, recalling these situations brought back difficult memories.

Finally, participants with PICCs described how they eventually became accustomed to their devices, even becoming unaware of them:

'I was cautious at first, but now I don't even think about it....' (Tina, PICC).

Tina felt so sure about her device that she could put it to the back of her mind and not worry about its ability to do the job. By no longer thinking about the device that was exiting her body, she had embodied it. Like Tina, Sam also described that he became accustomed to his PICC:

'I'm not aware of it at all. It's been fairly nicely positioned. It's under my arm so I don't feel like it's obtrusive, it doesn't get caught on anything, and it doesn't particularly annoy me. I think if it had been further round here (points to an area on his arm) that might have been an issue' (Sam, PICC).

In this extract, Sam highlights how he eventually became accustomed to the device. It appears not to impact on his daily activities. Over time, the PICC became incorporated into his representation of his body. Due to its positioning, Sam appeared to find it acceptable to have the device exiting from his arm. He did not appear to find the device an issue.

5.2.3.3 SUBORDINATE THEME: BETTER THAN THE REST

Participants with Vascular Access Device not only accepted their devices, but also increased their perception of their particular device's attractiveness while decreasing the attractiveness of the others, which they could see being used in the chemotherapy unit where all patients attended. This dissonance enabled participants to live positively with their TIVADs. Many participants spoke passionately and fondly about their devices.

During the interviews, most participants compared their devices to others, appearing to put their devices on a pedestal. They pointed out perceived faults with other devices and viewed their device as superior. This is recognised as cognitive dissonance and will be discussed in greater detail in Chapter Six. It could be suggested that increasing the attractiveness of their own device, while reducing the attractiveness of others, made it easier for participants to accept their own device. When talking about other devices, Anton said:

'When you're having chemo and the phone goes, it's someone whose Hickman line (TCVC) is not in place or PICC etc. And I think, I've never had this with my port (TIVAD)' (Anton, TIVAD).

Anton appeared to be aware of what was going on while he was in hospital having treatment. This account was possibly an exaggeration as it is unlikely that every call would have been about malfunctioning Vascular Access Devices. This account suggests that Anton felt lucky he had a device which did not have similar issues. It also suggests that Anton was using psychological strategies to boost his feelings about his VAD. Amaya also discussed negative aspects that she associated with other devices:

'You can get infections in lines (PICCs and TCVCs) and they move and everything, whereas, when this is in, that's it' (Amaya, TIVAD).

She went on to explain other positives of her device, as well as the negatives of others:

'You've nothing to keep clean, if you had the (TCVC) you'd have to clean it' (Amaya, TIVAD).

Amaya appeared to be knowledgeable about the care and maintenance of the TCVC and grateful that her device was easier to maintain. She believed her device was more reliable in comparison to the other options. Amaya also compared the visibility of her device to the others and suggested that this aspect made her device better:

'I can get my chemo and then get on with my life. If you had a PICC line, you'd have to wear different tops to hide it. If you had a Hickman line (TCVC) it would be restrictive' (Amaya, TIVAD).

Amaya believed that a TIVAD is superior to a PICC. She used the example of clothing in this extract, suggesting that she would not have wanted a device that was visible and that she would

have concealed it if she had. She mentioned that the TCVC would be restrictive, but it is unclear what she meant by this statement.

An account from Anton summed up his thoughts about the alternative devices:

'I couldn't see how someone would say 'I'd prefer a TCVC or a PICC'. I can't understand that' (Anton, TIVAD).

Anton was confused about why anyone would prefer other devices over a TIVAD. This highlights the superiority that Anton felt for his TIVAD. It puzzled him to think that others might not rate the TIVAD as highly as he did. This suggests a state of cognitive dissonance, with Anton increasing the attractiveness of his own device and lowering that of others. Such dissonance would allow Anton to be more comfortable with the device that he had.

All participants with a TCVC accepted their device and agreed it was superior to peripheral cannulas. Participants saw their devices as the best and stated that their device was better than the other VADs of which they were aware. Both Yasmin and Mary Rose said that they were glad they had a TCVC rather than a PICC. Yasmin spoke about the benefit of her TCVC over other external catheters:

'I was glad it was a Hickman line because I didn't have to have it dangling down my arm or anything like that... I saw some people walking around with them (PICCs) and I asked the nurse 'What is that in her arm?' and she said a PICC line. So, I thought, I'm glad I can just stick my wee tubes down my bra' (Yasmin, TCVC).

Yasmin's terminology – '*Sticking my wee tubes down my bra*' – expressed her fondness for 'her' TCVC. Using the words '*my wee tubes*' suggests acceptance and ownership of the TCVC. It appears that Yasmin has embodied her TCVC. Her words suggest a term of endearment. Yasmin seemed content with having a TCVC to receive her chemotherapy and spoke about it

as a better option than the PICC. She was pleased she was not required to have a device ‘dangling down her arm’, even though a TCVC is a device that dangles from the chest.

As well as the PICC, Yasmin compared her TCVC with a peripheral cannula and, again, highlighted the superiority of the TCVC.

‘It’s definitely the best thing to do, and, from what I’ve seen, it’s much better than getting a PICC. But it’s so much easier than getting stabbed every day. You don’t need to do anything; you can just chill out. You get your chemo, you just go ‘Here you go’, and give them your line. You just get your line back and leave. You don’t need to take out a cannula or put a cannula in. I think it makes things quicker as well. If you have to take cannulas out every couple of days. I’ve got three scars from cannulas and one is from March. If I had to get one in every couple of days, I’d have scars everywhere’ (Yasmin, TCVC).

The benefits of the TCVC compared to peripheral cannulation are clear to Yasmin. The TCVC allows her to ‘chill out’. This indicates her ability to completely relax and not to let anything upset her. This seems to be the opposite of Yasmin’s experiences prior to having her TCVC inserted. The taking out and putting in of the cannula was something that did not allow her to relax; instead, this repeated procedure caused her upset. The speed at which she could receive treatment was swifter, which, in turn, would have freed up precious time for Yasmin. Finally, the repeated need to break skin integrity on a regular basis scarred Yasmin. The wording ‘scars everywhere’ may have been an exaggeration, but, to voice this, suggested that Yasmin was affected by those scars.

Mary Rose also compared her TCVC to a PICC and discussed the disadvantages of a PICC. While she only had information received second hand, she seemed convinced of one benefit of the TCVC. This is captured in her statement.

'I would highly recommend it, even more so than the PICC line... how that can fall out very easily, so I've been told, and that's why this is amazing because you don't have to worry about it coming out' (Mary Rose, TCVC).

Mary Rose focused on information about the PICC that had been shared with her and used this fact to elevate the TCVC above the PICC. She was clearly satisfied with her TCVC, and one reason for this was that she did not have to worry about it falling out. Mary Rose went as far as to say that she would *'highly recommend it'*. This is a strong statement which highlights her satisfaction and preference for the TCVC. Once again, this suggests that Mary Rose was resolving an experience of cognitive dissonance. In order for Mary Rose to feel comfortable with her device, she found the positives of the TCVC and a negative of a PICC. This reduced the dissonance she may have been experiencing and became a way of helping her feel comfortable with her device. Like Mary Rose, all participants in this group eventually adapted to their TCVC, so much so that they soon forgot that it was there.

Finally, Ruby described her device as the 'perfect' one for her. She went on to say:

'You were sitting there with the device in your arm, in your hand, and I remember, it gets in the way. It gets caught on things and it pops out, it pops out and that vein collapses and you have to move onto another one. So, at least, with Hickman it was just the once' (Ruby, TCVC).

Ruby retained negative memories of a peripheral cannula and highlighted the positives of the TCVC. This superordinate theme has highlighted that the benefits of the TCVC over cannulation were clear to participants. They eventually accepted and adapted to their TCVCs to the point that they embodied their devices.

5.3 SUPERORDINATE THEME THREE: PROTECTION OF SELF / PROTECTION OF OTHERS

While participants expressed relief at getting a TCVC, they also described the need to conceal their devices. This was either as an act of self-preservation – to protect themselves – or to protect others. One of the reasons for concealment was to maintain privacy about their illness. This was captured in an extract from Ruby:

'It's hidden away, it's tucked away – depending on what you wear, you can be walking around, and no one would know that you were having chemicals pumped into your system ... what's the word? What's the word? It was, it was easily concealed. There you go' (Ruby, TCVC).

When asked if she didn't want people to see the device, Ruby replied:

'Even when I had my pump on with the bag it could be totally concealed, like you would not have any idea that I had anything on me' (Ruby, TCVC).

Ruby seemed relieved that, even though she was receiving chemotherapy while 'walking around', this was not visible to others. 'Having chemicals pumped around your body' captures this fact well. The language used conjures up images of something happening within a machine rather than a human being. Despite this happening within her body, Ruby saw this as a big secret, one that she was happy she could keep. Yasmin also commented on a need to hide her TCVC. This concealment was done because she felt disturbed when she saw the device exiting from her body. Yasmin did not appear to be accepting of her changed body and self:

'I try to keep it hidden most of the time, especially when it didn't have a Biopatch® on it [a small chlorhexidine disc] like you could see it come out of your skin' (Yasmin, TCVC).

Participants believed that others might be alarmed at the sight of their own devices, meaning they went out of their way to conceal those VADs. This was a perception held by many participants and is suggestive of perceived or public stigma - the perception that the presence of the TCVCs would be socially undesirable to others. Mary Rose possibly felt stigmatised, could have internalised perceived prejudices, and so developed negative feelings about herself and her TCVC. The result of this appeared to be self-stigma. Mary Rose, therefore, described one of the advantages of her device as her ability to hide it from others:

'Positives [are that] you can wear tops that hide it so that the general public... you're not scaring them' (Mary Rose, TCVC).

This statement demonstrates that Mary Rose saw her device as something others might be distressed to observe. She uses concealment as a method to protect the public and to ensure she does not impose her device upon them. The situation in the changing room seemed to have remained with her and it appeared that Mary Rose still worried that, by allowing others to have seen her device, she may have negatively affected them in some way. She had internalised this perceived stigma for a long time and was only now reflecting on the experience. Mary Rose later expressed this in another account:

'I don't really wear tops or things like that. If I'm going out with my husband, I don't want anything to be seen. I don't want to be a patient. I mean, I don't want people to know. I hate having cancer, so I don't want to... if someone sees that, they would know that something was wrong. So, for that reason, I don't want to ... so, in that case, I prefer to ... I do wear a top that will cover it' (Mary Rose, TCVC).

This statement was broken up with a lot of pauses, as if Mary Rose was attempting to understand her feelings. It was as if she was realising for the first time how the device was affecting her. She believed that she had a right to be private about her illness and to manage

her self-image. Image management appeared important to Mary Rose and the appearance of the TIVAD (which would signal a serious illness) was not an image she wanted to portray to others. She did not want to be sick and was possibly in denial about it. If she did not want to be reminded about her illness, then the last thing she would want was for others to notice the device because it would force her to talk about it and her illness. Mary Rose did not want to be forced into a sick role, which may have happened if others were aware of her cancer. Would she have to act like a sick person if her illness was public? Would others change their interactions and relationships with her if they saw her not just as a person, but as a sick person? The visibility of the TIVAD and the change in Mary Rose's body appeared to change her experience of her disease. This will be discussed in more depth in the next chapter.

In contrast, Mary Rose did not have this problem when it came to children seeing her device:

'Well the one [grandchild] of seven is really interested. She's like that to Gran, 'What's this?' And I've explained that Gran's medicine goes in there. Children are really resilient, very adaptable to everything, very interested' (Mary Rose, TCVC).

This statement suggests that Mary Rose felt her device might be shocking to people. However, since children are, as she says, '*resilient*', then they would less likely be affected when confronted with it. They are less likely to change their relationship with Mary Rose. This seemed to normalise the TCVC for Mary Rose.

The following extract from Sam describes his concerns about others seeing his PICC:

'If I was away on holiday and sitting at a pool or that, then it would probably be more of an issue.... Even being able to go into the water and stuff like that. Just really from that point of view, how people might perceive it. Like my daughter freaks out when she sees it and she's got aspirations to be a nurse!' (Sam, PICC).

Sam continued to talk about the visibility of his PICC in the following extract:

'My wife works in the pathology laboratory, so she's used to stuff in the hospital and most of the time it's covered up and you don't see it. The only thing you see is a bandage. It's only when you're in here [hospital] that the thing is really exposed. It doesn't put them up nor down either' (Sam, TIVAD).

These two statements indicate that Sam concealed his device to protect others. He was concerned about how others might perceive the PICC. He differentiated between lay people (people on the beach or his daughter) and those who have knowledge (healthcare workers and even his wife, who works in a healthcare setting). He believed that the perception of his device might differ between these groups. He talked about lying on a beach or going into the water as activities that he believed would cause him issues, as others would be able to see the device. These are personal leisure activities he could avoid if he chose to. However, attending healthcare settings where the perception of his PICC might be more positive is a situation Sam would have little choice but to endure.

Tina described how her choice of clothing helped her to keep her PICC concealed from others:

'Most of my garments are long-sleeved' (Tina, PICC).

And later:

'I thought it would restrict me more, but it doesn't, I just wear a long sleeve when I go shopping' (Tina, PICC).

In these extracts, Tina considered her clothing in relation to her PICC. The long sleeves of her clothes act to conceal her PICC and keep it out of the view of others. She talked about the restrictions that she thought she would face in order to go about hiding her PICC from others. This statement was very matter-of-fact. Tina's shopping routine would not be restricted by the PICC. She simply put on a long-sleeved top, which solved the issue.

Although participants appeared to welcome the introduction of their device, and to subsequently embody them, they highlighted challenges faced due to a lack of the knowledge of staff who were responsible for looking after and using their TCVC. Participants discussed a fear of device complications that could also result in device removal and a return to peripheral cannulation.

5.4 SUPERORDINATE THEME FOUR: BEWILDERMENT AND DISMAY AT THE LACK OF STAFF COMPETENCE

The presence of a Vascular Access Device exposes patients to many potential complications, some of which are serious. Participants were aware of potential complications as these are discussed during the consent process prior to device insertion. Fear of potential complications was increased due to participants' perception that some staff responsible for looking after the devices lacked the necessary knowledge.

The fear of infection was discussed by Yasmin:

'I remember when my dressing started to come off and I phoned the ward and said, 'What do I do?' They said, 'You're fine, some people don't even get a dressing on' and I was like, that's mental! I'd be so scared of that, a pure infection risk' (Yasmin, TCVC).

And later:

'They tell you about the infection risk and that was the scariest thing about it, especially in the last few weeks. Because I'm not on chemo anymore my counts are starting to come up. They keep saying to me, we need to get that line out as soon as possible because that's the only thing that will cause you an infection, and I'm like... Just get it out!' (Yasmin, TCVC).

Yasmin's fear appears to be driven by the information given to her by the staff. So much so that she felt a sense of urgency over having her device removed. Yasmin added:

'You knew there were people on the ward who had to get their line taken out for infection. So, that was scary' (Yasmin, TCVC).

This account suggests that the risk of infection was not unfounded. The competence, confidence, and knowledge of staff tasked with caring for and using the TCVC were often found to be lacking. This had a negative effect on participants' experiences. Ruby discussed this:

'When I had to get the dressings changed ... some of the nurses didn't know ... like Oh! A Hickman, do you know how to do that ... oh! Go get somebody else in and oh can you do it? No! We're not allowed to do it on this ward, but you can on that ward, but here we're not allowed to do it ... we'll need to get you a staff nurse. And it always seemed like a bit of a drama to change the dressing. It should be just an everyday thing, but in the waiting room there's like 20 or 30 people waiting for their dressings and bloods to be taken. But I was always the drama because we'd have to go find a staff nurse ... this is in the Beatson [specialist area] ... to go and find a staff nurse to take the dressing off. I mean really! You know... (Ruby, TCVC).

Ruby took control of her situation and made the decision to care for her device herself, perhaps because of the previous issues she faced and her resulting loss of trust in the staff. However, rather than being angry, Ruby expressed feelings of sympathy toward the staff:

'I sympathise with all of them ... it's not a big drama ... there's no point in making a big drama out of it ... so I'd just sit, and I'd wait until the staff nurse came. Occasionally, when I went to have my dressings changed, I was still attached to the pump. And because the actual treatment was over, but the pump was still there, I would have to go to another department to have the pump taken off and then go back to the [other room] ... to get my bloods and dressing changed. It was such, yeah it was never easy ... There was always a complication somewhere in the chain, for the

simple thing of getting your dressing changed to the point I ended up doing it myself'
(Ruby, TCVC).

It is interesting that Ruby contradicts herself within these two quotations. In one she states, *'it always seemed like a bit of a drama'* and later when she begins to sympathise with the nurses, she states that *'it's not a big drama'*. Ruby seems to have rationalised her experience and has become understanding of the issues that the staff have to face. The act of caring for the device herself gave Ruby a sense of ownership and allowed her to feel as if she was in control. Her involvement in the process saved her from the 'dramas' she had experienced previously. This was further highlighted in the following extract:

'It's mine, it's my Hickman. Yeah it's almost as if I have a job [laughs] everybody else has got a job, the nurse is doing this and the doctor's doing that and the surgeons doing this and all you do, all you are is like a ... you know, a person that's got a problem or an illness, and it was almost as if I had ... a job, I was part of it and it was my Hickman and I was looking after it and it was.... I'm not saying it was good because it's not good, but it does... you do feel part of it, and I felt I was responsible for the last few weeks... I've still got it in now, but these last few weeks it's been me that's been looking after it.' (Ruby, TCVC).

The repetition of *'it's mine'* reiterates that Ruby feels she owns her TCVC. Taking responsibility for it gives her a sense of purpose and self-control. This removes the stress of having to depend on others to be involved with her TCVC and makes her feel like more than just a person who is sick and is getting everything done to and for them. Taking control of her device may have allowed Ruby to function better and be more able to cope. Not doing this may have led to her feeling that things were beyond her control. Ruby took this control further and even began to teach others about looking after her TCVC:

'When I went to the GP to have my first set of dressings changed, which I was told to do, none of them had seen a Hickman and they were all quite frightened, the nurse there who was changing my dressing. I said, 'Listen, we'll do it together', and we did' (Ruby, TCVC).

This account suggests that Ruby took control of a situation that was frightening for the nurse. Ruby stated that the staff were *'frightened'*; she must have noticed this in their words or actions. Subsequently, there was a degree of role reversal, with the patient becoming the teacher. Suggesting working together with the nurse to change the dressing may have made Ruby feel more involved, knowledgeable, and in control of 'her' TCVC. This act would also have given Ruby a sense of power and may have made her feel like a stronger person. Similarly, Yasmin described issues she faced when practitioners had difficulties using her TCVC:

'I was getting access once a week. It was like, turn your head to the side, cough, move your arm, and all that to try and get it to work. After that, they just flushed it and got it working again' (Yasmin, TCVC).

Participants experienced variations in practice between the hospital and, particularly for participants with PICCs, the community setting. This resulted in feelings of uncertainty. A statement from Alfred highlights this problem:

'The practice nurse comes in and changes my dressing and takes my blood. The first time they only sent one nurse and she couldn't do it right because someone has to hold it while the other one takes it off, so she had to phone for a colleague. So, it's a two-nurse job now... The dressing was on for about a week and a half, so it was hard to come off. So, she had to get a colleague. One held it, one pulled it' (Alfred, PICC).

Alfred appeared to be aware of how the procedure of dressing change should take place, and so, was aware when it was being done incorrectly. Similarly, Tina described how she had to intervene to ensure the procedure was performed correctly:

'Last week the nurse had to persevere with it because last week the nurse had to change the dressings on it... I told the nurse, only one plaster... I said you'll get a row from the nurse because sometimes the district nurses don't have the supplies. They don't have the clips [securement devices] for example'

And later:

'The care is different in the community, yes, and you try to be loyal and you try not to be critical and you say, 'Well, if that's all you've got'. You shouldn't be caught in the middle like that' (Tina, PICC).

Tina wanted to remain a good person who did not judge or take sides. Rather, she accepted the situation without complaint. This made Tina feel as though she was *'caught in the middle'* between community and hospital staff. She experienced variations in the practice, equipment, and supplies required to care for her PICC, which appeared to frustrate her. Sam experienced similar issues of practice variation. When asked about how care in the community compared to care in the hospital setting, he stated:

'You know they are going to get blood without an issue. The changing of the dressing gets done here two out of three weeks, and once a week by the district nurses, and that can be a little problematic because again it's different. It is different people who will take the bloods here (from the PICC) and who will take the blood from a normal blood supply, and I'm not sure why that's the case. And it takes longer if you have one of these because you're sitting in the room, it's a ticket system, but if you've got one

of these they come around with a form and, as I say, it takes longer. I would see that as a training issue, there's no reason that I can see why they couldn't be trained to do it' (Sam, TIVAD).

Sam faced different challenges when having his blood taken within a hospital setting; challenges which made Sam feel dissatisfied with his treatment. His discussion of the ticket system highlights that, by having a PICC, Sam felt as though he has been placed at the back of the queue. He described how it took longer to have his blood taken due to the staff's lack of ability to use his PICC. He clearly identified an issue with staff training and was keen to highlight this in his account. Garud provided a similar quotation:

'The district nurses were taking the blood samples and they had some problems getting the blood samples through the PICC line. I think that sometimes they were a bit cautious of it, putting too much pressure on it because, out of 12 treatments, three out of four of them were straightforward, and seven or eight they had problems with it. They had me coughing and waving my arms in the air trying to get blood through' (Garud, PICC).

And again:

'Same [nurses] on most occasions, but quite a lot of others as well all seemed to have problems. They'd quite freely admit that they were wary of PICC lines, you know they always say, 'I hope this is going to go all right'' (Garud, PICC).

Garud described the issues he faced with blood withdrawal from his PICC as well as his own thoughts on why this was the case. He believed that it might not have been problems with the PICC, but rather with the skills and knowledge of the staff. He suggested that the staff were taking care to avoid mistakes or errors. He particularly thought they were wary of using

excessive pressure when aspirating from the device. Garud formed this theory as the problems seemed to occur sporadically. He deduced that, if the issues were not consistent, then his PICC was unobstructed and the problems were user related. Garud was not keen to have to go through such scenarios again, and so, to avoid this, he opted to attend hospital instead of relying on community staff:

'This time I just took the option of coming in on the Tuesday [the day before treatment] coming in here so I just get it done downstairs and I've had no problems at all. The staff in here are more familiar with PICC lines than the district nurses are. Plus, if there is a slight blockage, they're not so wary about putting a bit of pressure on it. Whereas, the district nurses haven't got the backup services that they have here. Somebody did put pressure on it here and it burst. I had to get it repaired. It wasn't a big deal. It was one of the male nurses. Yes, it wasn't a great problem. They weren't as confident in the community. It's just a familiarity, I suppose' (Garud, PICC).

In this extract, Garud seemed to have proved his own theory. He had taken control of his life to make things easier, and now has no problems with blood-giving through his PICC. He was correct to believe his PICC was fine and that the issue resulted from a lack of community staff competence. This confidence was apparent when it came to the hospital staff using the PICC since, as Garud stated, they are not 'so wary' if faced with problems. Garud was aware of the restrictions that the community nurses faced and realised that the backup services were not as easy to access. Indeed, he described his PICC being damaged by a nurse, who he suggested used excessive pressure while working with the device.

John was protective of his device when it came to allowing staff to work with it. He took control of his device and, therefore, control of himself. He wanted to ensure that, before anyone touched his TIVAD, they had undergone the necessary training and were competent:

'So, even when the district nurse comes out, they're qualified before they can touch it... The oncology nurse went out and trained them. The first week I got it in we had to come back here to get the pump off because she hadn't got out to the district nurses to show them how to do it.' (John, TIVAD).

This statement showed that John had an understanding of the process which ensured the staff were knowledgeable. He described the need to return to the hospital for TIVAD care prior to the nurses being trained to use his device. The account did not suggest that John had any issues with the situation. He did, however, recall a challenging episode while staff were attempting to aspirate his TIVAD:

'There was one day I came in and there were about six attempts to get blood. I had to come in the next day and the oncology nurse got it, but I had to lie flat out on my back, and she managed to get it and it's worked ever since then. There was six times in the one day and you feel that – they call it a jag or something, but you do feel it, it's not killing, it was six times and it gets a bit sore' (John, TIVAD).

As the TIVAD is implanted under the skin, this means that, unlike the PICC and TCVC, it must be accessed with a needle. Puncturing the skin is, therefore, a necessity with this device. During the scenario highlighted by John, he discussed the unpleasant pain of accessing his device. This was enhanced following multiple attempts to access his TIVAD successfully. So difficult was this attempt that he had to return a day later to retry. He described the punctures as painful, although stressed that they were not '*killing*'. This choice of word is unusual. It could be suggested that '*killing*' is the worst type of pain, and the pain that he experienced was close to, but not quite, the worst.

Participants appeared bewildered that nurses and doctors were either incompetent or not confident in dealing with their devices. At times, this led to staff being unwilling to use participants' devices and resulted in a return to peripheral cannulation for some participants.

Sam experienced problems in the care and ability of staff using his PICC:

'The only issue is that not everyone is trained to use them because I can get my district nurse to come out and take a sample, but if I go to my GP he has to do it through a cannula or a conventional syringe, and I find that strange, particularly as I've got this in place specifically for that purpose and you've got medics that aren't able to use it. Are there differences? Everybody's trained up, but my GP can't use it and the nurses at my GP practice can't use it, but my district nurses can use it' (Sam, TIVAD).

The realisation that there was no standard practices, and that not all staff had the knowledge or experience to look after a PICC, left participants feeling bewildered. Sam expressed his dismay:

'Is it a specific training that has to be done? When you look at the fittings, it's exactly the same as the cannula. This is the only thing that has bemused me. It should be a standard thing that everyone should be able to use. It's the same parts that they're actually touching the only difference is that it's a cannula rather than this' (Sam, TIVAD).

Sam appeared frustrated that, after going through the invasive procedure of having a PICC inserted, staff were unable to use the device due to a lack of training and competence. Subsequently, staff reverted to peripheral cannulation. Sam questioned the competence of staff over what he felt should be a straightforward procedure. The issue of staff competence was again highlighted when participants, or their relatives, were successfully taught to access and care for devices themselves.

'I wouldn't mind if they knew what they were doing with it, wouldn't bother me. But once, when I was unwell, they couldn't find my veins, but they point blank refused to use it and my husband said, 'I think that's disgusting'. I could access it, and they taught him to take me off it because the district nurses in the surgery couldn't. It didn't take long to train him, I said to the nurses, 'My husband learned in ten minutes and he's not medically minded and yet you are nurses and you're not willing to get trained. My 12-year-old used to come and clean it' (Amaya, TIVAD).

Amaya found herself in a difficult situation at a time when she was very unwell. This account demonstrated Amaya's anger and 'disgust' at the lack of staff knowledge when they attempted to access her veins for treatment. She described the nurse's failed attempts to find peripheral veins to cannulate. Even so, they *'point blank'* refused to use her device, which would have allowed them to access her veins easily. She implied that she would have been able to access the TIVAD, suggesting that it was a straightforward procedure. As well as her own anger, Amaya stated that her husband was equally distressed with the situation. Amaya described how her husband found the situation *'disgusting'*. Amaya and her husband appeared to be bewildered that staff were not able to deal with her device. This dismay was further impacted by the fact that her 12-year-old son could clean her device and that her husband, who was not medical, had been trained to deal with her device within ten minutes. Amaya seemed frustrated that district nurses were unable to look after her TCVC. Her frustration turned to anger as she suggested that, rather than not having been trained to look after devices, staff were, in fact, unwilling to get trained. If staff were unable to use their devices, participants had to return to the previous painful procedure of peripheral cannulation, which they thought they had left behind. They were bemused. Participants had a device inserted to make the process of giving blood and receiving chemotherapy easier, and yet, due to staff incompetence, devices were not always used.

5.5 SUMMARY OF CONVERGENT THEMES

In summary, the experience of living with a Vascular Access Device (VAD) began with a recollection of what it was like prior to having these long-term devices inserted. This was a traumatic experience that had to be 'endured'. Participants appeared to experience a loss of self-control and agency. Peripheral cannulation was described as a violent act that left participants feeling passive, traumatised, and victimised. The decision to insert a long-term device was made when peripheral cannulation was no longer possible. This came as a relief to participants, who welcomed the insertion of a VAD. Participants embodied the VAD, and eventually forgot it was there; the VAD became a part of them. However, they were not comfortable if the VAD was visible to others. Instead, participants chose to keep the device concealed. This was done for two reasons. Firstly, participants had a fear of a perceived stigma. They worried that if others saw their device, this might upset or distress them. They began to self-stigmatise the presence of the VAD. Secondly, the device was kept hidden to maintain a positive self-image and manage a sense of self. If participants did not want others to know they were unwell, the visibility of the TCVC might alert others to this fact. Participants used strategies to conceal their device in order to control and manage their self-image.

Most participants perceived that those caring for the devices had a lack of knowledge. When staff were not knowledgeable or competent enough to use the VADs, this resulted in bewilderment, dismay, and an eventual loss of trust. This situation also increased the worry about potential complications with the VAD, but, more importantly, the fear of a return to peripheral venous cannulation.

5.6 SECTION TWO: DIVERGENT THEMES

As well as convergent themes, some divergent themes were discovered. These occurred in only one or two of the groups: PICC, TCVC or TIVAD. These themes will be presented in the following section and include:

- The need for adaptation (PICC group)
- The ill-informed self (TCVC and TIVAD group)
- Maintaining a sense of self: Getting on with life (TIVAD group)

5.6.1 THE NEED FOR ADAPTATION

One superordinate theme – the need for adaptation – was identified in the PICC group only.

Table 5.2 demonstrates the key quotations that led to the development of this superordinate theme.

Participant	Quotation	Page: Line
Sam	‘Showering and that is a bit of a problem’	2:39
	‘I’ve got one of those things that go over your arm to keep it out of the water’	2:39
Garud	‘I have a bath as well; I just keep my arm out of the water’	2:46
	‘I’m conscious of it, I try to avoid laying directly on top of it’	1:29
	‘I try to avoid reaching up and lifting things’	1:33
Norman	‘I’ve just had a shower so what happens is that, this tucks in up here and a sleeve goes over here’	2:49
Alfred	‘Well I sleep on my right-hand side, so I changed to my left’	1:19
	‘I roll over and I wake up’	1:18
	‘You worry that you might lie on it’	1:20

Table 5.2: THE NEED FOR ADAPTATION

Participants with PICCs appeared to face the most disruption to everyday life. They discussed adaptations that they had to make during daily activities, such as showering, bathing, and sleeping. This was not such an issue for participants living with other devices. Moreover, in this study, participants faced many device complications, such as blockages, which resulted in participants having to return to hospital from the community. Furthermore, since these devices were often cared for in the community, participants described variations in practice between the community and the hospital. This led to feelings of uncertainty and anxiety in addition to a fear of further complications.

Following PICC insertion, participants had to adjust to life with the device. The addition of an external device meant that regular day-to-day activities required change. These adjustments seemed acceptable to some but were seen as a disadvantage by others.

Sam's account suggests that, although he employed strategies to enable him to shower with his PICC, the process was bothersome. Sam saw this as a disadvantage.

'Showering and that is a bit of a pain. I've got one of those things that go over your arm to keep the water out, so from that point of view that's the only disadvantage' (Sam, PICC).

Tina also discussed the issue of personal hygiene, stating how important it was to her to keep clean.

'I've got one of those sleeve things, it's fantastic. That's very, very good because one of those things was showering every morning, it's important to me. It's like, I need to get into the shower. It keeps you You can let the water run over you and breathe. It's a bit like respite.... Although you have a body wash and everything, I sometimes think I can smell myself. It's just that, I know I've not been in the shower' (Tina, PICC).

Showering seemed to be a period of relaxation and possible therapy for Tina. It was a period during which she could ‘let go’ of everything. She described the water running over her and the ability this gave her to ‘*breathe*’. She might use this as a time away from the struggles and stress of her situation. She had been holding her breath, possibly because of anxiety. Whether or not she could *smell herself* is uncertain, but she realised that this may be physiological, and may come from the knowledge that she has only had a body wash rather than a proper shower. Just standing in a shower seemed to be a time when Tina could forget about everything and relax.

Garud also described the methods he used to allow him to continue maintaining his personal hygiene while living with a PICC:

‘I just put a plastic cover over it, and it seems to be fine. I have a bath as well, I just keep my arm out of the water’ (Garud, PICC).

Initially, Garud says the plastic cover is ‘*fine*’ for protecting Garud’s PICC while he showers. However, he later appears uncertain about this. Typically, patients with PICCs are advised not to bathe or submerge their PICC in water. Garud had overcome this by bathing while keeping his arm out of the water. Similarly, Norman went to great lengths to explain how he managed the process of showering:

‘I’ve just had a shower, what happens is that, this tucks in [shows me the end of his PICC] here and that goes over here (shows me a cover/sleeve) and you just forget all about it’ (Norman, PICC).

Norman seemed familiar with this procedure, possibly because he does it daily. Once his PICC was covered, he appeared able to put it out of his mind. Alfred also said that he has no problems with showering and explained that he, too, uses a cover to allow the process.

Garud found that he had to adjust his sleeping routine as a result of the PICC:

'I've got the bag on the right, so if I lie too much on the right, I'm in danger of laying on the bag. If I lie too much on the left, I'm in danger of laying on the line. I've not had too much of a problem with it' (Garud, PICC).

He went on to state:

'I still sleep OK, it's just that I'm conscious of it, try to avoid laying directly on top of it so I keep my arm out from directly underneath me. Whether that's necessary or not, I don't know, but I'm not sure' (Garud, PICC).

Garud appeared to have found methods to make sleeping easier while having a PICC. Although he admitted to sleeping 'OK', he mentioned that he was conscious of the PICC. The presence of the PICC was on his mind, and he had to consciously negotiate how his body was when he slept. He was unaware of whether it was necessary to avoid laying on his PICC but had preemptively taken the decision to adjust his sleeping habits. Alfred also made some adjustments to his typical sleep routine in order to accommodate the PICC and reduce potential complications. This seemed to have a detrimental effect on his sleep pattern:

'Well, I sleep on my right-hand side, so I changed to my left. So, at night I roll over and I wake up... It's just that you're worried you might lie on it. Just the fact that you know it's there' (Alfred, PICC).

Alfred had to adjust his typical sleep position to accommodate the presence of the PICC. Even after this was done, he was unable to rest peacefully and sleep. His body took him back to his regular sleeping position and, as he became worried about his PICC, he woke up. This is a major disruption to one of the main activities of living.

5.6.2 SECTION CONCLUSION

This section described the adjustments that participants had to make in the initial stages of PICC device insertion. Participants described a period of cautiousness prior to this acceptance. Lifestyle modifications re-introduced a sense of personal control, self-esteem, and self-worth for the participants. By adjusting their lifestyle, they were able to continue with their lives despite the presence of the PICC.

5.7 THE ILL-INFORMED SELF

A theme that was evident in the TCVC and TIVAD groups, but not in the PICC group, was the ill-informed self. Table 5.2 demonstrates the key phrases that formed this superordinate theme.

Participant	Quotation	Page: Line
John	'I didn't take anything in'	2:50
	'It's a wee bit of a bump, when you see the diagram there's nothing there'	2:45
Anton	'I didn't take it in at the time'	5:175
	'I didn't realise what it was going to be like, what it looked like or what was involved in it'	2:73
Yasmin	'No, I wasn't prepared. No one talked me through what was going to happen'	1:24
Mary Rose	'I thought, how am I going to deal with this thing hanging out of here?'	2:58

TABLE 5.3: LIVING WITH A TCVC AND TIVAD: THE ILL-INFORMED SELF

Participants with TCVCs and TIVADs discussed feeling ill-informed during and following device insertion, which led to feelings of anxiety and uncertainty. This was not a finding for the PICC group. In this study, PICCs were the only devices inserted by nurses, while the TCVCs and TIVADs were inserted by interventional radiologists. This could be a reason for

participants' differing experiences. A lack of information resulted in negative experiences for participants with a TCVC or TIVAD.

Prior to device insertion, participants felt unsure about the insertion procedure and how to manage their TCVC once in situ. This was due to a lack of information. Patients vary in the amount and nature of information they want and have their own informational needs. These findings suggest that such needs were not met for these participants. Patients in the cancer centre in which the study took place had devices inserted by either nurses or interventional radiologists. Within these two services, the documentation and information given to participants varied. All participants in this study who had TCVCs had them inserted by interventional radiologists. It was apparent that participants desired more information and felt disappointed at the lack thereof. Yasmin described how the lack of pre-procedure knowledge affected her:

'I didn't know much about getting my line in. I just knew I had to get it done because they were like...Your veins are going to end up wrecked' (Yasmin, TCVC).

Yasmin continued to discuss her experience of going to get her TCVC inserted and her feeling of a lack of preparedness:

'I got sedated for the line going in. I was fine. Everything was fine until I got in the room. It was the radiologist who put it in, so it was very sterile, and I was like, I don't like this... No, I wasn't prepared. No one talked me through what was going to happen. I knew it was going to happen under an x-ray and I definitely knew it was going to be sterile. But it wasn't until I got in. It was actually like a surgery room. I don't like this, and I don't want to be awake. But obviously I was awake, but I didn't have a clue what was happening' (Yasmin, TCVC).

This extract highlights the effect that a lack of knowledge exerted upon Yasmin. She commented on the fact that no one had spoken to her about what was going to happen. This led to her being alarmed when she entered an environment that was different from that which she was expecting. Yasmin transports herself back and she talks as if she is back in the theatre, *'I don't like this, and I don't want to be awake'*. Yasmin's comment that she didn't want to be awake suggests that she wanted to take herself away from the situation. She did not want to be aware of what was happening. Everything was now becoming a reality, and so, to be asleep and unaware of what was happening may have been a better option for Yasmin at this time.

The word *'wrecked'* is powerful and would have suggested destruction and something badly damaged. For Yasmin, this information meant that TCVC device insertion was her only option. Despite knowing nothing about the procedure, she had no choice but to go ahead. Yasmin went on to state that, even after the TCVC had been inserted, she still felt that the information she had been given was lacking:

'I didn't know what I was allowed to do or not. I may have been sedated when I got that information. I don't know. I definitely didn't get any sort of pack... I think if I could change something, I would get more information. It might be because it was the doctor that did it. It was very much like 'This is what we are going to do' and you are actually sitting there. I think, someone needs to sit down with you. I think it needs to go back to when you're going to need a line, someone needs to speak to you then rather than just before you get it in... Obviously, I got told that'd need a line when I got told that I had cancer, so obviously, there is a lot to take in at that time. But I think someone should have given me a booklet and been like ... right this is what you are going to get, because getting told on the day, you're already worried and you start Googling and that's not what you should be doing. I was Googling and there were horror stories saying there was blood everywhere. All my friends at the hospital

were saying, 'It's fine getting it taken out, much easier than getting it in' but I was, like, sedated getting it in and I don't remember anything. I was talking to them, but I don't remember what I was saying' (Yasmin, TCVC).

Finding information from the internet or from others proved to be a negative experience for her. This may have added to her fear and anxiety over the procedure. However, she sought this information to regain a sense of control and knowledge. Having more control and knowledge may have given Yasmin a sense of agency which had been lost. She felt the knowledge she had was lacking, and so, she took control to rectify this.

Yasmin went on to admit that she was unaware of the actual amount of information she had received. This may have been related to the timing of information giving. Yasmin was sedated when receiving some vital information, plus she was given information about her TCVC at the same time as receiving her diagnosis. This would have been a difficult and traumatic time for Yasmin. Trauma can sometimes result from an overwhelming amount of stress. Yasmin is likely to have been suffering from stress when she received her diagnosis. If Yasmin had been suffering from the shock of the news that she had cancer, she may have felt stunned or numb, and so, may have cut off her feelings from what was going on around her. This may have been done to protect herself from the unwelcome news.

Yasmin offered suggestions about better timing and types of information giving. Being given information in the form of a booklet would have negated Yasmin's need to look for information herself. In addition, she suggested that someone should have sat down with her to discuss the TCVC. The information giving, according to Yasmin, would have been more effective if it had taken place at a different time, rather than just as she was given her diagnosis or just before going into a procedure room to have the device inserted. Before the end of her interview, Yasmin reiterated this point for a final time:

'I know this is a study, I just want to say, please tell us about it before. I didn't know anything about it' (Yasmin, TCVC).

This extract is a plea, which stresses how strongly Yasmin feels about pre-procedure and post-device insertion information. Mary Rose had a similar experience and felt unsure about how she should deal with her TCVC once it was inserted:

'When I got home, I have to say, when I got home, I thought, how am I going to deal with this thing hanging out of here? And the risk of infection, showering. So, for the first few days, I was a bit kind of careful, a bit kind of frightened of it actually' (Mary Rose, TCVC).

This extract shows that having no practical information about what to do with the TCVC or how to look after it can be an issue. It appeared that Mary Rose was left to negotiate living with her device and her altered body without any clear guidance or information. This was a new experience for Mary Rose; she had to learn to understand her new self. Initially, this led to anxiety and fear of the device. The uncertainty that Ruby also faced was evident during the insertion of her TCVC:

'You're awake all the way through the procedure, so I was worried about how it was going to feel. They always say, there'll be a little tugging, tugging and pushing, particularly pushing. There was quite a lot of tugging [laughs] much more than I thought. Particularly when he was putting it in. I could feel almost as if his fingers were in me when he pushed the sides in. I'm not exactly sure what he was doing. That was the most painful part' (Ruby, TCVC).

This account describes the feelings Ruby experienced during TCVC insertion. She mentioned tugging and pulling but felt unsure of what was happening to her body during this time. Her

laugh seemed inappropriate and may have been a nervous reaction. It appeared as if she felt uncomfortable admitting that the tugging was not *'a little bit' but was 'quite a lot'*. What she was told to expect and what she experienced were not the same. Ruby described the feeling of fingers inside of her body. As she did not know what was happening at this time, this could have been disturbing. This was the element of the procedure she described as the most painful, which could have been due to fear and tension.

John stated that, although he might have been given information at some point, he had not retained it:

'I didn't take anything in' (John, TIVAD)

It might have been that this information was imparted at a time of stress, which could have led to the inability to retain information. In order to fill this gap, John admitted to looking at the internet for additional information:

'We knew a bit because we looked it up on the internet. The oncology nurse had given us the paperwork when [I] got the TIVAD in because I was going on a trial' (John, TIVAD).

However, John felt that looking on the internet gave him misleading information.

'At first, I thought it was worse. It's a wee bit of a bump. When you see the diagrams, there's nothing, it's flat there and you get it...' (John, TIVAD).

John seemed disappointed that the TIVAD was not what he had expected. He had visualised what he thought the finished result would be and what he saw following insertion was different. His device was visible to him, which seemed to cause him to feel worse than he had imagined he might. Anton also discussed his inability to take in information:

'I didn't take it in at the time' (Anton, TIVAD).

Anton had just been given a terminal cancer diagnosis when he was given information about his port. While he says that this was a period which remained in his mind, it appears that it was the situation of being in the office rather than the words imparted that he recalled:

'I met the oncology nurse for the first time on the Wednesday. Just sitting in here, I'll never forget. In her office. She was telling me about this clinical trial and at the time I was just thinking. I was still in a daze and she told me about the TIVAD for the first time. I hadn't a clue' (Anton, TIVAD).

And later:

'So I didn't really know about the TIVAD and, when I came in, when the nurse was explaining it to me, and I was telling her what my lifestyle was like, she said, 'I really hope you get this' and I didn't really realise at the time because I was still reeling from I've only got six months to live, I was going through all that and, what's this chemo going to be like? And I suppose I still really didn't understand and even though I'd read it and thought that this was going to be better for me, I didn't realise what it was going to be like, what it looked like or what was involved in it' (Anton, TIVAD).

These extract highlights that Anton was not in the right state of mind to be given information regarding the TIVAD. He was in shock, trying to process the diagnosis and prognosis he had been given, when initially told about the device, and he admitted that he could not take the information in. Rather than retaining the information about the TIVAD, Anton was thinking about other things, such as the chemotherapy he was going to have. Anton remembered that the research nurse in the oncology unit said that she hoped he would be randomised to a TIVAD because of his lifestyle. He appeared to realise that the TIVAD was going to be the best option for him, but his understanding was limited. Due to the timing of information giving, Anton was ill-informed.

John stated that he only needed information that would be useful to him as a patient:

'Anything that helps will be accepted. I always say... a welder's a welder, a joiner's a joiner, and a doctor's a doctor'. (John, TIVAD).

This suggests that John feels everyone has their place and their responsibilities. He felt that the doctor should know how much and what type of information should be imparted. He gave the doctor his place in this scenario and allowed him to take control as he was the expert.

5.7.1 SECTION CONCLUSION

While participants stated they had received information, this may not have been at an optimal time. In some cases, the information was given at a time of extreme stress, meaning it was not retained, and participants were left not knowing what to do with their TCVCs or TIVADs once they were inserted. This led to anxiety and frustration. Participants felt that written information would have helped them become more accustomed to their devices. They expressed concern about the lack of information they received about their TIVADs and TCVCs.

5.7.2 MAINTAINING A SENSE OF SELF: GETTING ON WITH LIFE

A theme that was specific to the TIVAD group was Maintaining a sense of self: Getting on with life. Participants with TIVADs not only accepted their devices, but also described how having a device that was totally implanted under the skin allowed them to continue their lives with little disruption. This meant they had to make minimal changes and adjustments. They did not have to change themselves to live with their device. Table 5.3 demonstrates the key extracts that led to this theme.

Participant	Quotation	Page: Line
Anton	'It doesn't stop me doing anything'	3:107
	'It meant I could get on with my life'	2:56
Amaya	'With this there is nothing there, you go away and just deal with your life'	1:19

Table 5.4: MAINTAINING A SENSE OF SELF: GETTING ON WITH LIFE

This theme was highlighted by Anton, who described how his TIVAD had little impact on his life:

'It doesn't bother me at all, it doesn't stop me from playing football, it doesn't stop me from doing anything, it doesn't stop me sleeping' (Anton, TIVAD)

Anton listed some things he could continue to do even though he had a TIVAD. He mentioned two specific things which appeared important to him: sleeping and football. Anton was adamant that his TIVAD did not prevent him from doing anything or cause him any trouble whatsoever. In another quote, Anton clearly demonstrated how he felt about his TIVAD and its positive impact on his life. Originally, during the randomisation process for a different trial, Anton had been selected to receive a TCVC:

'I went to the car park, I was in floods of tears thinking, I can't even go for a swim now and they're telling me I've got six months to live, my whole quality of life is going downhill' (Anton, TIVAD).

Anton spoke in the present tense as if reliving this traumatic time. At this time, he was a broken man and many thoughts were going through his mind. He was considering that, although he did not have long to live, he would not be able to do the things he enjoyed such as swimming in the time he did have left. Again, using the present tense, Anton stated that his whole life was

going downhill. Using the word ‘*downhill*’ as an adverb suggests that things were going towards a worsened state. The fact that he thought he would have to adapt his life, and the possibility that he would lose his sense of self, were difficult for Anton to imagine:

‘My whole life is sport. My whole life is swimming. I swim about a mile three times a week, I play football three times a week. It’s got me through chemotherapy, it’s got me through surgery. It was my goal to get back into my sport because, in my head, if I’m playing a game of football I’m not dying of cancer, and if I swim a mile, I’m not dying of cancer...’ (Anton, TIVAD).

Anton described how he was an active man who swam and played football regularly. Following his terminal cancer diagnosis, he used his sport to keep his spirits up, live a life with some normality, and maintain his sense of self. By doing this, he could forget his situation. Anton described these activities as his ‘*whole life*’, highlighting their importance. Being able to continue with his leisure pursuits had a positive impact on his health. Anton stated that in his head, he was no longer dying of cancer if he could continue to play football and swim. He could adjust his mind and continue to be his old active self if he was doing the things he did before his diagnosis. The thought of no longer being able to do these things would have changed Anton, making him feel like a fragment of his former self. He may have felt that he had lost the physical expression of his persona.

When Anton was informed of the restrictions that he would face with a TCVC, he felt that his life pleasures would be taken away. He used his sport as therapy and as something that gave him a goal. Anton needed to continue to perform as his expected, former self. He felt that, on top of his devastating terminal diagnosis and limited life expectancy, having the TCVC would mean that the short time he had left in the world would be of a lesser quality because his hobbies and loves had been taken away from him. Anton felt devastated and was unwilling to accept

the device selection. He made the decision to go to a private hospital and pay for a TIVAD himself. He took control of the situation to maintain agency over his own life:

*'I thought, if I'm going to die, I'm going to go down fighting. I'm going to still swim'
(Anton, TIVAD).*

Finally, Anton summed up how living with a TIVAD rather than a TCVC improved his quality of life in this powerful account:

'It was the best decision by a million miles. Physiologically, what it does for you as a patient, for me it was everything. It meant I had a quality of life, even though I could potentially be dying. I went from playing football three times a week, to swimming three times a week, to being told you've got six months to live to 'bang', you can't shower, you can't swim, you can't play football. I was like.... What?! No way! I think when patients are at their lowest, you know, whether they are told their cancer is terminal or whether they've got so long to live or even just getting chemotherapy, you know as a patient a portacath (TIVAD) does improve every aspect of your life psychologically ... when they go through the hardest thing they have to go through, you know to take away five per cent of their quality of life, or ten per cent of their quality of life. I can't even imagine having the Hickman line or PICC line in. That would destroy me... so anything to improve a patient's quality of life surely has to be beneficial and they have to look into that' (Anton, TIVAD).

This final statement from Anton sums up the major benefit he perceives in having a TIVAD, rather than the alternative devices. Although Anton may have been dying, at this moment in time he was still living. He did not accept that his quality of life should be reduced due to the presence of a Vascular Access Device. Anton retained control of himself and his life, and, by doing so, shaped his experience positively. He described the suddenness of his life changing

by using the word ‘*bang*’. This suggests an exact, direct, and final act. His life had been changed abruptly. He went on to discuss how a cancer diagnosis leaves a patient at a low point. To add to this, if their lives are changed further, such as by positive things being taken away, this further adds to their low mood. He suggested that it doesn’t matter how much of this is taken away, this will have a negative effect. In fact, Anton used the word ‘*destroy*’, which suggests something is broken up or dismantled. He might have felt that, if he had been given a PICC or TCVC, his life would have been broken, wrecked, ruined, and fragmented. To Anton, quality of life is extremely important, and he speaks for all patients when he suggests that every effort should be made to ensure their best quality of life. For himself, while his life may have been limited, having his TIVAD and being able to continue to do the things he loved was more advantageous:

‘It meant I could get on with my life’ (Anton, TIVAD)

Similar statements from Amaya emphasised how the device enabled her to retain a decent quality of life whilst receiving chemotherapy.

‘...with this, there is nothing there, you go away and just deal with your life’ (Amaya, TIVAD).

When she stated that ‘*there is nothing*’, Amaya was reflecting on the fact that the TIVAD is situated under the skin with no visible external parts. To Amaya, this meant that when treatment had been given, she could return to dealing with everyday life. It appeared that her life was unchanged by her vascular access device.

‘It makes life so much easier’ (Amaya, TIVAD)

Saying life was made easier by the device suggests that life was hard for Amaya before she had the TIVAD inserted. From her previous comments about her memories of peripheral venous

access, this is understandable. It seemed that the presence of a TIVAD placed no restrictions on her life. Amaya felt she was still herself, that her body was not changed greatly, and her sense of self was maintained.

Finally, Amaya offered advice for others requiring treatment via a Vascular Access Device:

'Everyone should get the opportunity to get one' (Amaya, TIVAD).

Amaya stated that everyone should be able to take advantage of the TIVAD, which she found to be special and of great benefit. Anton echoed this:

'I know this clinical trial is going on and this is going to prove that it will improve every patient's life and I would say 100 per cent out of 100, no questions about it' (Anton, TIVAD).

Despite the positives of the TIVAD, Amaya discussed how her TIVAD did prevent her from doing something that she wished:

'I wanted to jump out of a plane, but the guys wouldn't let me do it because of the straps here' (Amaya, TIVAD).

This account shows that Amaya has lost control over an aspect of her life. The guys' *'wouldn't let her'*. Although the guys that she refers to are unlikely to be medical professionals, they have taken it upon themselves to decide for Amaya. This demonstrates a loss of self-control.

5.7.3 SECTION CONCLUSION

Participants who were living with a TIVAD believed that having this device afforded them a better quality of life than the other devices would have done. Over time, they embodied their TIVADs. In fact, they saw their device as superior to others, and recommended that every patient should have the opportunity to have one. Living with a device that is implanted under

the skin seemed to allow participants to retain a sense of self. They did not have to change themselves, adapt or adjust areas of their life when the device was in place. This meant they could retain their former sense of self and not be put into the role of an ill person.

REFLEXIVE BOX: FINDINGS

My study had a focus on longer-term Vascular Access Devices, but my participants want to all tell me about their PVC's. I didn't ask about this, but I has come up so often and so strongly that I know how important it is to the patients and their experience. I am going to make this a super ordinate theme.

I am struggling with the level of interpretation and I'm very cautious about this. I've returned to this chapter with fresh eyes a couple of times after leaving it for a period of time. On re-reading, I've noticed areas that were descriptive. I am growing more confident at digging deeper, and my level of interpretation is improving. I'm now seeing this process in terms of the 'hermeneutic cycle'.

5.8 CHAPTER CONCLUSION

The experience of living with a Vascular Access Device (VAD) began with a recollection of what it was like prior to having these long-term devices inserted. This was a traumatic experience that had to be 'endured'. Peripheral cannulation was described as a violent act that left participants feeling passive, traumatised, and victimised. Because they felt they had no option but to suffer this violation, they experienced a loss of self-control and agency. The decision to insert a long-term device came as a relief to participants. They embodied the VAD, and eventually forgot it was there; the VAD began part of them. However, they were not comfortable if the VAD was visible to others. Instead, participants chose to keep the device hidden from others. This was done for two reasons. Firstly, participants experienced a fear of a perceived stigma. They worried that, if others saw their device, this might upset or distress them. They began to self-stigmatise the presence of the VAD. Secondly, the device was kept hidden to maintain a positive self-image and manage a sense of self. If participants did not want others to know they were unwell, the visibility of the TCVC might alert others to this. Therefore, participants used strategies to conceal their device in order to control and manage their self-image.

Most participants perceived that those caring for the devices had a lack of knowledge. When staff were not knowledgeable or competent enough to use the VADs, this resulted in bewilderment, dismay, and an eventual loss of trust. This situation also increased the worry about potential complications with the VAD, but, more importantly, the fear of a return to peripheral venous cannulation.

Patients living with PICCs described having to make adjustments in everyday life whilst the device was in place. This included not being able to continue with everyday activities. Aspects of their life were taken from them whilst the device was in place. This included bathing and

participating in leisure activities. This was not as evident in the accounts of patients with TCVCs and TIVADs. In fact, the patient living with TIVADs were the only group who discussed the ability to get on with life, and of an improved quality of that life following device insertion.

Patients with TCVCs and TIVADs stated that the information received prior to device insertion was lacking. This could be because these devices were inserted by medical rather than nursing staff. This lack of information affected their experience of living with their devices and increased anxiety and fear.

Therefore, from these findings, I conclude that patients mostly experience each device equally. VADs are accepted and embodied. However, this seems to be as a result of previous negative experiences of peripheral cannulation and a fear of return to this. Therefore, the acceptance of a VAD is a lesser of two evils. Finally, it appears that adjustments to everyday life are a disadvantage of the PICC, and an improved quality of life are associated with the TIVAD.

This chapter has presented my interpretations of the participants' interviews. The lived experiences of participants with a Vascular Access Device have been described. Each participant's experience, and how they made sense of it, have been detailed. Convergent and divergent themes have been uncovered across both devices and participants' experiences. The following chapter will discuss a survey that was undertaken to test these study findings.

CHAPTER SIX: FACEBOOK SURVEY

6.1 : INTRODUCTION

Following this qualitative IPA study, I was interested to find out if my findings were generalisable over a larger population. Firstly, I submitted my study as both poster and oral presentations to various national and international conferences. These included the National Infusion and Vascular Access Society (NIVAS), World Congress for Vascular Access (WoCoVA), Association for Vascular Access (AVA), and the Intravenous forum of the Infection Prevention Society (IPS). Following these meetings and feedback from attendees it was discovered that the findings from this study resonated with colleagues' experiences. To strengthen this finding, I decided to design and perform a survey to further explore if the findings were a global phenomenon affecting patients with different disease processes.

6.2 METHODS

6.2.1 PARTICIPANTS

Participants were purposively sampled for their experience of CVADs. The use of specific inclusion/exclusion criterion ensured that patients were appropriately selected (*Table 1*). Participants were recruited from two closed Facebook groups. The first Facebook group 'PICC Line Club 2.0' is recorded as having 1400 members. Although set up specifically for people with PICC, membership now covers people with a range of different devices for various treatments. The second Facebook group 'IVs, Ports & PICCs & trades for PoTS' records having 2000 members. This group was set up initially for members to trade (give away or sell) personal surplus IV products. Both groups are now used for general discussions and support for people with a range of devices and conditions. Although there are over 3000 members

across the groups, many members were involved in both groups and some were no longer active.

6.2.2. ETHICAL CONSIDERATIONS

The changing nature of technology and recent use of social media in healthcare research can raise ethical issues (Turculet, 2014). The dramatic growth of media such as Twitter and Facebook are being used more frequently by patients and health professionals to disseminate information as well as for research purposes (McKee, 2013). Moreover, through the use of social media, patients with similar conditions can act as mutual support for each other. Despite the public nature of social media, concerns about privacy and anonymity remain the same as with traditional research and therefore ethical rigour was ensured. Ethical approval was sought and granted from the Edinburgh Napier University School of Health and Social Care Ethics Committee in January 2019 (SHSC18011) (Appendix 10). Permission was also granted by the administrators of each Facebook group. Following ethical approval, an introductory post was uploaded to each Facebook site. The post contained information on the study aims, objectives and purpose.

6.2.3 INCLUSION / EXCLUSION CRITERIA

An exclusion criterion was developed, Table 6.1. If the participants met the inclusion criteria, group members were invited to participate in the study.

Inclusion criteria	Exclusion criteria
Adults aged 18 or over	Children under the age of 18 years
Currently has a PICC, TCVC or TIVAD in place	Inability to read the English language
Has had a PICC, TCVC or TIVAD in place within the past 3 months	Patients without the capacity to provide consent

Device in place for any type of treatment

Patients with the capacity to provide consent

TABLE 6.1: INCLUSION / EXCLUSION CRITERIA

6.2.4 ETHICAL CONSIDERATIONS

If they chose to participate, the participants were directed to a link which took them to a patient information sheet (Appendix 11). Members were advised that there was no obligation to complete the survey. Those who decided to continue were firstly directed to a consent form (Appendix 12). To reassure participants, a link to a privacy notice was provided (Appendix 13). Once participants had agreed to the consent statements, they began the survey by clicking a link to the Novi database.

6.2.5 NOVI DATABASE

The NOVI system is hosted by Edinburgh Napier University. The database is accessible only by the principal investigator and is double password protected. Both the system and the virtual private network needed to access the software requires a password. Therefore, all data collected was securely stored. No personal data was collected and therefore it was unlikely that anyone could be identified by their responses to the questionnaires.

6.2.6 QUESTIONNAIRE

The questionnaire was devised using the themes that had been elicited from this current study. It consisted of drop-down menus for all questions plus the option of free text, where appropriate. The first questions collected demographical information, then asked about the device the respondent was living with. The main questions related to the objectives of the initial study. The survey was available on the Facebook sites for one month, with reminders posted weekly.

6.3 RESULTS

Seventy-four people responded to the survey. All but two were female, with one male and one not declaring gender. The majority were 21 to 40 years old, with 55% having had their device for more than 6 months (Figure 6.1). The majority had a totally implanted port (Table 2), and most respondents were from the US (n=62), with the remainder from the Netherlands (n=2), Canada (n=1), England (n=3), UK (n=3), Spain (n=1), Norway(n=1) and New Zealand (n=1). To maintain anonymity, only country (US or non-US) and age range is reported when citing respondents.

Device Type	Number of participants
Peripherally inserted central catheter (PICC)	19
Totally implanted port (port, portacath, implanted port)	45
Tunnelled catheter (Hickman type, Broviac type)	10

TABLE 6.2: NUMBER OF PATIENTS WITH EACH DEVICE TYPE

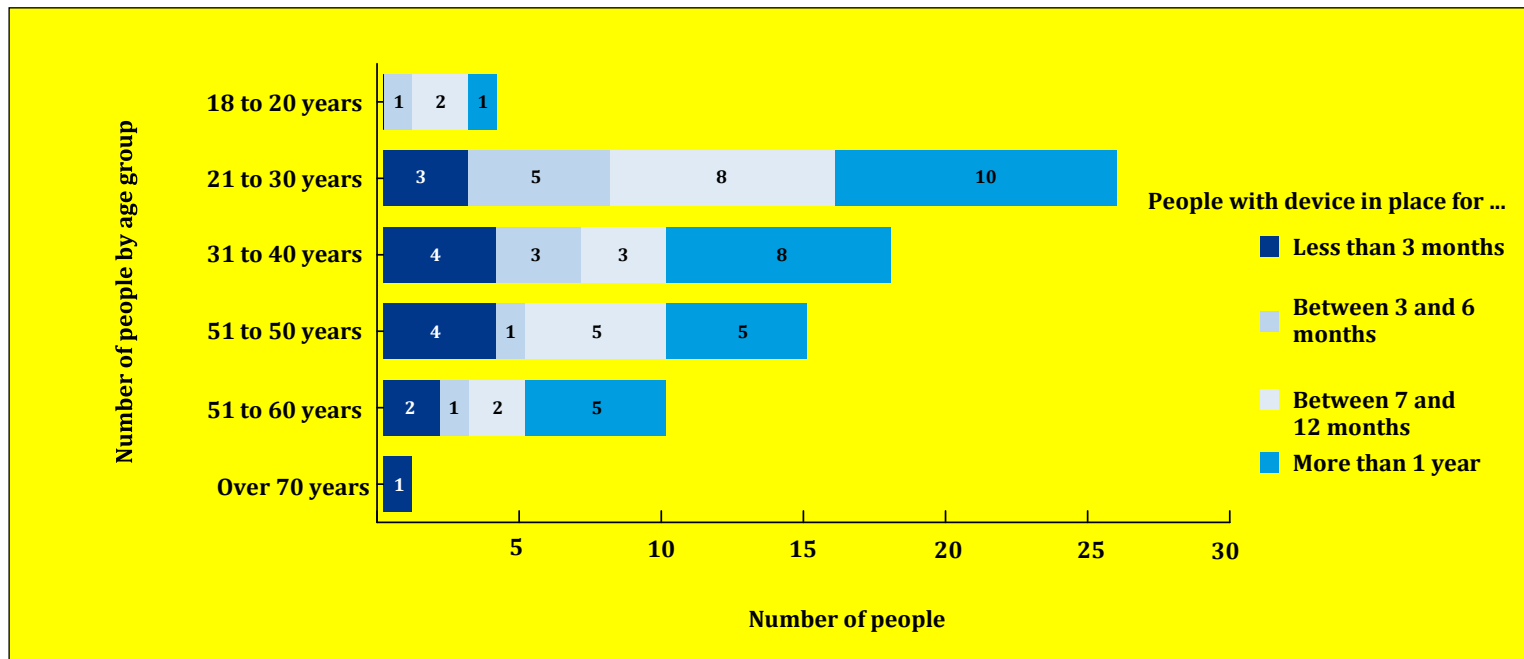


Figure 6.3. AGE OF RESPONDENTS AND LENGTH OF TIME A VAD HAD BEEN IN PLACE

6.3.1 QUESTIONS AND RESPONSES FROM PARTICIPANTS

Question One: Patients in my PhD study held vivid memories of painful, repeated and frequent access of their peripheral veins access device inserted. Is this something that you can relate to?

All except one responded to this question and only six people said no. Over 90% held vivid memories of painful, repeated and frequent access of their peripheral veins before they got their long-term vascular access device inserted. Thirty-two participants added detail to their responses and below are some sample:

- *'Approximately 30 cannulas over a period of 3 weeks prior to PICC line insertion. Cannulas included in feet and knees when arm/hand veins were exhausted.'* (Non-US, 40-51 years)
- *'I have post-traumatic stress disorder (PTSD) from this.'* (US, 21-30 years)
- *'Has caused medical PTSD.'* (US, 18-20 years)
- *'Doctors see you as a challenge when you say you have no veins'* (US, 18-20 years)
- *'I've had needles stuck in my shins, my toes, my wrists and often hospital staff carry on trying long after I've said ... "enough" '. (Non-US, 21-30 years)*

Question Two: Patients in my PhD study described times that nurses, or doctors were unable to use their device because they were unfamiliar with it. Is this something that has happened to you?

All (n=74) responded to this question and 28 said no. Of those who said yes (n=46) two people said this had happened once, 17 said between two and five times (including one participant who had said 'no' to the main question), and the majority (n=28) reported more than six times. Twenty-four participants also made further comments, for example:

- *'...had to teach everyone who thought about touching my line-how to protect it. (US, 41-50 years)*
- *'Out of 52 weeks last year my own home health nurses sent me to the ER 32 times because they were not trained properly.' (US, 31-40 years)*
- *'I've learnt (how to take blood, change dressings and to administer drugs as staff blocked my line and didn't use aseptic technique. It was safer for me to learn.' (Non-US, 31-40 years)*
- *'I've managed to get a port-trained nurse eventually but have sometimes had to wait unnecessarily especially in emergency department for pain relief, fluids and anti-emetics.' Non-US, 41-50 years)*

Question Three: Patients in my PhD study reported having to have their peripheral veins accessed because doctors and nurses were unfamiliar with the device. Is this something that has happened to you?

All (n=74) responded to this question and 30 said no, with the majority (n=44) agreeing.

- *'During general anaesthetic, the anaesthetist refused to use the PICC—instead cannulating in very painful swollen hand.' (Non-US, 41-50 years)*
- *'I preferred them to do a peripheral vein access because I was afraid they would do something wrong and I would get an infection.' (US, 18-20 years)*
- *'It is not that they are unfamiliar with it, they don't WANT to use it.' (US, 31-40 years)*
- *'Only twice has this happened because they wanted my blood cultured due to sepsis and couldn't wait. I demand they use my port for the most part.' (Non-US, 41-50 years).*

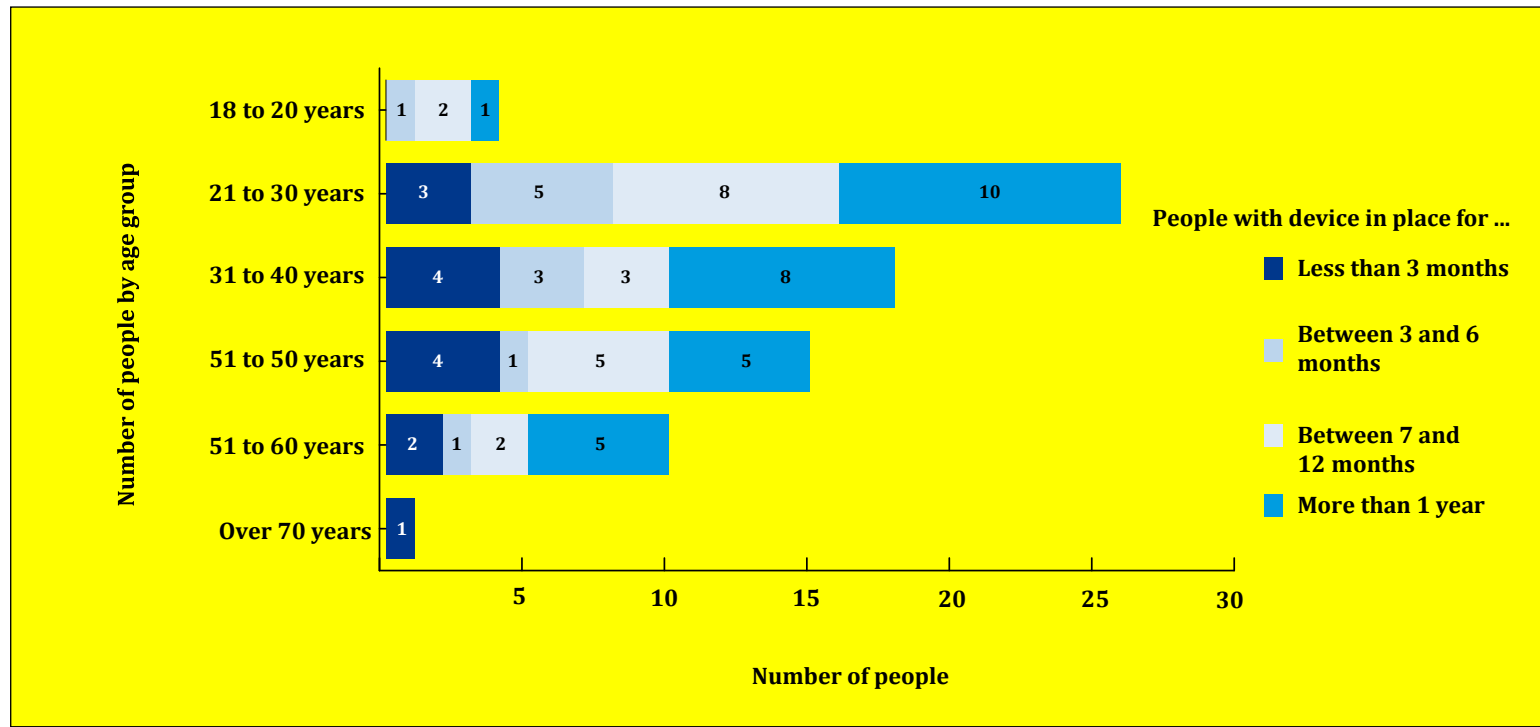


Table 6.4: NUMBER OF PARTICIPANTS BY AGE RANGE

6.4 SURVEY CONCLUSION

Like the participants in the original study, many respondents in this survey agreed that they had experienced traumatic, painful, repeated and frequent attempts of peripheral vascular access procedures. Following the insertion of a central venous access device, they appeared to be bewildered by finding out that many clinicians lacked knowledge and competence to safely use and care for their devices. Of those who stated that they could, a further proportion did not seem to use an aseptic technique, thereby causing anxiety and potentially putting the patients at serious risk of infection. This led many of the participants to take matters into their own hands. To prevent anyone else from touching their device they learned to manage the device themselves.

6.5 LIMITATIONS

This was a small, self-selecting sample of participants. I had hoped for more responses, given there were thousands of members on the online forums. However, of those who responded, the majority agreed with the findings of the original study. A related issue was that the majority of the respondents were from the United States of America (US), a society known to be more litigious and therefore perhaps more likely to self-manage. However, although the non-US sample was smaller (n=21), again there was consistency of response.

6.6 CHAPTER CONCLUSION

This study demonstrated that although patients accept having long term vascular access devices, it showed that painful, repeated attempts at cannulation persisted, despite possession of a device designed to help reduce it. It showed that the majority experienced a degree of health professional incompetence, which led many to take matters into their own hands to

prevent device complications. The findings of this study therefore support and strengthen the IPA study findings and demonstrates consistency of experience across an international sample of patients living with CVADs. The next chapter will discuss the findings from these studies.

CHAPTER SEVEN: DISCUSSION

7.1 INTRODUCTION

The literature search described in Chapter Two revealed that the majority of published studies on life with a VAD are quantitative and elucidate only superficial details about the lived experiences of these patients. Most studies focused on individual devices, and none compared all three types of device. The aim of this study, therefore, was to explore, in depth, the lived experience of people living with VADs. The selected research design is unique for the very reason that it is the first IPA study to explore the lived experience of these people. The analysis and interpretation of the spoken words of the participants in Chapter Five led to a deeper understanding of how living with a long-term VAD affected these individuals' being in the world. These findings were tested and supported by a survey which is detailed in Chapter six.

This chapter now situates these findings within the current literature and concludes by considering theoretical explanations that can support yet deeper understanding of these experiences, and their wider implications for patients and staff. Theories of self-protection, stigma, cognitive dissonance, and impression management all help to explain how and why the experiences described here can become more understandable, and, thus, improvable. This is interpreted here as the Vicious Cycle of Vascular Access. The components of this process are described in detail, but the chapter begins first by considering the importance of these original findings and their key contribution to knowledge. Such consideration is achieved by reflecting on the importance of IPA and its ability, in this case, to reveal an underlying process capable of explaining the experience of living with a VAD.

7.1.1 WHY THIS STUDY IS IMPORTANT

The study findings are important because, as detailed in Chapter One, the number of people living with VADs has increased, and will continue to do so. Furthermore, at present, there remains no clear preference for any of the three devices for infusion of therapies. They are regarded as being equally suitable (Bodenham *et al.*, 2016). Consequently, the decision of which device is inserted is based on clinician preference, with little patient input.

This study's findings will arm HCPs with information about how patients experience life with VADs. This will enable evidence-based device selection, with patient input. Equally, the findings will allow clinicians to confidently inform, prepare, support, and counsel patients on the consequences, pros and cons, and psychological impact of living with a VAD. This will, subsequently, lead to a more structured and sensitive approach to device selection decisions and will empower patient involvement. Although this is an exploratory study and further work is required, the findings herein will, nonetheless, contribute to an improvement of the patient experience.

This chapter provides a discussion of the study findings in relation to existing literature. Throughout the discussion, there will be a clear argument for the contribution to and development of knowledge in relation to our understanding of how people experience living their lives with the presence of a VAD. Firstly, the key study findings will be described.

7.1.2 CONTRIBUTION TO KNOWLEDGE

This study builds on previous literature that focused on the lived experience of having a VAD inserted. However, rather than concentrating on the ‘what’ of the experience, by using IPA, this study has provided a detailed explanation of ‘how’ people experience life with a VAD. A new conceptual framework entitled the Vicious Cycle of Vascular Access has been developed from this study. Such a framework adds an additional layer of information and knowledge that will help our understanding of the lived experience of having a VAD inserted.

7.1.3 KEY STUDY FINDINGS

- Prior to the insertion of a long-term VAD, patients often experience a traumatic period of peripheral cannulation for treatment delivery. This results in lowered self-esteem and a reduced sense of agency. When a long-term device is inserted, and peripheral cannulation negated, patients experience relief and regain a degree of self-control. Eventually patients will embody their device.
- When living with a device, patients experience perceived and self-stigma, as well as a loss of personal choice around hygiene practices, sports, and social activities. They employ strategies such as concealment to maintain both a positive self-image and privacy about their illness.
- Patients are left bewildered and dismayed when HCPs are unable to use their devices. Patients experience distrust and are left feeling fearful. This places them in a self-protective mode, and so, in order to keep safe, they often resort to self-care. Unfortunately, in some instances, due to the inability of clinicians to use these devices, patients are, once again, subjected to the violation of peripheral cannulation they thought they had left behind.

Therefore, a VAD affects the psychological, social, and personal self, and also impacts on self-esteem and self-image. The insertion of a VAD results in restrictions and limitations to life and can lead to living with distrust and fear whilst it is in place. Despite this, VADs are accepted by patients and are eventually embodied.

7.1.4 THE VICIOUS CYCLE OF VASCULAR ACCESS

One of the touchstones of IPA is the notion of partnership (Smith, Flowers and Larkin, 2009). Within this study, there was a ‘merger of meanings’ voiced by the participant and myself as the researcher (Koch, 1995; Lopez and Willis, 2004). The metaphor Fusion of Horizons was coined by Gadamer (1976). Gadamer describes a horizon as the total of everything that can be realised or thought about by a person at a given time in history and in a particular culture. In this context, the horizon is the backcloth of assumptions, ideas, meanings, and experiences that individuals have, simply by living. These backcloths remain dynamic and variable (Lopez and Willis, 2004). The communication between the participants and myself was bound by our separate and intersecting horizons. We both held our own horizons, which can be described as being far as we could see or understand. Following our conversation, we left with our own new horizons. Understanding happens when our current understanding (horizon) has been moved to a new understanding by our encounter. Therefore, this process of understanding is a fusion of horizons: the old and new horizons combining to form new meanings.

As a consequence of this fusion, no singular true meaning can ever be generated; however, I believe that my findings reflect the reality of the participants. My dynamic engagement with literature and existing theories assisted in the development of a new conceptual framework of the Vicious Cycle of Vascular Access (Figure 6.1). The process of an interpretive activity, which is circular, demonstrates my engagement of hermeneutic analysis (Smith, Flowers and Larkin, 2009).

The experience of living with a VAD involves a number of processes that impact on the self (Chapter Five). By synthesising relevant literature and using iterative analysis, I argue that this study has led to a nuanced description of the lived experience of vascular access, which has highlighted the concepts of a self under attack, being rescued, being robbed, a mechanism of self-protection, distrust and fear, and acceptance and embodiment.

- **The self under attack:** Conceptualises the lived experience prior to having a long-term VAD inserted. This experience impacted on self-esteem and resulted in a reduced sense of agency.
- **Being rescued, being robbed:** Conceptualises the experience of and relief at getting a device that will negate the requirement for repeated, painful peripheral cannulation. However, this concept also conceptualises a loss of self due to being restricted in aspects of personal and social life activities.
- **A mechanism of self-protection:** Conceptualises the experience of perceived and self-stigma, as well as the need to maintain a positive self-image. This is also concerned with the need to protect others from having to see the device.
- **Distrust and Fear:** Conceptualises the experience of living with fear of device complications. This being increased due to the inability of HCPs to use the VAD. In addition, it conceptualises the loss of trust in healthcare, and the experience of fear of a return to the violation of painful and repeated peripheral cannulation.
- **Acceptance and embodiment:** The Vascular Access Device is eventually accepted and embodied. The theory of cognitive dissonance is a psychological explanation for this.

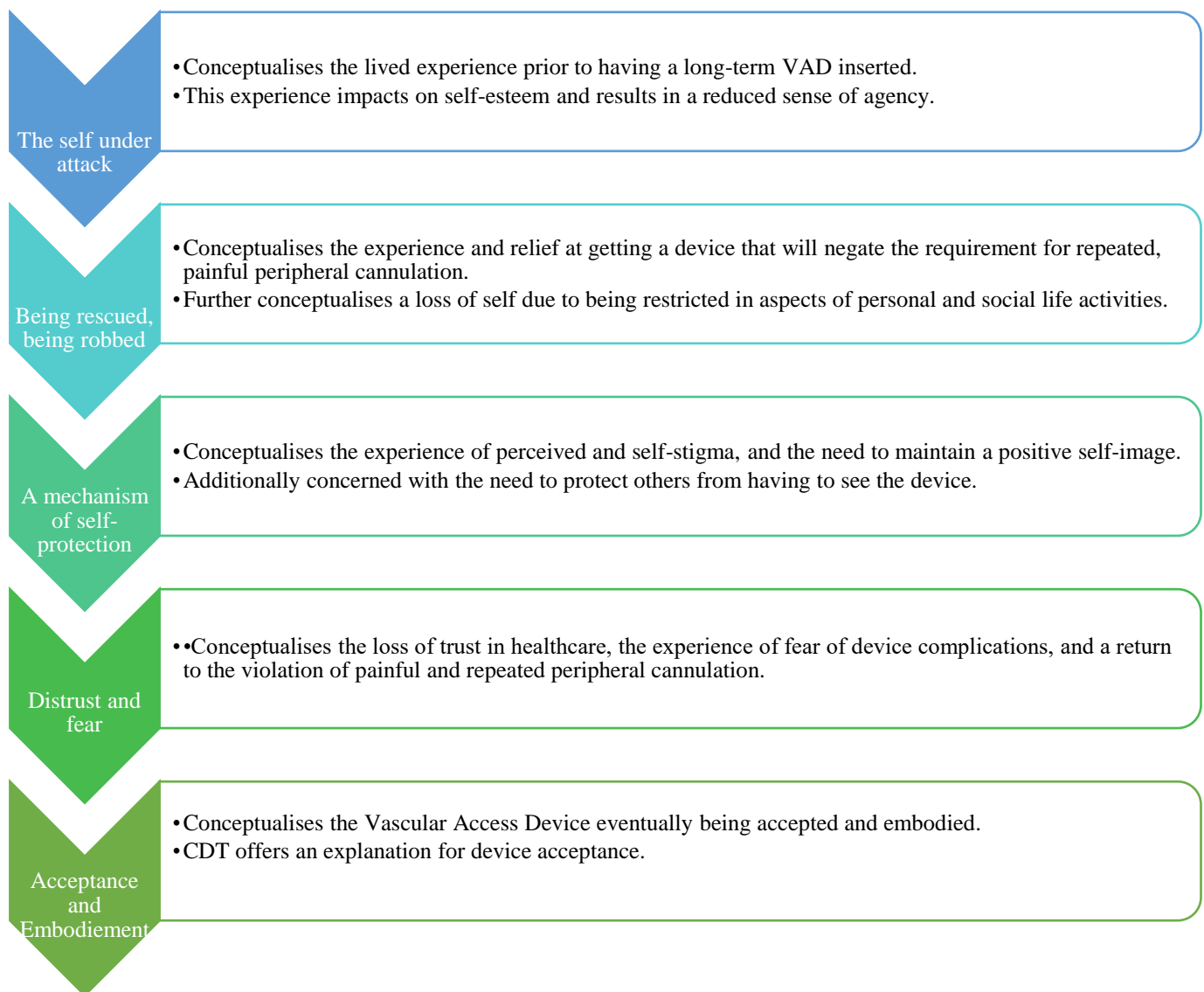


Figure 7.1: CONCEPTUAL FRAMEWORK ELEMENTS

These processes become circular when, despite having a long-term Vascular Access Device in place, and due to the lack of competence and knowledge of staff, patients are subjected to peripheral cannulation once again.

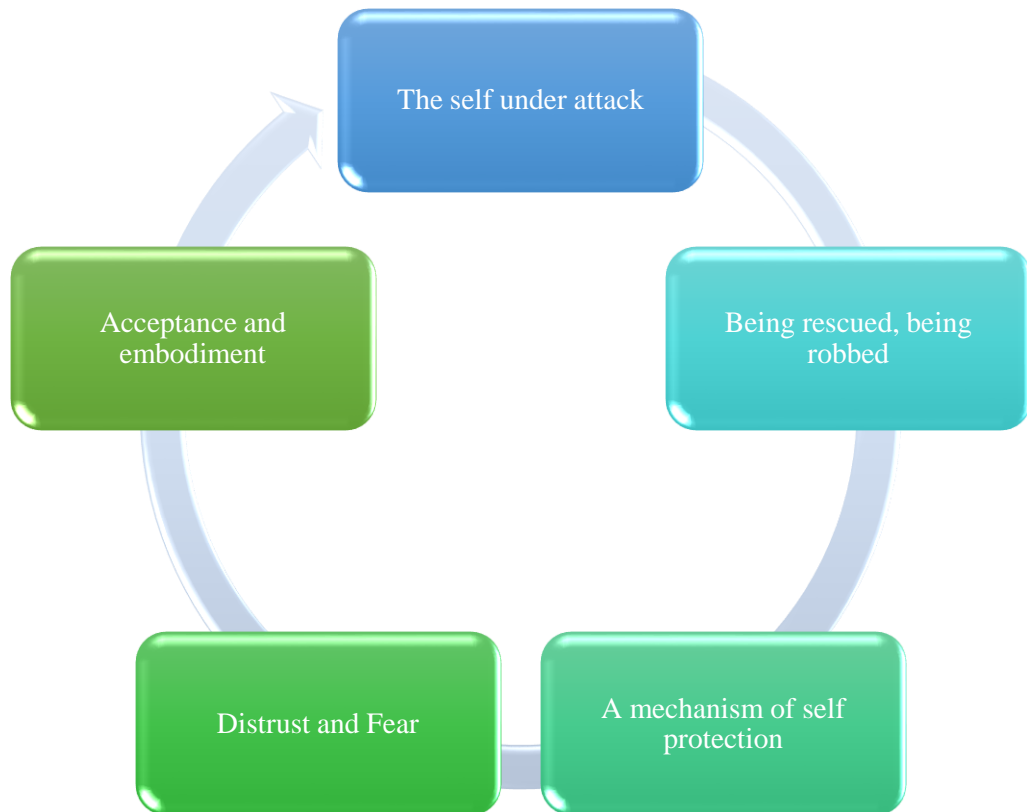


Figure 7.2: THE VICIOUS CYCLE OF VASCULAR ACCESS

A discussion of each process of the conceptual framework will now be presented.

7.2 PROCESS ONE: THE SELF UNDER ATTACK

This title reflects the experiences of peripheral cannulation as described by the participants, and by the interpretation of their accounts. The subtitles that make up the discussion in this section are:

- The iatrogenic harm of cannulation
- Pain resulting in the loss of self

Although the purpose of this study was to explore the experiences of participants living with a long-term VAD (TCVC, TIVAD, or PICC), eight out of the 11 participants began their stories by looking to the past and recalling memories of repeated painful peripheral cannulation. The

memories and stories shared during this study demonstrated that these experiences resulted in a reduction in self-esteem and loss of self.

Existing literature on the patient experience of PVC cannulation in the adult population is sparse, with more research focusing on the paediatric population (Walco, 2008; Slifer *et al.*, 2011; Uman Lindsay *et al.*, 2013; Pavlova and Noel, 2017; Orenius *et al.*, 2018). The findings of previous research which does focus on the adult population support the findings presented herein, and highlight the negative effects of repeated intravenous cannulation on adults (Szmuk, Szmuk and Ezri, 2005; Kim *et al.*, 2007; McGowan, 2014; Robinson-Reilly, Paliadelis and Cruickshank, 2016; Barton, Ventura and Vavrik, 2017). It has been identified that the pain of cannulation can lead to extreme discomfort (Halter *et al.*, 2000; McNaughton *et al.*, 2008; Bond *et al.*, 2016). These studies discuss how, traditionally, in the adult population, we underestimate cannulation pain. In a study by Robinson-Reilly, Paliadelis and Cruickshank (2016), participants explained that they had not been informed or prepared for how painful advancing a sharp-pointed instrument through the skin on the back of the hand was going to be. This severe pain has been linked to missed medical appointments and follow-up care due to fear, distress, and needle phobias (Szmuk, Szmuk and Ezri, 2005; McMurtry *et al.*, 2016; Trost *et al.*, 2017).

Experience of previous difficult and painful peripheral cannulation identified in this study also echoes findings from previous literature on the experiences of patients living with a VAD (Gabriel, 2000; Molloy, Smith and Aitchison, 2008; Ritchie *et al.*, 2015; Alpenberg, Joelsson and Rosengren, 2015; Källenius Edström, Lindqvist and Rosengren, 2016). As in this study, prior to the insertion of a long-term VAD, most participants experienced previous episodes of repeated peripheral cannulation, which they found distressing. A study by Song and Oh (2016) exploring the experiences of patients with burns found that repeated cannulations left those

patients with scars and bruises. It went on to describe how participants eventually became tired and stressed with the procedure of repeated cannulations.

Sharp *et al.* (2014) stated that patients experienced multiple peripheral punctures – in some cases, more than ten attempts – before successful access was obtained. Although this current study supports findings from previous literature, previous research did not consider the effect of repeated cannulation on the self. Therefore, findings from the current study have added to current knowledge on this phenomenon. This thesis argues that recalling repeated, painful cannulation means that this experience was traumatic, resulting in negative self-esteem. The participants in this study recalled detailed experiences from the past which demonstrated the lasting effect on the self. Autobiographical memories are memories about personal experiences that go further than purely factual descriptions (Fivush, 2010). These networks of memories contain personal beliefs, thoughts, and emotions, and support well-being and effective functioning of the self in many ways (Vanderveren, Bijttebier and Hermans, 2017). Personal stories contain various layers of autobiographical memories.

Self-esteem is important in the formation and recollection of autobiographical memories, such as those recalled in this study (Klein and Nichols, 2012). It is believed that people with positive self-esteem remember more positive events, whereas those with negative self-esteem recall more negative events (Christensen, Wood and Barrett, 2003). Tafarodi, Marshall and Milne (2003) agree that self-esteem is associated with selective memory for negative information. Moreover, individuals who are in a profound state of unease or dissatisfaction recall more negative memories. Conversely, cognitive appraisal is associated with more positivity (Wisco and Nolen-Hoeksema, 2010). One way in which self-esteem can be lowered is if we feel that we have been ignored. This is because the negative aspects of the self-concept are more accessible in such situations, which was evident in the current study when HCPs repeatedly

attempted to place a cannula. This example is from Tina's account, where she describes being ignored as she pleaded for a nurse to stop:

'... the nurse insisted in doing it here and I said stop right there. I said stop that's very painful. She said, that's the way'. (Recall - Tina, PICC, Chapter five)

An event's biological relevance also makes it important. Painful, aversive events are remembered so that we can avoid repeating them (Alberini, 2010). Emotional events also remain with us; according to Klein and Nichols (2012), the stronger the emotion, the longer-lasting the memory. In fact, Alberini (2010) suggests that individuals can retain memories of painful or traumatic details for a lifetime. Most participants in this study had their long-term devices in place for many months. Despite this timeframe, they vividly recalled the experience of cannulation that they had suffered prior to VAD insertion. The recollection of this negative period of time suggests that participants in this study may have experienced negative self-esteem as the result of the cannulation pain they had endured (Christensen, Wood and Barrett, 2003).

7.2.1 THE IATROGENIC HARM OF CANNULATION

Participants in this study had all received a cancer diagnosis and required intravenous chemotherapy. The duration of chemotherapy treatment is usually lengthy. If the patient does not have a long-term VAD, frequent placements of PVCs are necessary for treatment regimens (Gallieni, Pittiruti and Biffi, 2008). As described in the previous section, it is known that PVC is a procedure that induces pain.

Pain is a somatic experience that reflects a person's apprehension of threat to their bodily or existential integrity (Cohen, Quintner and van Rysewyk, 2018). It has also been described as *'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage'* (International Association for the Study of

Pain, 2017, p. 209). Shifts in self-esteem can be caused by many specific incidents, including pain (Emler, 2002). It is postulated that, over time, consequences of the continued pain of cannulation can lead to decreased self-esteem. Over the past few decades, numerous studies have shown that this pain can be negated with the use of a local anaesthetic (Harris, Cameron and Ugoni, 2001; Sado and Deakin, 2005; Bond *et al.*, 2016). However, despite the option of LA, and the development of numerous innovative strategies that mitigate the pain of PIVC insertion, patients continue to be exposed to painful cannulation.

The participants in this study did not appear to have been offered LA, nor was the use of vein visualisation tools utilised in an attempt to make this a less traumatic procedure (Kelly, 2013). This resulted in the neglected ‘complication’ of venous access; that is, pain. This iatrogenic harm was highlighted on numerous occasions within the current study. In recent years, there has been an increasing interest in cannulation pain, with suggestions that it should be treated as an adverse event (Chorney, McGrath and Finley, 2010). Such an argument suggests that cannulation, and its associated pain, should be considered to cause harm to the patient.

Ethically, HCPs have a duty of care to their patients and society, and it is generally accepted that they should always act in the best interest of patients (Herring, 2010). Ethical awareness is necessary if practitioners want to critically evaluate their practice. This awareness is essential in the process of carrying out a skill such as cannulation, where the first steps involve making a decision about whether the device is appropriate and if the procedure can be carried with minimal discomfort and risk (Hallam *et al.*, 2016). Arguably, one of the best-known medical phases is ‘first do no harm’ (Sokol, 2013). However, for HCPs to truly do no harm would mean they would do nothing at all because most procedures and examinations will cause some level of harm to patients. HCPs must balance their obligation to benefit the patient – known as the

principle of beneficence – against their obligation to cause no harm to the patients – the principle of non-maleficence. These obligations go hand in hand and are weighed against each other (Sokol, 2013).

The obligations for HCPs to relieve human suffering stretches back to antiquity (Cassell, 2004). However, it is not uncommon for suffering to occur during disease and as a result of its treatment. Cassell (2004, p. 640) defines suffering as ‘*the state of severe distress associated with events that threaten the intactness of the person*’. When using this definition, persistent pain, as well as repeated, lengthy procedures that result in pain, can lead to suffering. A narrow, medicalised view of suffering that is simply defined as a physical discomfort fails to recognise the broader significance of the suffering of someone who is unwell (Cassell, 2013). Pain and suffering resulting from cannulation attempts were evident within the current study.

7.2.2 PAIN RESULTING IN A LOSS OF SELF

It is clear from this study that physical pain, psychological distress, and the harmful effects of medical procedures, such as peripheral cannulation, can cause suffering. Although not an illness in itself, vascular access is often necessary to allow the treatment of illness. Charmaz (1983) has written expansively about the relationship between chronic illness and the self. She suggests that several sources of suffering can be discerned. Firstly, living the restricted life imposed by chronic illness is perceived as undermining autonomy. Next, people with chronic illness receive various discrediting definitions of self. An example of this is being talked down to or, in the context of this study and as described by Tina in Chapter five, being ignored. Charmaz (1983) highlights these sources, as well as the loss of self in ill persons who perceive their former self-images crumbling away with no growth of valuable new ones. Eventually, the loss of a previously sustaining self-image results in a diminished self-concept. While this study is concerned with the experiences of living with a long-term VAD and not chronic illness, the

work of Charmaz (1983) provides an important context for the research. In addition, her methodology is consonant with this project. This study complements the work of Charmaz by providing a picture of how individuals living with VADs perceive sources of suffering, and how these can lead to a loss of self. This was predominantly related to the pain of repeated cannulation attempts.

Pain can be threatening, even if it is momentary (Morley, Davies and Barton, 2005). Research emphasises the interruptive effect of pain on both behavioural and cognitive performance. The extent of interruption is a function of both the stimulus characteristics of the pain and the threat appraisal, or the meaning, of pain for the individual. Pain that is momentary and acute is unpleasant but has little impact on the sense of self. In this study, cannulation pain was repeated on a regular basis and often for an extended period. According to Morley (2010), this type of pain can impose interruptions and interference, and may be much more damaging to one's sense of self or identity. Therefore, it could be suggested that it was the frequency of painful cannulation experienced by the participants in this study which resulted in a loss of self-esteem and lowered sense of self.

7.2.4 CONCLUSION TO DISCUSSION OF PROCESS ONE: THE SELF UNDER ATTACK AND ARTICULATION OF NEW KNOWLEDGE

Prior to having a long-term VAD inserted, patients often experience a period of repeated, painful, and sometimes traumatic peripheral venous access procedures. This is because the treatment is necessary, and alternatives do not tend to be offered. The participants in this study were all suffering from cancer. It is widely accepted that having cancer and receiving chemotherapy affects a patient's sense of self (Barr, Semple and Seaton, 2012; Jayde, Boughton and Blomfield, 2013; Hassan *et al.*, 2015; Leite, Nogueira and Terra, 2015; Mohd-

Sidik *et al.*, 2018). This study asserts that frequent, recurrent attempts at painful cannulation is an additional aspect of receiving IV chemotherapy. Such repeated attempts, consequently, add to a diminished self and lowered self-esteem, as well as a reduced sense of self.

7.3 PROCESS TWO: BEING RESCUED, BEING ROBBED

This title refers to the experience of being given a device that negates the need for peripheral cannulation. As demonstrated herein, this is initially seen as a blessing, with participants expressing their relief in receiving a long-term VAD. However, once inserted, vascular access means restrictions and challenges to individuals living with VADs. The subtitles that make up the discussions within this section are:

- Being rescued
- Being robbed

7.3.1 BEING RESCUED

When peripheral venous access was no longer possible, the decision to insert a long-term VAD was made. This was a pivotal moment that potentially spelled the end of the pain and trauma of PVC insertions and fuelled feelings of being rescued. When recalling the experience of getting their long-term devices, participants' tone changed from one of negativity to one of near euphoria.

The participants in this study expressed relief at no longer having to endure the challenges of peripheral venous access. They found that treatment through their long-term Vascular Access Device was easier and less invasive. Previous studies have reported positive effects of having a long-term VAD on the quality of life. This included: freedom of movement, feelings of happiness with the devices, greater independence, and ease of treatment delivery (Gabriel, 2000; Chernecky, 2001; Martins *et al.*, 2008).

Early studies concluded that a VAD had little or no impact on the quality of life of patients (Oakley, Wright and Ream, 2000; Gabriel *et al.*, 2000; Goossens *et al.*, 2005). However, more recently, restrictions in daily activities associated with the presence of a VAD have been reported in the literature (Marcy *et al.*, 2014; Ritchie, *et al.*, 2015; Edström, 2016; Minichsdorfer, *et al.*, 2016; Parás-Bravo *et al.*, 2018). Ritchie, *et al.*, (2015) found that the presence of a TIVAD could be perceived to confer pure freedom; however, the limitation on activities could negate the perceived benefits of the device. Similarly Minichsdorfer *et al.*, (2016) described the inability of patients to pursue their hobbies and sports because of their VAD. Marcy *et al.*, (2017) also described how the VAD had an effect on daily and professional activities of patients. Although it is now recognised that VAD's can impact on the daily personal and social activities of patients, this is the first study to describe how these restrictions impact on the self. Therefore, it is a novel finding that adds to the body of knowledge.

7.3.2 BEING ROBBED

Despite the positive aspect of no longer having to endure the pain of repeated peripheral venous access, participants experienced restrictions, limitations, and adaptations in their daily lives as a result of their VADs. An ability to live their previous lives, or make certain decisions, was taken away from participants.

The need for restrictions and adaptations while living with a VAD has been recognised in previous literature (Molloy, Smith and Aitchison, 2008; Johansson *et al.*, 2009; Goltz *et al.*, 2013; Edström, Lindqvist and Rosengren, 2016). These studies concluded that the presence of a VAD required patients to adjust to a different life than that which was previously lived. Whilst Chernecky (2001) concluded that, once the device was accepted, it improved patients' quality of life. However, Martins and de Carvalho (2008) highlighted that patients endured negative consequences related to the difficulty of performing activities that they had previously enjoyed.

Goltz *et al.* (2013) discovered that patients living with VADs experienced negative feelings while driving a car or wearing a bra. The study supports and adds to these previous study findings by exploring how such experiences result in a loss of self-identity.

Unlike TCVCs and TIVADs, which can be showered over, participants in this study living with PICCs described going through a process of applying waterproof sleeves over their devices prior to showering. This was to ensure they remained dry and to reduce the risk of device infection. Submerging in baths is also not recommended when a PICC is in situ. This meant that, if patients wished to bathe, they had to keep one arm out of the bathwater. As personal hygiene is a regular process, it proved frustrating for some of the patients. However, for others, such as Tina, this was accepted:

'I've got one of those sleeve things, it's fantastic. That's very, very good because one of those things was showering every morning, it's important to me. It's, like, I need to get into the shower. It keeps you You can let the water run over you and breathe. It's a bit like respite.... Although, you have a body wash and everything, I sometimes think I can smell myself. It's just that I know I've not been in the shower'. (Recall - Tina, PICC, Chapter five).

In addition to personal hygiene aspects, patients living with external VADs had to refrain from other leisure activities, including contact sports and swimming (Gorski, 2016). This important study finding suggests that restricting activities which are important to patients can have a negative effect. When told that he was going to have a TCVC inserted and informed of the restrictions this would bring, Anton took matters into his own hands. His life revolved around playing football and swimming, and such was his determination not to have these activities taken from him that he made the decision to seek private medical care. This was so he could have his treatment through a TIVAD, rather than a TCVC, and continue with his activities:

'I went to the car park, I was in floods of tears thinking, I can't even go for a swim now and they're telling me I've got six months to live, my whole quality of life is going downhill' (Recall – Anton, TIVAD, Chapter five).

It is recognised that participation in leisure activities can improve patients' mental wellbeing (Fuchs, 2015). Physical activity has been shown to enhance feelings of wellbeing in several populations, such as children, adults, and those who are ill (Jerstad *et al.*, 2010; Rothon *et al.*, 2010; Lindwall, Larsman and Hagger, 2011). Additionally, it is claimed that participation in fitness and activity programs is associated positively with feelings of increased self-esteem (Petrie, Stover and Horswill, 2004; Dishman *et al.*, 2006). A possible physiological mechanism for these feelings of wellbeing has been linked to the release of endorphins during exercise (Doeller, Barry and Burgess, 2012). Restrictions on activities could be more crucial when patients are terminally ill, as were some of the patients in this study.

A study by Rawlings, Miller-Lewis and Tieman (2018) aimed to discover what was important to people facing their own mortality. Twelve themes emerged, including do an activity, personal aspiration, live life fully, and happiness. Reflecting what is important to these patients, as well as what they wish to achieve or address while they are still alive, can be seen as part of the process of advanced care planning around managing death (Rawlings, Miller-Lewis and Tieman, 2018). Recently, the idea of a 'bucket list' as well as an attitude of 'you only live once' have become popular (Periyakoil, Neri and Kraemer, 2018). Additionally, palliative care professionals report that the primary emotion witnessed when a patient is dying is regret (Rawlings, Miller-Lewis and Tieman, 2018). When a bucket list is created, a narrative is initiated that guides us to discover how we want to spend our final years, months, or even days. To take this away from patients could be seen as denying them their end of life wishes.

In this current study, Amaya, who had a terminal diagnosis, spoke about how the presence of her TIVAD prevented her from achieving something she had hoped to accomplish during her lifetime; that is, jumping from a plane. However, the position of her TIVAD would have been in direct contact with the straps and it was, therefore, not possible for her to do the jump:

'I wanted to jump out of a plane, but the guys wouldn't let me do it because of the straps here'
(Recall - Amaya, TIVAD, Chapter five).

Had it been known that this was Amaya's ambition, her TIVAD could have been inserted in a more suitable area. In the context of this study, I believe that medical attention focuses on the disease and the technology available to treat it. However, there also needs to be concern about the person. Before issuing restrictions, patients should be advised and supported. If sports and activities are an important part of patients' lives, a device that allows this should be considered where possible. Contemplation should be given to how certain technologies impact on the person and if life quality is adversely affected, which could be said of the experiences found in this study. As far as I am aware, this strong finding is novel and, therefore, contributes to current literature.

This study suggests that the presence of a VAD places restrictions on patients and can prevent them from doing the activities that they used to do. Such activities were once central to a sense of self as a typical, healthy, independent, competent person. In reality, this thesis argues that when a person is unable to do the things they used to do, they are no longer the person they were. As previously discussed, and in support of Charmaz (1983), this study suggests that these restrictions result in a loss of self.

Anton summed this up well in a powerful statement:

'... I had a quality of life, even though I could potentially be dying. I went from playing football three times a week, to swimming three times a week, to being told you've got six months to live to 'bang', you can't shower, you can't swim, you can't play football. I was like.... What?! No way!' (Recall – Anton, TIVAD, Chapter five)

Recently, researchers have called for a consideration that bucket lists should be shared during end-of-life medical care (You, Fowler and Heyland, 2014). This approach could be used as a starting point to initiate goals of care discussions, and a strategy to personalise care based on the life goals of each patient (You, Fowler and Heyland, 2014). To ensure patient-centred care, such issues should be considered and discussed with patients before long-term VADs are inserted.

7.3.3 CONCLUSION TO DISCUSSION OF PROCESS TWO: BEING RESCUED AND BEING ROBBED, AND ARTICULATION OF NEW KNOWLEDGE

The insertion of a long-term VAD is largely a positive moment in the vascular access journey. The long-term device is viewed as a resolution to the previous negative experience of painful cannulation. However, living with a long-term Vascular Access Device results in the need to adapt and adjust to a life that changes the self. One of the most negative aspects is that restrictions are placed on leisure and sporting activities, which can affect self-esteem. From the study findings, it could be extrapolated that a TIVAD results in fewer restrictions, and subsequently, a better quality of life for patients. This is because it resulted in fewer life adjustments or restrictions, and retention of self. Therefore, the findings from this study suggest that having this additional knowledge could result in a more informed device selection process, which is ultimately patient focused.

7.4 PROCESS THREE: A MECHANISM OF SELF-PROTECTION

A key finding from this study is that when a VAD is inserted and left in the body, it alters the self and becomes a potential source of stigma. This was irrespective of which device was in situ. The title of this section refers to the experience of having to protect the self from a perceived stigma, and to maintain a positive sense of self. This section will also discuss the need to protect others from having to see the VAD. The subsections that make up the discussions in this section are:

- Stigma and image management
- Impression management
- The altered self
- Mind and body dualism

The findings presented in this study concur with previous studies on patient experience of vascular access. Alpenberg, Joelsson and Rosengren (2015) studied the experiences of patients with a PICC. Patients in this study described the reactions of friends and relatives; they thought their devices fuelled disgust and fear in others. These patients subsequently chose to hide their PICCs (Alpenberg, Joelsson and Rosengren, 2015). Similarly, the desire to hide the device emerged as a strong theme in a study by Ritchie *et al.* (2015). Sharp *et al.* (2014) described how the visibility of the PICC symbolised disease for some patients, which was a reason to keep it hidden. Similarly, Oakley, Wright and Ream (2000) found that the PICC reminded patients of their disease and had an effect on body image. Patients in this study found it distressing when people enquired about their device, and also reported feeling that others were too frightened to ask what it was. Therefore, they chose to conceal it where possible due to perceived stigma (Oakley, Wright and Ream, 2000). This was echoed in a study by Parás-Bravo *et al.* (2016), who concluded that the PICC resulted in altered body perception, avoidance of sexual activity, and a feeling of stigmatisation.

Similar results were found in an early study by Ignatov *et al.* (2009). Patients in this study described poor cosmetic results following TIVAD insertion. Subsequently, they experienced anxiety due to having a foreign body under their skin (Ignatov *et al.*, 2009). In a study by Minichsdorfer *et al.* (2016), patients also discussed how a TIVAD, although totally implanted under the skin, became a symbol that reminded them of their disease. Like patients with PICCs, those with TIVADs selected clothing to keep their device hidden.

7.4.1 STIGMA AND IMAGE MANAGEMENT

Stigma is often defined as a mark of shame or an attribute that is deeply discrediting within a particular social interaction (Pettit, 2008). According to Goffman (1959), when individuals possess traits that damage their identity and prevent their full participation in society - they carry a sigma. Stigmatised individuals develop coping strategies to protect themselves. They may hide their stigma if it can be disguised. This has been identified more commonly in patients with mental health issues (Corrigan, 2004; Corrigan & Watson, 2002; Rüsçh, Angermeyer, & Corrigan, 2005) and in individuals with cancer (Fife and Wright, 2000; Else-Quest and Jackson, 2014; Rosser, Njoroge and Huchko, 2016).

As suggested in previous literature (Sharp *et al.*, 2014; Alpenberg, Joelsson and Rosengren, 2015; Ritchie, *et al.*, 2015), and from the findings of this current study, I would argue that the presence of any VAD can result in stigma. This discovery is surprising because, unlike external devices (PICC and TCVC), the main benefit of a TIVAD is that it is totally implanted under the skin and is often referred to as invisible. It is obvious from this study that this is not always the case. As the insertion of a TIVAD involves minor surgery, an unfortunate consequence often seen after suture placement is suture marks (Field, 2006). Wound healing and scarring have been a focus of clinical and academic interest in recent years, and we are now in an area in which public awareness and expectations of scar cosmesis have increased (Arora *et al.*,

2016). It appears that since VADs are the remit of nurses, radiologists, and anaesthetists, surgeons may not possess the necessary skills or knowledge of suturing techniques to reduce scarring or to employ measures to obtain satisfactory cosmetic results, despite their recognition of the importance of appearance (Field, 2006). This issue needs to be addressed in order to improve patient experience and reduce stigma.

In the current study, another reason for VAD concealment was to hide the seriousness of participants' illness, or to shelter and protect others from seeing that illness. Most patients in this study did not want to reveal their illness to others.

Mary Rose described her thoughts when her device was inadvertently exposed to others:

'I've gone in to try on in the changing room and I've forgotten sometimes, and I've come out and the girls are there, and I've tried a top on and I'm aware of them, I've thought, maybe I shouldn't have tried it on or I'm maybe alarming them...'. (Recall – Mary Rose, TCVC, Chapter five)

Based on the findings of this study, the presence of an internally- or externally-sited VAD, and the potential scarring around it, changes a patient's identity and places them in an illness or sick role status (Parsons, 1951). This may not be the impression the patient wishes to portray. In addition, the presence of a VAD leads to stigma, which is either real or perceived, and results in patients feeling differently about themselves and concerned about how others view them. To reduce visibility and to fit in, the act of concealment is employed.

7.4.2 IMPRESSION MANAGEMENT

The term Impression Management (IM) was originally coined by Goffman (1959). Subsequently, sociologists and other theorists added weight to the concept (Tedeschi & Riess, 1981; Sinha, 2008; Newman, 2009). IM refers to techniques of control or influence of other

people's perceptions about us, and explains our need for people to view us in a particular way (Tedeschi and Riess, 1981). According to Sinha (2008), IM is an active process; that is, the act of presenting a positive public image (Newman, 2009). People, whether ill or well, are sensitive to how others see them and can use many forms of IM to compel others to react in the way they wish.

The presence of an external VAD impacts on the way individuals are viewed by others. Concealment limits this social impact on the individual's identity and allows them to be viewed in a positive way by others. Participants in this study described how they felt when they saw their devices, which was not always positive. To reduce this, rather than risk the negative reaction of others, they chose to either disguise or hide their devices or to avoid situations in which the device might be seen. Participants did not know how others felt about their devices. However, their own perception of the device led them to imagine that others would perceive it similarly. In this study, Yasmin didn't like to see her TCVC exiting her skin:

'I try to keep it hidden most of the time, especially when it didn't have a Biopatch® on it [a small chlorhexidine disc] like you could see it come out of your skin'. (Recall – Yasmin, TCVC, Chapter five).

Yasmin cared about other people and did not want them to see what the VAD looked like. Given that she could not bear the way the device looked where it exited her body, Yasmin perceived that others would have the same reaction to it. Subsequently, she hid the device to protect others. According to Cooley (1902), we are aware that people are constantly watching us, reacting to us, and judging us, and we use this knowledge to shape the impressions we give off. In this thesis, the concealment of the devices was the way in which participants attempted to maintain the impression and image they wished others to see; an impression other than that of a person so ill a special device was placed into their bodies in order to receive treatment.

Concealment is, therefore, undertaken to maintain privacy about illness and avoid having to share information with others. According to Charmaz (1983), sick people frequently experience fragmentation of their former self-image.

7.4.3 THE ALTERED SELF

Developments in medical technology and practice in the field of vascular access have allowed irritant and vesicant medications, such as chemotherapy drugs, to be delivered directly into the large central veins of the body. The presence of a long-term VAD, whether externally placed or implanted, alters the anatomy of the body to create an extension to the vascular system. This creation has been designed to allow the body to be treated for disease. I argue that the effect of this artificial extension to the human body and mind of the patient may not have been fully considered.

7.4.3.1 MIND AND BODY DUALISM

This thesis argues that the insertion of a VAD, without proper consideration for the physiological consequences of doing so, divorces the mind from the body. Mind and body dualism is the concept that the mind and body are two separate entities and, subsequently, are not one and the same (Descartes, 1985). It is also described as Cartesian dualism, or substance dualism. The alternative concept is physicalism, also known as materialistic monism. This is the concept that the mind and body are the same, and are strictly material rather than supernatural (Sturm, 2012). Physicalism requires us to believe that sensations such as thoughts, emotions, desires, beliefs, and free choice do not exist because materials do not have such properties. In biblical beliefs, mind and body dualism fits well as ancient scriptures taught that man was created with a body and soul, whereas the philosophy of dualism teaches the difference between the brain (matter) and the mind (soul).

The introduction of a long-term VAD is done to enable the delivery of vesicant medications into the central system to attempt to treat disease. Although the device is necessary to facilitate treatment, it cannot be forgotten that the individuals who receive them must readjust and learn to live with a changed self. The impersonal and technical nature of this intravenous access practice could be viewed as a disempowerment and dehumanisation of patients (Mehta, 2011), and highlights the persistence of body dualism in medical practices. As discussed in Chapter One, technological advancements in the field of interventional medicine has reinforced the philosophy that formed the basis of biomedical paradigm (Kriel, 1988).

Models of illness be they cultural or professional, have influenced decisions on patients and the delivery of health care. The biomedical model of illness has dominated health care for the past century (Wade and Halligan, 2004). This model views disease in isolation from the patient, with the disease taking centre stage. The biomedical model does not focus on the psychological impact that having an acute or chronic illness might have on patients. The insertion of a VAD is to allow treatment of an illness to be safely administered; it, then, becomes part of the illness rather than a separate part of the treatment. Because of this, the device often becomes a less crucial factor in the illness scenario.

The biopsychological model is an alternative to the biomedical model, and claims that the body does not function in a vacuum. In contrast, it recognises that psychological and social factors also influence the perceptions and actions, and, therefore, the experience of what it feels like to be ill (Wade and Halligan, 2004). The biopsychological model holds that, if we do not look at the psychological impact of the condition, or the patient's attitudes that impact the management of the condition, then routine care from a purely biomedical perspective might constitute under-treatment. It could amount to treating the patient without acknowledging the bigger picture. In the field of vascular access, because the device is viewed as necessary to enable treatment, the impact of it on the patient is not considered in the full clinical picture.

This would not be the case in the biopsychological model where the mind and body are closely related. Instead, we would begin to reconsider visible devices which can result in perceived stigma and issues with self-image, as highlighted in this study.

The phenomenological distinction between the living body and the lived body is necessary to understand our pre-reflective connection with the world. The living body is the image one has of a body, it is an object of perception. However, the lived body is what our body, in the world, allows us to sense and to do (Laroche, Berardi and Brangier, 2014). According to Thompson, (2004), bodily self-consciousness is required if we want our experiences to be and feel ‘for us’. It is also the point from which we see, do, and live. The lived body is, therefore, constantly reformed by the constant activity of the living body. The living and lived body co-constitute one another, and this is what defines embodiment (Thompson and Varela, 2001).

When considering body image, Bolton, Lobben and Stern (2010) ask us to remember the often-used phrases: *beauty is in the eye of the beholder*, *beauty is only skin deep*, and *never judge a book by its cover*. These phrases take on a different meaning when we focus on body image and its role in the mediation of reactions to physical conditions. The worth and beauty of the body has been highlighted with a rise of interest in appearance. This is evidenced in the focus of newspapers, magazines, and television on health and physical beauty (Monro and Huon, 2005). Television, advertisements, and print media have all become a dominant force in creating an idealised perception of female and male body image. These are often unrealistic goals (McCabe, Butler and Watt, 2007), which is further exaggerated by the explosion of social media (Fardouly *et al.*, 2015; Ghaznavi and Taylor, 2015; Burnette, Kwitowski and Mazzeo, 2017). The position of the body in popular culture reflects an individualisation of that body. Generally, people are concerned with the appearance of their bodies as an expression of their individual identity. It is my belief that this concern with bodily appearance does not change

because a patient has an illness, nor should it be expected that an individual's standards should fall due to illness and resulting treatment.

7.4.3 CONCLUSION OF PROCESS THREE AND ARTICULATION OF NEW KNOWLEDGE

A VAD alters the look and feel of the body for the length of time it is in place, which can be for many years. As cancer patients, the participants in this study may have already been facing body image issues resulting from reconstructive surgery or hair loss following chemotherapy or radiotherapy. The presence of a VAD also negatively affects body image and can lead to perceived stigma. It also takes away the right of patients to maintain a positive self-image. The experience of having a VAD inserted and the subsequent alteration of the body is a central consideration for this study. An important aspect of consciousness is the experience of the body as part of the self (Longo *et al.*, 2009). Furthermore, the experience that my body in all its parts belongs to me is equally fundamental. During daily interactions with elements of the outside world, a sense of body ownership is crucial. This study adds that, along with stigma, patients can experience fragmentation of the former self and a lowered self-value. This occurs no matter which device a patient has inserted.

7.5 PROCESS FOUR: LIVING WITH FEAR AND DISTRUST

This title refers to the experience of participants realising that not all HCPs were able to use their device. The subtitles that make up the discussions in this section are:

- Device complications
- Variations in practice
- A loss of trust and the need to protect self

In the current study, participants experienced dismay when some practitioners were unable to use their VAD. This led to feelings of distrust in healthcare professionals. Participants either voiced their fears and concerns to the practitioner, refused the practitioner access to their devices, resorted to self-care, or had to revert to having treatment delivered through peripheral veins.

This is in line with findings from Ritchie *et al.* (2015, p. 411), who described patients taking a *'defensive stance'* when approached by healthcare professionals who did not appear competent. This was an act of self-preservation as there was a fear that devices may become infected. Similarly, Alpenberg, Joelsson and Rosengren (2015) found that patients described feelings of insecurity and concern about potential complications resulting from the incompetence of staff caring for their devices. Mutti *et al.* (2016) also highlighted a lack of competence of staff managing TIVADs. Participants in this study discussed the need for trust in the competence of HCPs. Concurring, Oakley, Wright and Ream (2000) demonstrated the importance of ongoing training in the care of patients with VADs.

In an attempt to protect themselves from harm, participants in the current study explained how they stopped practitioners from accessing their devices if they felt they were not competent.

*'He was in the hospital with a chest infection and he wouldn't let the doctors touch it.
... He said you can't touch it unless you're qualified'* (Wife of John, TIVAD).

It is understandable that patients feel concerned about device complications arising from poor care and management. Device complications are real and, unfortunately, quite common (Moureau, 2013).

7.5.1 DEVICE COMPLICATIONS

Although VADs have many advantages, the burden of harm associated with them is significant (Napalkov *et al.*, 2013). Complications can occur in all devices and are a significant burden on healthcare. Complications can be encountered either on insertion or post-insertion, and can be operator or patient-related (Ge *et al.*, 2012; Coady *et al.*, 2015; Takashima *et al.*, 2018). Complications include failure to cannulate; ecchymosis; haematoma; vaso-vagal reaction; syncope; nerve injury; arterial puncture; mechanical, chemical, and infective phlebitis; infiltration; extravasation; and infection (Ray-Barruel *et al.*, 2013). Although some of these complications might be viewed as minor, according to Zhang *et al.* (2016), there is potential for significant economic consequences as a result of catheter-related bloodstream infections (CR-BSIs).

Although decreasing in certain areas, CR-BSIs are a known cause of morbidity and mortality worldwide. The most recent national prevalence survey by the Health Protection Agency reported that the prevalence of bloodstream infections (BSIs) was 0.5%. This accounts for 7.3% of detected health-care-associated infections (HCAIs); 64% of BSIs occurred in patients with a VAD (H. P. Loveday *et al.*, 2014). The Institute of Healthcare Improvement warns that CR-BSIs are one of the most costly and deadly HCAIs across the globe (Bonfiglio *et al.*, 2010). Although the incidence of CR-BSIs has decreased in the past decade, the mortality rate remains high at 12 to 25% (Antoňáková Němčíková and Bednárovská, 2017). Therefore, CR-BSIs are recognised as a healthcare priority and should not be underestimated. Potential complications are discussed with patients prior to device insertion, meaning they are aware of the risks. In this study, the knowledge of potential infections caused patients to feel protective of their devices.

Devices can also malfunction. Goossens, Stas and Moons (2012) report malfunction rates in adult onco-haematology populations of between 0% and 47% of TCVCs. Additionally, they estimate that nurses spend an extra 27 to 29 minutes of troubleshooting problems due to malfunctions. As well as the increased costs resulting from extended hospital stays due to complications, the well-being of the patient in addition to the potential for morbidity and mortality should not be underestimated (Norn, Kruse and Kruse, 2005). This could be a reason for nursing staff refusing to work with devices, especially if they are unfamiliar with them or uncertain about how they function. Participants in this study did not understand this consideration.

Most post-insertion complications are attributed to poor care and maintenance practices. According to Ullman *et al.* (2016), many such complications and failures are preventable. Broadhurst, Moureau and Ullman (2016) agree and claim that the prevention of complications is possible with appropriate evidence-based practices. Therefore, to reduce or prevent complications, HCPs dealing with VADs must possess the knowledge and skills to manage them safely. Unfortunately, it is often decided at a local level what specific training and education are required. As a result, many HCPs do not routinely receive education and training for VAD care and maintenance (Kelly, Green and Hainey, 2015).

The presence of a VAD immediately places patients at risk of complications and, thus, inspires the need to defend themselves. Every time the device is accessed, there is a risk of infection (Loveday *et al.*, 2014). This is particularly relevant for cancer patients, whose immune systems are often compromised due to chemotherapy (Galloway and Bodenham, 2004). Therefore, to reduce the risk of complications, morbidity, and mortality, practitioners who manage VADs need to be educated about potential complications and skilled in the strategies and methods necessary to reduce them (Frasca, Dahyot-Fizelier and Mimosz, 2010; O'Grady *et al.*, 2011; Moureau, 2013; Loveday *et al.*, 2014).

7.5.2 VARIATIONS IN PRACTICE

In addition to a lack of staff competence, participants in this study described variations in practice. Findings suggested a lack of standardisation in guidance for VAD care and maintenance across the community and in-patient settings. The National Health Service (NHS) Alliance recognises that there is a negative effect if care is varied. They have committed to training HCPs, managers, commissioners, and providers to deliver patient care that is excellent (NHS Alliance, 2016). In addition, it states that individuals working in the NHS should take responsibility for reducing clinical variation while ensuring quality and safety. Variations in practice could be a result of variation in practitioners' guidelines. Hainey, Green and Kelly (2017) explored the experiences of nurses caring for patients with VADs using a survey consisting of a self-completion questionnaire and open-ended questions. Nurses in this study described variations in guidelines which led to variations in practice. This occurred because the patients they cared for attended the specialist cancer hospital for treatment as well as device care and maintenance procedures. They then returned to their local hospitals, which were often in a different health board area. Nurses reported that hospital settings had different guidelines than community settings. This resulted in variations in practices. Although nurses became accustomed to their own practices, patients recognised variations and, as reported in this study by Tina, did not understand why this is the case.

Over the past few decades, there have been many scientific advances in technology and techniques in the field of vascular access (Pieger-Mooney, 2005). In addition to advances in insertion techniques, which include the use of ultrasound guidance (Maecken and Grau, 2007; Simon and Saad, 2012) and the use of electrocardiography to determine catheter tip position (Kupka and Lovejoy, 2011; Gibault, Desruennes and Bourgain, 2015; Pittiruti, 2015), advances in techniques and technology for the post-insertion management of VADs have erupted. These

advances include the use of needle-free devices, securement devices, and antiseptic caps, as well as chlorhexidine-impregnated discs and dressings (Ullman *et al.*, 2016; Apata *et al.*, 2017; Kelly, Jones and Kirkham, 2017). The availability of these innovative technologies has led to a selection of products from which practitioners may choose. This has, in turn, led to variations in products and practices across patient settings (Chopra *et al.*, 2017). Patients in the current study offered an insight into practice variations, which echoes and builds on findings from previous research into this subject.

Although some variation in clinical practice is justified, unwarranted variation remains common. According to Corallo *et al.* (2014), unwarranted variations are those that are not based on illness, patient risk factors, or patient preference. In the case of caring for and maintaining VADs, variation in practice is often unwarranted given that all devices, once inserted, can be maintained in a standard fashion (Denton, 2016; Gorski, 2016). Unwarranted variation is associated with suboptimal outcomes and increased costs (Wennberg, 2011).

One method for reducing practice variation is with the use of clinical practice guidelines (Woolf *et al.*, 1999). Grytten, Monkerud and Sørensen (2016) agree that the most common measure for reducing practice variation is the use of practice guidelines. Typically, guidelines are based on systematic reviews of available evidence and effectiveness of interventions. Guidelines are created with the intention of reducing unwarranted variations and to ensure that the highest quality of care is delivered. Furthermore, guidelines should empower HCPs to deliver evidence-based healthcare. Several authors (O'Grady *et al.*, 2002; McGee and Gould, 2003; Gorski, 2016) agree that continuous updating of vascular access care guidelines is necessary to help reduce device-related complications. Finally, the introduction of guidelines into practice provides a mechanism by which HCPs can be made accountable for the clinical activities they deliver (Woolf *et al.*, 1999).

According to Patel *et al.* (2015) and Arts *et al.* (2016), guidelines are often met with resistance and non-adherence. Moreover, national (external) guidelines are often adapted for local use. These become internal guidelines, which is often where variations in practice begin. There are many guidelines available for vascular access care, and it is from these that HCPs can build their local guidelines (O’Grady *et al.*, 2011; Loveday *et al.*, 2014; Bodenham *et al.*, 2016; Denton, 2016; Gorski, 2016). Internal guidelines often require fewer resources and, according to Thomas (1999), these guidelines are more likely to be adopted because individuals feel more ownership of them. Resistance to guidelines is recognised and attributed to decreased autonomy, oversimplification, and uncertainty in the evidence base (Carlsen, Glenton and Pope, 2007; Cabana, 2008). Although similar in content, when consulted and redeveloped into local guidelines for practice, the result is a selection of different guidelines to which practitioners may adhere.

Although the care of VADs could be standardised nationally or even internationally, this is, bizarrely, not the case. It makes sense that HCPs should strive to achieve standardisation and reduce variation, which could ultimately improve patients’ experience.

7.5.3 A LOSS OF TRUST AND THE NEED TO PROTECT SELF

The issues of staff competence and practice variation result in patients losing trust in those caring for devices. In fact, participants in this study often made the decision to look after their own devices rather than to risk putting their trust in a practitioner who appeared to lack knowledge. This was done in order to protect themselves from potential harm.

It is recognised that there is a growing focus on patient-centred care within the global healthcare system. Engendering personal accountability and ownership of health issues coheres with the current policy drive towards self-care and management (Calderwood, 2017). Nevertheless, self-care should be planned in collaboration with patients and not born out of necessity.

According to Rolfe *et al.* (2014), trust is a fundamental part of a patient-doctor relationship. This relationship is one in which caring and healing can occur (Hall *et al.*, 2002). Trust has been characterised as a multi-layered concept which consists of a cognitive element and an affective dimension (Gambetta, 1988; Rolfe *et al.*, 2014). It is essentially a psychological state and voluntary action that is based on the expectations of how others will treat you (Luhmann, 2000). Trust can vary in quality and quantity. It has been divided into *thick* trust, which is associated with close family relationships, and *thin* trust, which is associated with more casual relationships (Oberle, 2016).

McKnight and Chervany (2000) claim that there are three main constructions of the concept of trust:

- Personal trust
- Interpersonal trust
- Impersonal trust

Interpersonal trust relates to the vulnerability associated with being ill and is, therefore, associated with the study findings herein. As suggested by Hall *et al.* (2001) and Coulson (1998), being ill places individuals in a vulnerable position, meaning that trust in the context of medical setting holds a strong emotional element. In this setting, trust is associated with adherence to treatment and increased levels of satisfaction (Jin *et al.*, 2008). Moreover, Luhmann (2000) argues that trust is necessary as it increases tolerance of uncertainty. This could be linked to the uncertainty of periods of ill health or hospitalisation. In the context of this study, trust was related to the knowledge and competence of staff responsible for caring for participants' devices.

Hall *et al.* (2002, p. 615) characterise trust as '*the optimistic acceptance of a vulnerable situation in which the trustor believes the trustee will care for their interest*'. Jones and George (1998) add that trust is necessary where there is an element of uncertainty and risk. This is so regardless of whether the risk is low, moderate, or high, and stems from the individual's uncertainty of the motives, intentions, and future actions of another on whom the individual is dependent (Mishra, 2012). Such necessity of trust is important in the context of this study as there is a risk associated with the competence and intentions of the practitioner on whom the participants were reliant.

7.5.4 SUMMARY OF PROCESS FOUR: LIVING WITH FEAR AND DISTRUST AND ARTICULATION OF NEW KNOWLEDGE

This study supports previous literature that claims patients experience a lack of staff competence around the use and care of VADs (Oakley, Wright and Ream, 2000; Alpenberg, Joelsson and Rosengren, 2015; Ritchie, *et al.*, 2015; Mutti *et al.*, 2016). This study adds that patients experience distrust and fear when an HCP appears incompetent or refuses to use a patient's devices. The reason for this is that patients with VADs are often aware of the potential complication of CR-BSIs and, subsequently, live with such fear while the device is in situ. In an attempt to protect themselves from potential device complications and subsequent harm, some participants in this study chose to care for devices themselves. Due to the inability of staff to use their devices, others found themselves in the unfortunate situation of a return to the violation of PVC insertions.

7.6 PROCESS FIVE: ACCEPTANCE AND EMBODIMENT

This title reflects the fact that patients in this study will eventually accept their devices. The subtitles that make up the discussions in this section are:

- Cognitive dissonance theory
- Free choice paradigm
- Hypocrisy paradigm

Patients in this study voiced acceptance of their devices despite resulting effects on the self. However, to not accept their device would mean looking for alternatives, which would either be a return to the procedure of repeated, painful PVC cannulation, or potentially no treatment whatsoever. Therefore, acceptance of the device and its resulting implications, even those that are negative, might be the only possible response. Patients with a cancer diagnosis and an array of other illnesses and diseases – such as infectious diseases, and cardiac and respiratory conditions – require treatment via a long-term VAD (Barr, Semple and Seaton, 2012; Toggweiler *et al.*, 2013; Vashi *et al.*, 2017; May *et al.*, 2018). Participants in this study all had cancer, which is a devastating diagnosis to face. According to Robb *et al.* (2014), the initial response and worries identified in patients diagnosed with cancer is fear, trauma, or death. On top of a diagnosis and subsequent treatment regimen, a VAD must often be inserted. This means living with a foreign object which is often left visible and external to the body. This could be considered unnatural. However, refusal of a long-term VAD, be it internally- or externally-sited, would result in repeated PVC insertion procedures.

It has long been accepted that physical health is closely related to emotional and mental health (Larson, 1978, Palmore and Luikart, 1972). When faced with illness, the ways in which patients cope with and accept their situation have been linked to outcomes (Kurpas *et al.*, 2013; Obieglo *et al.*, 2014; Reed *et al.*, 2016).

In psychology, acceptance is described as a person's assent to the reality of a situation, recognising a process or condition, or a negative or uncomfortable situation, with no attempt to change or protest it (Kurpas *et al.*, 2013).

In healthcare, emotional acceptance is an important emotional regulation process which involves a person's willingness to feel both positive and negative emotions, as well as to allow emotions to develop and dissipate without attempting to change, control, or reject them (Politi, Enright and Weihs, 2007). The acceptance of diagnosis, disease, and treatment has been studied by many (Kurpas *et al.*, 2013, Obieglo *et al.*, 2014; Reed *et al.*, 2016). These studies conclude that successful treatment depends on illness acceptance. In addition, patients who accept their illness are more eager to participate in and adhere to treatment (Kurpas *et al.*, 2013; Obieglo *et al.*, 2014). Such studies also suggest that an elevated level of acceptance, in turn, enhances self-reliance and self-esteem, and creates the capacity to cope with chronic disease and its treatments. More recently, Cybulski *et al.* (2017) found that illness acceptance resulted in a better quality of life and better mental adaptation to disease.

In addition to illness acceptance, emotional acceptance and emotional regulation have also been studied. Emotional regulation is a process by which individuals influence that they emotions they have, when they have them, how they experience those emotions, and how they are expressed (Gross, 1998). Emotional acceptance (EA) is a salient emotion and regulation process that involves a desire to feel equal amounts of positive and negative emotions. Emotions are allowed to develop and dissipate with no attempt to alter, restrict, or discard them (Politi, Enright and Weihs, 2007). Studies suggest that EA is associated with fewer depressive symptoms (Wang *et al.*, 2004) and lower distress (Jenson *et al.* 2014). Furthermore, Büssing, Mattessen and Muddle (2008) advise that disease acceptance should not be regarded as a coping style with fatalistic resignation, but as a complex and active process of dealing with

chronic disease. They add that acceptance of disease will result in a therapeutic coping process associated with a higher level of life satisfaction and overall quality of life.

People – such as those in this study – who were faced with illness, having previously been in good health, are forced to redefine themselves as someone who is ill. Without acceptance, they are less likely to respond to medical recommendations (Obieglo, 2016). Acceptance can be used to resolve situations in which a person feels disturbed by a person, place, thing, or situation. Having to live with a foreign object, such as a VAD, in one's body could be considered disturbing and unnatural. However, in order to receive lifesaving treatment, it is something that one must eventually accept.

Patients in this study explained that, following an initial period of adjustment, they learned to accept and adapt to life with their VAD. They often forgot that it was there and felt that it became part of them. This would suggest that the devices became embodied. An extract from Ruby captures this:

'I don't feel it's there at all, it's almost like it's not.... It's part of me now' (Recall – Ruby, TCVC, Chapter five)

Previous studies describe that patients will eventually adapt to and accept their VAD. This has been highlighted in studies on TIVADs (Ignatov *et al.*, 2009; Nagel *et al.*, 2012; Minichsdorfer *et al.*, 2016; Mutti *et al.*, 2016) and PICCs (Gabriel *et al.*, 2000; Oakley, Wright and Ream, 2000; Sharp *et al.*, 2014; Parás-Bravo *et al.*, 2018). These studies all demonstrated patients' eventual acceptance of VADs. Participants in these studies viewed their VADs as a solution to difficult venous access problems and as an improvement on their quality of life. Molloy, Smith and Aitchison (2008) concluded that the positive aspects of having treatment through a PICC outweighed any negatives, and that patients felt they had adapted to and accepted their device.

This thesis argues that device acceptance may be associated with cognitive dissonance theory (CDT).

7.6.1 COGNITIVE DISSONANCE THEORY (CDT)

CDT is among *'the most influential and extensively studied theories in social psychology'* (Alfnes, Yue and Jensen, 2010, p. 147). Festinger's (1962) theory of CDT describes the notion of rebalance. Cognitive dissonance (CD) occurs when events or information conflict with existing attitudes, beliefs, or behaviours, which, in turn, leads to feelings of discomfort. To reduce this discomfort, there needs to be an alteration in one of these attitudes, beliefs, or behaviours, leading to balance and the restoration of harmony. According to Ent and Gerend (2016), individuals are motivated to resolve conflicting cognitions, particularly when such cognitions involve the self. According to CDT, three ways in which dissonance can be lessened are:

- Individuals changing one or more of their attitudes to make the relationship between the conflicts faced a consonant one
- Gaining additional information
- Reducing the importance of the cognitions

There have been some revisions of CDT, such as self-consistency (Aronson, 2004) and self-affirmation (Steele, 1988), and research and conceptual development of the theory continues at full force (Chapanis and Chapanis, 2018). Since being described in the 1960s, many authors have examined CDT, leading to an extensive body of literature (Naughton, Eborall and Sutton, 2013; Fotuhi *et al.*, 2013; Chammat *et al.*, 2017). The abstract way in which CDT was described meant it could be applied to an array of issues (Dillard and Pfau, 2002), which has resulted in the longevity of the theory. It is clear that cognitive dissonance can affect people's health-related attitudes and behaviours; however, McLeod (2014) is sceptical about this theory and

argues that as it is not possible to physically observe cognitive dissonance, and, therefore, we are subsequently unable to objectively measure it. The term cognitive dissonance could, thus, be considered subjective. Despite this, cognitive dissonance appears to offer a consistent theoretical explanation for the patient's experience of VADs.

7.6.2 FREE CHOICE PARADIGM

Free choice, also known as '*spreading of the alternatives*' (Harmon-Jones, 2012, p. 101), is one of the paradigms of CDT. This paradigm purports that dissonance might be aroused once a decision is made, such as when a patient decides to have a certain type of VAD inserted. Once the decision is confirmed, each of the negative aspects of the rejected alternatives (the other devices) becomes dissonant with the decision. In contrast, each of the positive aspects of the selected alternative is consonant with the decision. Post-decision, dissonance can be reduced by subtracting any negative aspects of the chosen alternative (the device a patient has in situ) or by subtracting the positive aspects of the rejected alternative (the other devices). Alternatively, dissonance can be reduced by adding positive aspects of the chosen alternative (their device) or negative aspects of the rejected alternative (other devices). Therefore, dissonance can be reduced by viewing the chosen alternative as more desirable and the alternative as less desirable (Harmon-Jones, Harmon-Jones and Levy, 2015). The alternative to any long-term VAD is often repeated, painful PVC insertions, which we now know can be traumatic for patients. This paradigm was also evident when patients discussed the other VADs they knew were available. Participants in this study were exposed to other patients receiving chemotherapy via different devices and, therefore, had knowledge of the various device options for treatment delivery. Participants spoke ardently and fondly about their devices. They placed their devices on a pedestal and believed their chosen devices were superior to the others of which they were aware.

In an attempt to reduce the extent of their dissonance, participants increased the attractiveness of the device they had while decreasing the attractiveness of other devices. This is a unique finding that has not been described in previous studies exploring experiences of living with a VAD.

7.6.3 HYPOCRISY PARADIGM

Another paradigm developed to test CDT is the hypocrisy paradigm (Aronson, Fried and Stone, 1991). This suggests that people are encouraged to make a statement that is consistent with the public attitude. Subsequently, they are reminded of situations where they failed to act within this accord. Simply put, people are induced to say one thing whilst acting against this; they do not '*practice what they preach*' (Dillard and Pfau, 2002, p. 101). Such a paradigm was evident in this thesis when participants stated strongly that they accepted their devices in their initial statements. However, they subsequently discussed many negative aspects of those devices. Stone, Adler and Cohen (1979) demonstrated that individuals reduce dissonance by acting in accordance with their pro-attitudinal statement, or by changing their attitudes to be more consistent with past behaviour, depending on whether recent speech or prior behaviour are more resistant to change.

Participants in this study all had cancer, which is a devastating situation to face. According to Robb *et al.* (2014), one of the initial responses identified in patients diagnosed with cancer is fear. On top of a diagnosis and subsequent treatment regimen, a VAD often must be inserted. CDT would predict that the patients would turn a negative (having a long-term device inserted into the body) into a positive. This is done to achieve consonance and to focus on the positive aspects of the device rather than the negatives.

Therefore, although previous research concludes that devices are accepted, this study highlights that CDT might play a part in this acceptance and embodiment. The impact of the VAD on the

self should not be ignored. CDT would suggest that patients have little alternative but to accept an altered life with a VAD and will alter their behaviours to allow acceptance. Strategies should still be explored that would improve the lives of patients with VADs.

7.7 SUMMARY OF PROCESS FIVE: ACCEPTANCE AND EMBODIEMENT AND ARTICULATION OF NEW KNOWLEDGE

The findings in this section concur with previous study findings that demonstrate the acceptance of VADs by patients (Gabriel *et al.*, 2000; Chernecky, 2001; Goossens *et al.*, 2005). Most of the participants in this study compared their long-term devices with previous traumatic experiences of repeated peripheral cannulation. The decision to insert a long-term device was made because peripheral access was no longer possible. Therefore, the insertion of a long-term Vascular Access Device was a positive event and a better experience than what participants had endured previously. Therefore, this would have had an influence on the acceptability of the devices.

Patients with cancer who require chemotherapy treatment via an intravenous route are facing a situation which can be devastating. On top of a diagnosis and subsequent treatment regimen, the patient has another issue to face: vascular access. This is clearly an additional stress, and yet, as discussed, the participants in this study seemed to display not only an acceptance, but an attachment to the device that they had been given. Festinger's (1962) theory predicts that patients would turn a negative into a positive to achieve consonance. The use of CD to explain device acceptance is novel and one that should be explored in future studies.

7.8 SUMMARY OF DISCUSSIONS

The purpose of this study was to develop an understanding of the lived experience of vascular access, in particular, the impact on individuals' sense of self. The use of IPA allowed the participants to reflect deeply on their experiences and constructed narratives around those experiences. These narratives helped to communicate how participants made sense of their experience of living with their devices. My study adds to the body of existing knowledge by supporting previous literature and developing an understanding of life with a VAD. It demonstrates that the experience of living with a VAD involves a number of processes which affects the psychological, social and personal self as well as impacting on self-esteem and self-image.

Advancements in technology have enabled the delivery of medications into the venous system via a variety of devices. The most common method is through the peripheral veins. For patients receiving chemotherapy, over time, due to endothelium damage, peripheral veins can become challenging to access. In attempts to provide the treatment necessary it often takes several attempts to gain peripheral venous access. Subsequently, patients can experience painful, distressing and traumatic episodes of challenging venous access which leaves them feeling violated.

These episodes are not recorded as complications nor are they regularly documented as adverse events. Patients are reluctant to complain about peripheral venous access attempts or about the repeated episodes of pain experience at the time. Rather, because they know that access is crucial to their treatment and health, they tend to grim and bear it. However, from this study, it appears that the memories of the repeated, painful cannulations remain with the patients long after the events. This demonstrates the effect that this has on them and their experience.

Eventually, when peripheral venous access is no longer possible, a long – term VAD becomes necessary. Longer term VADs allow medication to be delivered directly into the central system, thus avoiding damage to the small peripheral veins. The requirement for repeated exchanges of devices is no longer a necessity because these devices can remain in situ for the length of treatment. Therefore, when inserted, patients experienced feelings of relief that painful peripheral cannulation would cease. However, this relief was soon replaced with the realisation that their bodies and lives were altered due to the VAD presence. Two of the devices exit the body and therefore change the body schema which can lead to issues with image management and the fear of stigma. It could be suggested that the insertion of a VAD does not consider the mind of the person and only to physical body.

In addition, the presence of these devices restricts patients from undertaking activities of day living such as showering and bathing. Patients are also asked to refrain from activities such as swimming and golf. The remaining device, although implanted under the skin still results in cosmetic issues for patients and can restrict patients from participating in certain contact sports and activities. It is known that continuing to participate in activities when unwell has a positive effect on mental health and to take these away from patients, particularly at the end of life, seems unfair and unacceptable. This thesis argues that the insertion of a VAD results in restrictions and limitations to life and can lead to a lowered self-image and a lack of self-control.

Finally, due to a lack of a lack of knowledge, understanding and training, staff working with VADs are often unable or unsure of how to use them. This can lead to a return to the violation and pain of peripheral venous cannulation for patients. If the long term VAD is used, this is often done without following guidance and evidence-based practice. Because the VAD is necessary for treatment delivery, patients embody the device and become protective of it. They fear potential device malfunction or infection which would potentially lead to device removal

and delays in treatment. Subsequently patients experienced anxiety when their device is accessed by an inexperienced HCP. This thesis argues that due to lack of knowledge, patients experience distrust and fear whilst the device is in place.

Despite these issues, VADs are accepted by patients and are eventually embodied. CDT offers an explanation to this. Because the long – term VAD is necessary, patients have no choice but to accept them the restrictions and anxiety that come with them. They focus on the positives and accept the negatives of their devices.

The findings of the current study led to a conceptual framework named the vicious cycle of vascular access. The conceptual framework highlights the concepts of a self under attack; being rescued, being robbed; a mechanism of self-defence; distrust and fear; and acceptance and embodiment. This thesis argues for the understanding of the lived experience of vascular access to be understood through this proposed framework. The conceptual framework was developed following an in-depth analysis of the study data and contextualised within the existing literature. As such, this makes an original contribution to knowledge and understanding of how patients experience life with a VAD. Findings from this study have led to a better understanding of how the presence of a VAD in the body impacts on the self. CDT offers a novel explanation for patient voicing device acceptance.

The thesis argues that the vicious cycle of vascular access can be broken. When the decision is made to insert a long- term VAD, both the body and mind should be considered. Steps should be taken to improve the lives of people living with a VAD through improved education and training for HCPs and by adequately supporting people with VAD.

This chapter has presented an in-depth discussion of the study findings. The following chapter will offer implications and recommendations for practice. In addition, the strengths and

limitations of the study and dissemination strategies will be described. Recommendations for future research will be presented. Finally, a reflection of the study will conclude this thesis.

CHAPTER EIGHT: IMPLICATIONS AND RECOMMENDATIONS

8.1 INTRODUCTION

This thesis has explored the experience of living with a VAD. The purpose of the study was to develop an understanding of how individuals experience life with a VAD in situ. It claims that a VAD affects the psychological, social, and personal self, and impacts on self-esteem and self-image. The insertion of a VAD results in restrictions and limitations to life and can lead to distrust and fear whilst the device is in place. Despite this, VADs are accepted by patients and eventually embodied.

According to Helman (1995), patient education in chronic disease should always take into account the many maps (individual, cultural, and medical) that patients have of their own bodies, in health and in disease. As suggested by Helman (1995), clinicians should become explorers, and work with patients and their families to understand their perception of body and self and whether these perceptions are compatible with medical interventions. The findings of this study have provided an insight into the deep-rooted feelings and emotions of patients living with a VAD, and such findings will allow a more sophisticated approach to care.

This thesis describes the conceptual framework of the Vicious Cycle of Vascular Access. Although it is acknowledged that the proposed conceptual framework requires further exploration and refinement, it is the first to consider the experiences of patients living with a VAD. The framework is, therefore, a starting point and can be used to educate both patients and HCPs in the future.

The implications and recommendations arising from this study are intended to provide some guidance to support practitioners inserting and caring for the devices, as well as to improve the vascular access journey for patients. From the research findings, I propose several

recommendations that are relevant to a proposed proactive and patient-centred approach to vascular access. The recommendations offered are related to the following issues:

- Methods to alleviate the pain of cannulation
- Supporting patients requiring long-term vascular access
- Increasing staff knowledge and competence
- Strategies to reduce device visibility

8.2 METHODS TO ALLEVIATE THE PAIN OF CANNULATION

The first issue to consider is the trauma experienced by patients due to repeated, peripheral venous access. My study suggests that other available methods to reduce the pain of peripheral venous cannulation should be considered. More importantly, early insertion of a long-term VAD should be considered when indicated.

This study has highlighted that the pain and trauma associated with the procedure of PVC insertion has an effect on patients' self-esteem. Therefore, it is recommended that as soon as HCPs recognise that treatment is likely to be extensive, the decision to insert a long-term VAD should be promptly made. It is recognised, however, that, due to clinical and economic factors including an under-resourced and overstretched health service, short-term devices are often still used despite long-term devices being indicated (Al-Balas *et al.*, 2017). This practice results in repeated device exchanges to complete a course of treatment.

As a result of the pain and trauma associated with this practice, methods to minimise the pain of PVC insertion should be employed. Numerous strategies exist which should be considered to improve the patient experience. One of these is the use of topical or local anaesthesia (LA). In their systematic review of 37 primary research studies using 17 types of anaesthetic, Bond *et al.* (2015) concluded that the pain of applying any type of LA is less than the pain of

cannulation with LA. Similarly, the findings of a Cochrane systematic review of nine studies suggested that the use of vapocollant spray reduces the pain of device insertion (Griffith *et al.*, 2016). Most of the studies that included aspects of patient satisfaction found that patients would choose to utilise these pain reduction methods again (Griffith *et al.*, 2016). As suggested earlier in this thesis, pain is an unreported and often-accepted ‘complication’ of vascular access. However, as can be seen in this study, the impact that this has on a patient’s sense of agency and self-esteem should not be underestimated. Such pain should be acknowledged and addressed as an aspect of vascular access that should no longer be ‘the norm’. Instead, strategies should be used to ensure that patients are not traumatised due to poor venous health.

The term DIVA (Difficult Intravenous Access) has recently been used to describe patients with veins that are non-palpable and non-visible (Yen, Riegert and Gorelick, 2008; Riker *et al.*, 2011; O’Neill, Dillane and Hanipah, 2012; Sou *et al.*, 2017). Protocols have been developed to make the vascular access journeys of these patients easier and less traumatic (Carr *et al.*, 2013; Loon *et al.*, 2016; Pagnutti *et al.*, 2016; Sou *et al.*, 2017). It should be ensured that all clinical facilities where peripheral cannulas are inserted have a DIVA tool available as this could reduce these preventable experiences. At the moment, the most common method for selecting a vein for cannulation is through palpation (Phillips, Collins and Dougherty, 2011). However, the use of ultrasound guidance or vein visualisation technology provide alternative methods for finding appropriate veins, and are now considered for peripheral cannulation as well as central vein cannulation (Troianos *et al.*, 2011; Denadai *et al.*, 2015; Stolz *et al.*, 2015; van Loon *et al.*, 2018). This thesis argues that it is necessary to increase the first-time success of peripheral cannulation. The use of vein visualisation, rather than blind, landmark techniques, should be used routinely. This will improve the patient experience.

8.3 SUPPORTING PATIENTS REQUIRING A LONG-TERM VAD

This study highlights that patients generally accept and adapt to living with a VAD while receiving medical treatments. However, the study has also provided an insight into a process of emotional and physical change that is experienced before a device is accepted. To make this process seamless, patients require support, counselling, education, and adequate information before a long-term device is inserted. This is due to the impact of the device on the self. If patients are aware that they may undergo the stages of the conceptual framework described in this chapter, it may reassure them that it is a 'normal' process and so prepare them for their journey through life with a VAD.

Discussing the visibility of devices with patients prior to them being inserted and preparing those patients for how their devices will look once in place will allow them to mentally become accustomed to it. This could be done by giving patients photographic images of devices in situ, or by teaming patients up with a 'buddy' who has a device in place. A discussion around stigma, whether real or perceived, could allow patients to explore how they might feel about others seeing their device. Thinking about why they may conceal the device might encourage patients to review their thoughts and make them more comfortable living with their device without the fear of stigma.

At the moment, patient information focuses on the technical aspects of having a VAD. As a vascular access clinician, I have been involved in the development of patient information books and have reviewed many of these publications. These resources do not touch on how patients might feel about living with their device. Rather, the information within the publications focuses on device insertion and potential complications, which is echoed in the information discussed during the consent procedure.

Recently, I became a member of two Facebook sites for patients who live with a VAD. I was encouraged to join as a vascular access specialist and permission was granted by page

administrators. This has opened my eyes to the lack of information patients have before their devices are inserted. These pages seem to be where patients go to get support and information from one another. They learn from each other's experiences rather than from information given by HCPs prior to device insertion. Recently, a patient with a newly placed PICC asked the group 'can someone tell me how to live with my PICC?' This highlights that formal support for patients appears to be missing. People with VADs are seeking support from social media groups. It is recognised that advice and recommendations from these sources may not be evidence-based or reliable. However, they appear to be a necessary support source for patients. This suggests there is a need to provide patients with better information and more support to prepare them for a different life with a VAD before the device is inserted.

This study also demonstrated that the presence of certain VADs meant that patients were unable to continue with hobbies or to undertake tasks and activities that they wished. The patients in the study were all receiving treatment for cancer and some of them had a terminal diagnosis. It is tragic that such patients are denied the opportunity to continue to live their lives as a consequence of VAD insertion. A significant proportion of people within the health care system are in the last 100 days of their life. Therefore, they are the very people who have little time to waste. The shift is on to make patients central in the decision-making process. It is vital to understand what is truly important to those on the receiving end of medical care.

The sensitive and personal issues surrounding living life with a VAD should be brought to the fore. Patient information in a physical format should be available, which could be provided in the form of support groups or programmes for people living with a VAD, or the use of technology such as apps, websites, videos, and photographs. In order to enhance patient experience, psychological support should be readily available for people requiring the insertion of a long-term VAD.

8.4 INCREASING STAFF KNOWLEDGE AND COMPETENCE

This study has highlighted that patients with a VAD live with fear of device complications due to the lack of staff knowledge and competence, which leads to a distrust of HCPs looking after their devices. As more patients receive long-term VADs, we should ensure that training and education in the care and maintenance of these devices is available. We are aware that care, maintenance training, and education in the form of dedicated theoretical and practical workshops can improve the confidence and competence of staff (Kelly, Green and Hainey, 2015) and this is further strengthened when coupled with an eLearning element (Hainey, Green and Kelly, 2016). Initiatives such as these would ensure staff competence and, thus, increase outcomes and satisfaction for patients.

Finally, we should consider making education and training in VAD care and maintenance mandatory, which should be performed within pre-registration nursing and at medical schools. An alternative would be dedicated vascular access teams who could provide the necessary care and training (Moureau, 2019).

Some participants in this study ended up caring for devices themselves. This could be seen as a positive step and one that could be considered to help improve the patient experience. Encouraging personal accountability and ownership of their devices is coherent with the present policy drive to increase self-care and management (Calderwood, 2017). It must be ensured that the decision to allow patients to care for their own devices is driven by collaboration and trust, rather than out of necessity. More importantly, training and support must be available for patients and careers to allow this initiative to both be achievable and remain safe.

8.5 STRATEGIES TO REDUCE DEVICE VISIBILITY

VADs are inserted by a variety of HCPs including nurses, radiographers, radiologists, anaesthetists, and surgeons. Despite being totally implanted, this study demonstrates that even TIVADs can be a source of stigma for patients due to the poor cosmetic results of the insertion procedure. This could be as a result of the placement site or suturing techniques. From my experience as a vascular access specialist and trainer, training on device insertion still has a focus on the VAD and not on surgical techniques (incisions and suturing). It should be ensured that any HCP who takes on the procedure of device insertion undergoes a course in surgical techniques. The input of a plastic surgeon, for instance, would help HCPs to consider alternative suturing techniques and so reduce post-procedure scarring, which would reduce potential stigma for patients.

Typically, TIVADs have been implanted in the chest. It is recognised that the placement of the ‘port’ can be situated in other areas. Recently TIVADs have been inserted in the upper arm or the trapezius area (Burbridge and Goyal, 2016; Hill, 2016), making them less visible. In addition, lower profile devices have become available for use. Discussions with patients about the most suitable place for the device should be part of the consent procedure. This would ensure patient involvement and could give the patient more ownership over their device.

8.6 SUMMARY OF RECOMMENDATIONS:

- The prompt insertion of a long-term VAD should be the goal because this will negate repeated and painful peripheral cannulation.
- Patient counselling, support, and involvement are required prior to device selection and during the time the device is in place.
- Training and education of staff about all aspects of VAD will increase patients' trust and reduce anxiety.
- There should be a consideration for the use of strategies to reduce device visibility.

8.7 REFLECTION ON STUDY

8.7.1 STUDY STRENGTHS

As far as is known, this is the first study to use IPA to research the lived experience of vascular access. This is a strength as it brings a new perspective to our current knowledge on the topic. This was also the first study to consider all three VADs (PICC, TCVC, and TIVAD). Therefore, convergent and divergent experiences of living with the different devices were able to be made. The use of one-to-one, face-to-face, in-depth interviews was a strength. This approach allowed the participants to tell their stories. Since participants were able to discuss what was important to them, rather than following a structured interview guide, their stories to reflect their experiences, hence ensuring idiography.

IPA allows for a robust analytic process. The analytic process has been explained throughout the thesis. Active engagement in the hermeneutic cycle helped to achieve the interpretation presented in this thesis, which was developed during the interview, analysis, and discussion elements of the research. Hermeneutic reflection resulted in a partnership of meaning.

I actively engaged in a dialogue with the data, meaning the findings could be viewed as subjective. In IPA, a researcher's position is as '*an instrument of the research*' (Pezalla, Pettigrew and Miller-Day, 2012, p. 167), and the research interview is seen as a conversation with a meaning (Smith, Flowers and Larkin, 2009). Subsequently, throughout this thesis, I adopted a meta-reflexive voice and highlighted sections in which my position has been important and possibly influential - one of which was the challenge of switching between the nurse and researcher role.

8.7.2 STUDY LIMITATIONS

The themes identified by my study may have been interpreted differently by other researchers. However, early analysis has laid the foundation for the development of a conceptual framework and offers new insight into the understanding of the lived experience of vascular access.

The participants in this study were recruited from a single centre and were all oncology patients receiving chemotherapy because oncology is one of the only specialities to use all three Vascular Access Devices. However, policies, practices, and care received in alternative centres might have been different, leading to different findings. Despite this, many of the findings of this study reflect findings from previous literature. This could suggest that these experiences are common for patients with VADs. Moreover, the method was consistent with the state of knowledge on the topic, and the evidence obtained allows for larger, hypothesis-driven studies.

Rather than a longitudinal study, this study included one set of participants who were interviewed on only one occasion. This could be viewed as a limitation. A longitudinal study was considered but I believed that if the right questions and prompts are used, in-depth data could be obtained and follow up interviews would therefore not be required.

Finally, there was no member checking performed with the participants. Therefore participants did not have the opportunity to clarify or expand on the data analysis performed. A survey was subsequently carried out however and this acted as a follow up to the study and provided a means to test the study findings and determine the study transferability.

8.7.3 CONTRIBUTION TO RESEARCH

This is the first known study to use IPA to explore the experience of living with a VAD and to compare experiences between devices. The suggestion that mind and body dualism still exists in this field has also come from this research. Although technical advancement means we can

extend the vascular system by the insertion of long-term VADs, we must consider the impact that this change in the body has for patients. The interpretive aspect of the approach allowed this study to stand apart from other similar studies. The interpreted meaning of participants' accounts has added a vital additional layer to our understanding of the phenomenon, which would not have been achieved if an alternative approach had been used.

This thesis has contributed to the existing body of knowledge on the lived experience of vascular access by the proposal of a new conceptual framework which articulates this experience. Such experience is not prescribed by pre-existing, theoretical preconceptions, but in its own terms. This is because IPA recognises human beings as sense-making organisms. The conceptual framework arose from my findings and is, therefore, defined in its own terms. Although CDT helped to explain one of the stages in the framework, it did not prescribe the model. I believe my thesis has added depth to previous understandings and, therefore, is my original contribution to the body of knowledge on the lived experiences of vascular access.

8.7.4 RECOMMENDATIONS FOR FUTURE RESEARCH

Research focusing on the effects of a VAD on close family members would be useful to obtain a greater understanding of the impact of these devices. Similarly, a study focusing on staff inserting VADs and those who care for them should be considered.

8.8 DISSEMINATION STRATEGY

I will disseminate the findings from this study in many formats.

I submitted a poster to the National Infusion and Vascular Access Society (NIVAS) and was awarded the prize for the best poster. I was invited to submit a short overview of my study to the *British Journal of Nursing*. This was subsequently published (Kelly, 2017).

I have published clinical papers focusing on vascular access issues. I was also invited to write two book chapters for a vascular access book (*Vessel, Health and Preservation, Moureau, 2019*). The authors were vascular access specialists from across the globe.

I have been delivering oral and poster presentations at meetings and conferences throughout my study. This has been on a local, national, and international basis, and includes NIVAS, UK; World Congress for Vascular Access (WoCoVA); Association for Vascular Access (AVA), USA; and the IV Forum of the Infection Prevention Society (IPS). During these conferences, I networked with delegates and received positive feedback about my findings. These interactions demonstrated that the study findings resonated with colleagues' experience.

Following my study, I wanted to explore whether my findings were echoed in the literature that had been published since I had undertaken my initial literature review. I chose to do this with the use of concurrent analysis (Snowden and Atkinson, 2012; Kelly and Snowden, 2020). (Appendix eleven). This concurrent analysis has since been written up and published in the *Nurse Researcher Journal* for publication.

8.9. FINAL PERSONAL REFLECTION

I began my research whilst working in academia. However, two years after commencing my study, I made the decision to change career path and take up a role as a clinical nurse advisor for a medical device company. I knew the company because it manufactured the VADs that I inserted whilst in practice. My job now involves teaching others to insert and care for the devices. This fits closely with both my interests and my study and means that I am able to spend time back in clinical areas across the country working with medical and nursing staff and, most importantly, patients. I am now in a great position to offer advice about product development and how the design can impact on patients who have to live with them.

The company I now work for is committed to the patients who receive their devices and, as a result of this, they offered to support and fund this study.

Working full-time whilst completing my PhD has required commitment and determination. I have learned that linking with others in similar situations helps with feelings of isolation. I have joined many online groups and forums which has helped me to remain focused and kept me on track.

During this study, as a vascular access specialist, I identified the potential for bringing my own knowledge, experience, and assumptions to the research. This could have brought an element of bias to the study. Although it is important for an IPA researcher to acknowledge their foreknowledge, I had to ensure that it was the participants' voices that were dominant. By adopting a phenomenological position of openness and setting aside any judgements about the accounts of the participants, I believe this bias has been limited. As a phenomenological researcher, my ontological stance of social constructionism has influenced data interpretation. I maintained a diary of reflexive notes which helped me explore my learning and development throughout the thesis.

During this period of study, I have gained valuable skills in project management, time management, and organisation. Personally, I have discovered that I have self-discipline and integrity. These attributes have further developed and have enabled me to persevere and reach the end of this project. Although I am not a perfectionist, I now understand the importance of attention to detail, and I have learned to always try to deliver work of high quality.

7.7.1 FINAL SUMMARY

This thesis has presented a robust analysis which explores the lived experience of vascular access. The use of IPA principles has provided a rich and in-depth analysis of this experience. Throughout this thesis, I have provided a reflexive commentary, which has highlighted my personal intellectual journey as a researcher.

The process I have experienced has been in-depth, complex, and challenging, and the intricacy of the research process has been highlighted. The discipline, dedication and determination required to complete this project has had a positive impact on me as a person. The skills I have developed will be honed, and I intend to continue developing as a researcher in the future.

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APPENDIX ONE: SEARCH STRATEGY EXAMPLE

The screenshot displays a search results page on EBSCOhost. The search query is "S6 AND (experience OR attitudes OR opinion OR view)". The results table lists several search terms and their corresponding options and actions.

Search ID#	Search Terms	Search Options	Actions
S7	S6 AND (experience OR attitudes OR opinion OR view)	Limiters - Date of Publication: 20000101-20131231; English Language; Age Related: All Adult: 19+ years Search modes - Boolean/Phrase	View Results (224) View Details Edit
S8	S4 not (renal or haemodialysis, dialysis or kidney)	Limiters - Date of Publication: 20000101-20131231; English Language; Age Related: All Adult: 19+ years Search modes - Boolean/Phrase	View Results (2,487) View Details Edit
S5	S4 not (renal or haemodialysis, dialysis or kidney)	Search modes - Boolean/Phrase	View Results (14,501) View Details Edit
S4	S1 OR S2 OR S3	Search modes - Boolean/Phrase	View Results (16,938) View Details Edit
S3	("Catheterization, peripheral central venous") OR (MH "peripherally inserted central catheter") OR PICC	Search modes - Boolean/Phrase	View Results (1,105) View Details Edit
S2	(MH "catheterization, central venous") OR tunneled central venous catheter OR TCVC OR tunneled catheter OR tunneled cuffed catheter OR Hickman catheter OR Broviac catheter	Search modes - Boolean/Phrase	View Results (14,998) View Details Edit
S1	(MH "vascular access devices") OR (MH "vascular access devices implantable") OR Portacath OR TIVAD or totally implanted port	Search modes - Boolean/Phrase	View Results (1,742) View Details Edit

Refine Results: Search Results: 1 - 10 of 177

APPENDIX TWO: CRITICAL APPRAISAL FRAMEWORK

Critical Appraisal Framework (Moule et al., 2003)

Introduction

Is there a clear statement about the topic being investigated?

Is there a clear rationale for the research?

Is there a clear statement about the limitations of the research?

The literature reviews

Do the researchers use contemporary materials about the topic being investigated?

Do the researchers link their work to a wider body of knowledge through the references cited?

Do the researchers link the topic to the questions about theory?

Is there a clear link between the literature and the formation of the research question(s)?

Is the research question clearly stated?

The Methods Section

Is the research design clearly described?

Are the research methods appropriate for the topic being investigated?

Are any advantages or disadvantages of the design acknowledged by the researchers?

Is there a clear statement about who participated in the research?

Is there a clear statement about how the participants were selected?

Is the selection of participants appropriate to the design?

Is there a clear statement about the number of people taking part in the research?

Data Collection and Analysis

Is there a clear description about how the data was collected?

Was the data collected by appropriate people?

Is the approach to data analysis appropriate to the type of data collected?

QUANTITATIVE

Is there any explanation of the sample size used?

Is the level of significance of the test (alpha) used indicated, or implied to be the customary 5%. If Pearson correlation coefficients are being calculated, is there any evidence of a check for a linear relationship?

If t-tests or analysis of variance (ANOVA) are to be performed, is there any evidence of check(s) to demonstrate that the data follows a normal distribution, or of assumptions made?

Are reasons / assumptions re the level of measurement of the data given? (This affects the appropriateness of the descriptive statistics given and the tests used).

Is there a clear statement describing how valid and reliable the measures are?

Are the types of statistical tests used appropriate for the sorts of data collected?

Is the use of any statistical analysis package, such as SPSS discussed?

Is there evidence of a statistician's input to the analysis?

QUALITATIVE

Is there a clear reflective statement about the researcher's role in the analysis?

Is the approach taken to data analysis clear?

Is the use of any electronic analysis package discussed?

Is there a clear statement about how the researcher validated interpretations?

Ethics

Is there a clear statement about ethical committee approval?

Is there a clear description about gaining consent, maintaining anonymity and or confidentiality?

The results / findings

Are the results related back to the literature review?

Are the weaknesses acknowledged?

Quantitative

Is the presentation of results clear and unambiguous?

Are all the results presented?

Do the tables and charts used give a clear picture of the sample data and results?

Are the charts used appropriate?

Are the tables easy to use?

If percentages are recorded, are actual numbers also clearly shown?

Are results of tests interpreted rightly?

Qualitative

Does the research present evidence of the data collected?

Does the data presented as part of the theme support the analysis suggested?

Is there a clear audit trail?

The conclusions

Are the implications for further research acknowledged?

Are areas for further research identified?

Are further recommendations made for practice that come from the results / discussion?

(Moule, P. Pontin, D. Gilchrist, M. Ingram, R. (2003) Critical appraisal framework)

APPENDIX THREE: EXPLANATIONS OF QUALITY APPRAISAL METHOD

1. Is the qualitative approach appropriate to answer the research question?

Explanations The qualitative approach used in a study (see non-exhaustive list on the left side of this table) should be appropriate for the research question and problem. For example, the use of a grounded theory approach should address the development of a theory and ethnography should study human cultures and societies. This criterion was considered important to add in the MMAT since there is only one category of criteria for qualitative studies (compared to three for quantitative studies).

2. Are the qualitative data collection methods adequate to address the research question?

Explanations This criterion is related to data collection method, including data sources (e.g., archives, documents), used to address the research question. To judge this criterion, consider whether the method of data collection (e.g., in depth interviews and/or group interviews, and/or observations) and the form of the data (e.g., tape recording, video material, diary, photo, and/or field notes) are adequate. Also, clear justifications are needed when data collection methods are modified during the study.

3. Are the findings adequately derived from the data?

Explanations This criterion is related to the data analysis used. Several data analysis methods have been developed and their use depends on the research question and qualitative approach. For example, open, axial and selective coding is often associated with grounded theory, and within- and cross-case analysis is often seen in case study.

4. Is the interpretation of results sufficiently substantiated by data?

Explanations The interpretation of results should be supported by the data collected. For example, the quotes provided to justify the themes should be adequate.

5. Is there coherence between qualitative data sources, collection, analysis and interpretation?

Explanations There should be clear links between data sources, collection, analysis and interpretation.



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1st April, 2015

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

Dear Linda

Outcome of School of Health Nursing and Midwifery Ethics Committee

Thank you for your recent submission to the above Committee.

I can confirm your submission was reviewed by the Committee, where the outcome has been:

- **APPROVED (subject to recommended amendments)**

This outcome requires you to refer to feedback, and address issues. There is no requirement to resubmit to the Committee.

Feedback from the Committee is attached for your information.

On behalf of the School Ethics Committee, I take this opportunity to wish you well with your study.

Yours sincerely



INVESTOR IN PEOPLE



Professor Austyn Snowden

Chair

School of Health Nursing & Midwifery Ethics Committee

cc Prof Austyn Snowden

Karen Wilson MSc, RGN, RM, DipDN, RNT

Dean of School

University of the West of Scotland is a registered Scottish charity, Charity number SC002520

APPENDIX FIVE: ETHICAL APPROVAL (NHSGGC)



WoSRES

West of Scotland Research Ethics
Service Mrs Linda J Kelly

Lecturer in Adult Health

University of the West of Scotland

Caird Building

Almada Street

Hamilton

ML3 0JB

Date

Direct line

Fax

e-mail

West of Scotland REC 4

Ground Floor, Tennent Building

Western Infirmary

38 Church Street

Glasgow

G11 6NT

www.nhsggc.org.uk

3 July 2015

0141-211-6270

0141-211-1847

Wosrec4@ggc.scot.nhs.uk

Dear Mrs Kelly **Study title:**

**The Experience of living with a Vascular Access
Device (A qualitative, phenomenological study)**

REC reference:

15/WS/0108

IRAS project ID:

168223

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by the by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Mrs Evelyn Jackson, wosrec4@ggc.scot.nhs.uk. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation, as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

	<i>Version</i>	<i>Date</i>
The final list of documents reviewed and approved by the Committee is as follows: <i>Document</i>		
Covering letter on headed paper [covering letter]	1	16 June 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance UWS]	1	25 August 2014
Interview schedules or topic guides for participants [Interview schedule]	One	14 May 2015
Interview schedules or topic guides for participants [Questionnaire]	One	14 May 2015
IRAS Checklist XML [Checklist_22062015]		22 June 2015
Letters of invitation to participant [Letter of Invitation]	2	14 June 2015
Participant consent form [Consent form]	2	14 June 2015
Participant information sheet (PIS) [Patient Information sheet]	2	14 June 2015
REC Application Form [REC_Form_14052015]		14 May 2015
Research protocol or project proposal [Protocol]	2	14 June 2015
Summary CV for Chief Investigator (CI) [CV]	One	14 May 2015
Summary CV for supervisor (student research) [Dr M Fleming's CV]	-	

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/WS/0108 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project.

Yours sincerely

For Dr Ken James

Vice-Chair

Enclosures: List of names and professions of members who were present at the meeting

“After ethical review – guidance for researchers”

Copy to:

Mrs Lorn MacKenzie, R&D, Tennent Building, Western Infirmary

APPENDIX SIX: PARTICIPANT INFORMATION SHEET



14th May 2015

Participant Information Sheet

Study title: The lived experience of patients with a long-term vascular access device

What is the purpose of the study? The purpose of this study is to explore patient's experiences of living with a long-term vascular access devices.

Why have I been chosen? You have been chosen because you have had a long-term vascular access device as part of your treatment.

What will happen if I take part in the study? If you agree to take part in this study, you will be invited to take part in an interview with the researcher. This will take approximately one hour. There will be a nurse available if you feel you require any support during the interviews.

What will happen during the interview? As well being asked questions about your vascular access device, you will be able to talk about any issues relating to living with the device in place.

What will happen to the information I give to you? This information will be used to gain an understanding of what it is like to live with a device. This will be done by using your own words and those of others who are taking part in the study. You will be given the chance to edit any quotations prior to the study being published or being made available to others. Although, your own words (direct quotations) used by you during the interviews may be used, you will not be identified by name if they are.

Anonymity / Confidentiality: Your anonymity will be ensured during the study. There will be no patient identifiable information on the data and therefore anonymity will be ensured. All documentation relating to the study will be stored securely in a locked cupboard with only the research team having access. All access to data will be password protected. You will not be identified in the final report and all data collected will be destroyed at the end of the study

Right to Withdraw: The decision to participate in this study is voluntary and you should not feel in any pressure to take part. If you chose to participate and then change your mind, you will be allowed to withdraw from the study at any time and this decision will have no negative effect on your care or treatment. Any data collected prior to your withdrawal from the study may still be used.

When do I need to decide? We would hope to have your decision with 72 hours. Feel free to discuss and seek advice about it from your friends and family.

Consent: If you agree to participate you will be asked to sign a consent form.

Benefits of taking part in the study: By taking part in this study you will help to inform patients who have to have a long-term device in in the future. You will also be providing vital information to healthcare professionals about the experience of living with a device.

Further information: If you require more information, please contact: The researcher: [redacted] or the CAVA champion at your hospital [redacted]
Complaints: If you have any issues or complaints about the study please contact the CAVA champion at the Beatson Oncology Centre [redacted]

APPENDIX SEVEN: CONSENT FORM



Consent form

Study Title

The lived experience of patients with a vascular access device

Methodology: A interpretive phenomenological study

Researcher: Linda J Kelly

Study purpose: To explore patient's experiences of living with a long - term vascular access device

Initial

1. I confirm that I have read and understand the information sheet
2. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily
3. I understand that I will be taking part in a one to one interview relating to my experience of having a vascular access device.
4. I understand that any of my quotes used as part of the study will remain anonymous, and that I will not be identified within the study.
5. All information that I disclose during the interviews will remain confidential.
6. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving my reason and with no detriment to my care.

This is to certify that I _____ hereby agree to participate as a volunteer in the study.

Participants' signature _____ Date _____

Research Supervisor _____

Signature _____ Date _____

When completed please return this form to: The researcher (Linda J Kelly) or the CAVA champion

APPENDIX EIGHT: INTERVIEW SCHEDULE

Opening: Rapport will be established with introductions. The purpose of the interview and information about how the responses to the questions will be used within the study will be reiterated. The issue of confidentiality and consent issues will also be clarified with the participant. The participant will be told the anticipated length of time of the interview, and it will be assured that they are available for the duration of the interview.

Recording: The participant will be reminded that the interview will be digitally recorded, and it will be clarified that they are comfortable with that.

Question One	Describe in as much detail as possible how it feels to have a long-term device in place for your treatment.
Question Two	Describe what the benefits of your device are?
Prompt	Probe: I will pick up on any emotional words used and ask the participant to further discuss (Funnelling probe) <ul style="list-style-type: none"> You said can you explain that to me in a bit more detail?
Question Three	Do you experience any feeling of anxiety when living with your device?
Prompt	Probe: I will pick up on any emotional words used and ask the participant to further discuss (Funnelling probe) <ul style="list-style-type: none"> You said can you explain that to me in a bit more detail?
Question Four	Does your device restrict you in any way?
Prompt	Probe: I will pick up on any emotional words used and ask the participant to further discuss (Funnelling probe) <ul style="list-style-type: none"> You said can you explain that to me in a bit more detail?
Question Five	Describe how you feel about your device when you are not receiving treatment.
Prompt	Probe: I will pick up on any emotional words used and ask the participant to further discuss (Funnelling probe) <ul style="list-style-type: none"> You said can you explain that to me in a bit more detail?
Question Six	Describe any aspects of living with the device that affected your day to day life in general?
Prompt	<ul style="list-style-type: none"> If they answer yes: Can you explain that in more detail?
Question Seven	How do you feel about other people seeing your device?
Prompt	<ul style="list-style-type: none"> If they answer yes: Can you explain that in more detail?
Question	Is there anything else that you would like to add that you think is important?

APPENDIX NINE: FULL SCRIPT

ID: RUBY

Date:

Venue

Interviewer will be identified as LJK

Participant will be identified as RUBY

This will be transcribed verbatim

LJK: OK, Um my name's Linda as I said and I'm doing my study on patients experiences of vascular access devices. Ah so I'm just going to ask you a couple of questions I've explained to you already that we will be recording this,

Ruby (ahum).

LJK: You've signed your consent form

RUBY: Yes

LJKL You're free to talk about whatever you want, if you feel uncomfortable at any point you can ask me to stop. Um, we should be here for about ½ hour 45 mins but if you feel you want to leave or take a break just let me know. Is that OK?

RUBY: Yeah

LJK:OK we'll just I've got a sheet of paper here, I'm going to work my way round. To start off I just want you to give me an idea of how you got to where you are, um why your device is in and um, we'll take it from there. You just tell me...

RUBY: Well, I think um (hesitant) Once I was diagnosed um we know there was going to be an awful lot of blood testing, bloods for this, bloods for that and over the past 11. 12 years since my last – my cancer treatment and reconstruction, the right hand side of my body is not to be used for taking the samples or anything particularly my right hand, my right arm. Um, so while I was going through he first part of the um treatment going through my first half of my appointments at at Gartnavel and the Beatson we knew we were going to have problems because every time I needed to have bloods sample it took 2 or 3 people to get, to get the

vein to take the blood. And after 2 or 3 of those (the last one I had done.) we took .. my hand we couldn't find any veins in my, in my arm, every time she found a vein it just collapsed. It took um, I think, um, it took 9 – 3 people 2 goes each – how many's that... 2,4,6! 6 pin holes in my arm before they decided to try and take it from my hand with a much smaller (I don't know what you do) a tube? Tube isn't it? yeah a smaller tube and it just popped right back out. She found a vein and as soon as she started putting the fluid in it just popped out and um at that point I just said ah, listen you can use my right arm because um you know you're not just gonna have any luck on my left. (Laughing) and I feel like, like you're stabbing me to death (laughs).

And um I gave them permission for my right arm um and the nurse that was doing um said that yeah there is a protocol in place for um for that when you can't find anything on the left then you go to the other or visa versa, whatever. Anyway they went into the right arm and blood came out first time. Perfect. And at that point I took advice on what to do for further um um further uses for taking bloods or putting things into me and um we came up (we decided) we decided we might look at the PICC line but that wasn't suitable because, every vein in my arm was collapsing. And um the next um um um or suitable way (to to) for my blood to come out or for things to go in would be the Hickman. Which goes in just below your neck and that was the perfect one for me.

LJK: OK, so we know now why you have your device in, do you remember how long it's been in – roughly about?

RUBY: Well, it went in on the 8th of June um, my chemo started on the 15th.... No it wasn't the 8th it was the 10th it was moves. So It was the 10th of June and the chemo was supposed to start on the 15th (did it?) my memory's not to good.

LJK: No so roughly about 8 weeks or something? 2 months

RUBY: yes yes

LJK: So how have you found, generally how have you felt having the device in place, um, how has it been? In your own words - how's it been? Living with the Hickman?

RUBY: (overlap) living with the Hickman. Umm, it took a bit of getting used to of course I mean you've got a big white tuby wire going into your chest um but it was more just getting used to the initial having that having that in you and on you um, I mean the day after having the Hickman put it was, it was, still quite painful um if you looked at – I took a picture actually the

day after and you can see that it's quite ah bloody and it looks (Coughs) kinda looks horrible and it was throbbing and a bit painful of course but within about a week um it had really tidied up as it were and it settle beautifully and now it's a, I don't feel it's there at all (emphasies) it's almost like it's not ... it's part of me now (laughs).Um, It can be cumbersome if you've not got the correct plasters or dressings that seem to hold it up if you know what I mean- the bit that actually goes into you um is sensitive and if you don't have support on that it can get tangled up when you're having a wash, changing your clothes or during your sleep – you know you feel tug on you and if you've not got something supporting that it can be painful.(6.11)

LJK: OK, do you remember who inserted your device? Was it a doctor or a nurse?

RUBY: It was a doctor, a chatty doctor. Mr Chatty doctor his name was (laughs)

LJK: The insertion itself, how did you feel

RUBY: It was I didn't mind getting the device in....um, I was worried about how .. because you're awake all the way through the procedure so um I was worried about how it was going to feel, you know they always say there'll be a little tugging, tugging and pushing , particularly pushing ...there was quite a lot of tugging (.....) laughs – more, more than I thought. Particularly when he was putting it **IN** , **I could feel** almost as if his fingers were in me when he pushed the sides in... I'm not exactly sure what he was doing – that was the most painful part.....

LJK: Ok thanks for that . I just want to talk about ... you've had your device In for a while now, you spoken about some of the positives of having the device... what were the positives of having the device in?

RUBY: Well it gave me the ability to have the pump for my treatment(in audible) ... and they were just sitting there with the device in your arm – in your hand and I remember that from the last time I had cancer um. It gets in the way, again it gets caught on things and it does pop out – it pops out and that vein collapses and you have to move onto another one. So at least with the Hickman it was just in once . they didn't have to think about going through the .. looking for ... being attacked by a needle. So very good with a pump for the chemotherapy , perfect, perfect.. also it's hidden away um, it's tucked away – depending on what you wear you can be walking around and no one would know that you were having chemicals pumped into your system ... what's the word.. what's the word it was, it was easily concealed. There you go.

LJK: So you talk about concealing or hiding .. did you feel you had to hide it away?

RUBY: No, no, no I'm not saying that it was just occasionally when I got dressed to do something or go somewhere and I would look down and I would be like OH! I don't even see it. It's like – it's not there, you know, and even when I had my pump on with the bag it could be totally concealed, like you would not have any idea that you had anything on me.

LJK: and um, any negatives?

HICK: Um, when I had to get the dressings changed, that was... because a lot of people – some of the nurses didn't know – like OH! A Hickman, do you know how to do that – oh! Go get somebody else in and oh can you do it? No! We're allowed to do it on this ward but not on that ward but here were not allowed to do it – we'll need to get you a staff nurse. And it always seemed like a bit of a drama um.. to get the, to get the .. off – but to change the dressing – it should be just an everyday thing but because in the waiting room there's like 20 / 30 people waiting for their dressings and bloods to be taken but I was always the drama because we'd have to go find a staff nurse – this is in the Beatson – to go and find a staff nurse to take dressing off. I mean really! You know...

LJK: How did that make you feel?

RUBY: Um, Um I sympathise with all of them – it's not a big drama – there's no point in making a big drama out of it – so I'd just sit and I'd wait until .. the staff nurse um and then occasionally when I went to have my dressings changed, I was still attached to the pump. And um because the actual treatment was over but the pump was still there – and so I would have to go to another department to have the pump taken off and then go back to the dressing – to get my bloods and dressing changed – it was such, yeah it was never ...

LJK:

RUBY: Yeah, exactly – I mean it was always, it was always a complication somewhere in the chain um, for the simple thing of getting your dressing changed to the point I ended up doing it myself

LJK: and how did you feel doing it yourself.

RUBY; I actually.... I liked it. I think I did a better job (coughs) It was always a bit of a problem – I was like should it go round that way? Which was like – when I went to the GP to have my first set of dressings changed, which I was told to do that, none of them had seen a Hickman and they were all quite frightened, so the girl, the nurse there who was changing my dressing, she .. I said listen we'll do it together, um ah and we did, she was really quite, quite proud of

herself at the end, she was like ohh.... She was proud of herself, nevertheless the dressing was quite, she'd done it OK, she hadn't done it perfectly umm...

LJK: Did you have any worries about it?

Ruby: No, because if I, they, I always, I, fortunately I know someone who knows all about Hickmans and what it should look like and how it should feel and if I had any concerns I could, I could, I could call her she'd be able to tell me if that was correct or not, so I had a lot of information from from umm someone I knew that worked at the hospital.

LJK: So who, how.. how did it feel having treatment through the line, did you feel it going through the Hickman line?

Ruby: No, no,no, I think someone said that when it goes in at first that it might be a little bit tingly, but it wasn't particularly but it was it lasted was less than a minute it was.. I felt absolutely nothing.

LJK: So the last question I've got really, activities of daily life, did your line affect any part of your daily activities?

Ruby: No, no nothing, nothing at all

LJK: That's fine, and um obviously, when you were having treatment.. we've probably covered this already, when you're not having treatment, your line, how do you feel about it because it's obviously just there.

Ruby: I mean... laughs... It's just part of me... coughs, as I said, I'm changing my own dressings.. I got to the point where I was like I didn't need any more dressings on the skin around the entry point to get come proper air (laughs) as it were. Um, and eventually I ended up taking it off myself – I didn't feel I had to speak to anyone about it or anything like that so I took the dressing off, umm, I do think that I should have been given some kind of leaflet, pamphlet of things to do with your Hickman – you know, um a breakdown of how long it should be on... um how long the dressing should be on, what it should look like, what it should feel like, you know. I wasn't really given anything that I could refer back to to say when you could take all of the dressings off myself and just have it like, you know umm naked on your body.Um, once I took the dressing off myself and just left the Hickman loose as it were. It was very different umm because if it was tugged up or down I did feel it whereas before with the dressing it never moved umm, I've thought what would have been handy would be to have maybe some strips of dressing. I tried to make some but it didn't work just to holdit, hold the loop in, just

to keep it tidy against my skin without having the whole square dressing on so yeah I feel the whole that would have been helpful.

LJK: Yeah, so you talk about this being part of you and you doing your own dressing – you you feel that you, that you own it more?

Ruby: Yeah, it's mine, it's my Hickman .. yeah it's almost as if I have a job (laughs) everybody else has got a job, the nurse is doing this and the doctor's doing that and the surgeons doing this and all you do, all you are is like a – you know a person that's got a problem or an illness, and it was almost as if I had ... a job, I was part of it and it was my Hickman and I was looking after it and it was.... I'm not saying it was good.. cause it's not good, but it does.. you do feel part of it and I felt I was responsible for the last few weeks... I've still got it in now, but these last few weeks it's been me that's been looking after it.

LJK: OK, that's interesting, so you're ready to have your Hickman line removed?

Ruby: Yes

LJK: How do you feel about that?

Ruby: Oh no I'm not going to miss it (laughs) absolutely not. In fact it's almost like a signal that that part of my treatment is over – umm- one thing that I want to make absolutely sure about was that I didn't have anymore bloods to go because I.. if I had anymore bloods in the next 3 weeks. I'd rather keep it in, because I don't want anyone to stab me again. So umm, but again nobody can give me that, umm nobody can answer that question.

LJK: we,... I haven't got any more, Kinda questions. Is there anything you want to add?

Ruby: No, no, no, I've given you my personal experience, verbally but I did keep a little diary umm not so much toward the end but I kept a diary at the very beginning which unfortunately I don't have access to at the moment right here, now but maybe what I'll do is I'll email it if I get some time and enough energy is to maybe email that to you. It's not just about the Hickman it's also about how I was feeling, about what I was going through.

LJK: That's great, thanks for participating and we'll let you know what happens with the study and...

Ruby: You're welcome. I hope you've got some good some information that you can, sometimes you don't think of... so thank you.

LJK: No thank you very much

END

Appendix 10

Dear Linda

Edinburgh Napier University
School of Health and Social Care
Research Integrity Ethical Approvals
Committee
9 Sighthill Court
Edinburgh
EH11 4BN

Project Title: The Lived Experience of Vascular Access

Project start date: 18/02/2019

Project end date: 31/03/2019

Project reference: SHSC18011

Date of letter: 16/02/2019

Further to your application for ethical review to undertake a research study at Edinburgh Napier University, I am pleased to inform you that the committee is able to give your application a favourable ethical opinion and we approve that your study is able to proceed. It is your responsibility to inform the SHSC ethics when your study has completed.

Data from your study should be held securely for a period of ten years after the completion of the research project or longer if specified by the funder. Please adhere to data management policy for the storage and destruction of data, including identifiable data, please see:

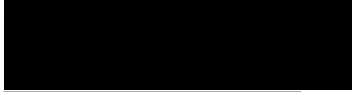
<http://staff.napier.ac.uk/services/research-innovation-office/Documents/Research%20Data%20Management%20Policy.pdf>

May I also remind you of the need to apply to the Research Integrity Committee prior to making any amendments to this study or of any changes to the duration of the project. Any proposed changes in the protocol should be submitted for reassessment as an amendment to the original application. If required please request the Amendments to an Approved Application form (contact: ethics.shsc@napier.ac.uk). All documents related to the research should be maintained throughout the life of the project, and kept up to date at all times. If your study is funded please ensure to upload your ethical review letter and data management forms on worktribe.

Please bear in mind that your study could be audited for adherence to research governance and research ethics.

We wish you well with your study.

Yours sincerely,



Dr. Anne Rowat, SHSC Ethics Chair

Appendix 11



Participant Information Sheet

Study title: The lived experience of vascular access

What is the purpose of the study? The purpose of this study is to explore patient's experiences of living with a long-term vascular access devices.

Why have I been chosen? You have been chosen because you have had a long-term vascular access device as part of your treatment.

What will happen if I take part in the study? If you agree to take part in this study, you will be invited to complete a survey. This will take approximately 5 minutes.

What will happen to the information I give to you? This information will be used to gain an understanding of what it is like to live with a device.

Anonymity / Confidentiality: Your anonymity will always be ensured. There will be no identifiable information on the data and therefore anonymity will be ensured. All documentation relating to the study will be stored securely with only the research team having access. All access to data will be password protected. You will not be identified in the final report and all data collected will be destroyed at the end of the study

Right to Withdraw: The decision to participate in this study is voluntary and you should not feel in any pressure to take part. If you chose to participate and then change your mind, you will be allowed to withdraw from the study at any time.

When do I need to decide? The survey will be available until 12TH November 2018 Feel free to discuss and seek advice about it from your friends and family.

Consent: If you agree to participate you will be asked to agree to a consent statement online. Completion of the survey will then be taken consent.

Benefits of taking part in the study: By taking part in this study you will help to inform patients who have to have a long-term device in in the future. You will also be providing vital information to healthcare professionals about the experience of living with a device.

Further information: If you require more information, please contact: The researcher:

████████████████████

If you have any issues or complaints about the study please contact linda.kelly@napier.ac.uk

APPENDIX 12

Study Title
The lived experience of patients with a vascular access device

Methodology: A qualitative phenomenological study

Researcher: Linda J Kelly

Study purpose: To explore patient's experiences of living with a long-term vascular access device

- | | Initials |
|---|----------------------|
| 7. I confirm that I have read and understand the information sheet | <input type="text"/> |
| 8. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily | <input type="text"/> |
| 9. I understand that I will be completing a questionnaire relating to my experience of having a vascular access device. | <input type="text"/> |
| 10. I understand that any of my quotes used as part of the study will remain anonymous, and that I will not be identified within the study. | <input type="text"/> |
| 11. All information that I disclose will remain confidential. | <input type="text"/> |
| 12. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving my reason and with no detrimental effects. Any data collected prior to withdrawal may still be used. | <input type="text"/> |

This is to certify that I _____ hereby agree to participate as a volunteer in the study.

Participants' signature _____ Date _____

Research Supervisor _____

Signature _____ Date _____

APPENDIX 13

Privacy Notice

Name of research project: The experience of living with a long-term vascular access device

Description of research project: The research team in this study consist of PI Linda J Kelly (PhD student, ENU); DOS Professor Austyn Snowden (ENU), Dr Ruth Patterson (ENU) and Karen Campbell (Macmillan). Following permission from the moderators, a hyperlink to a survey will be posted on a closed vascular access Facebook group. The survey will contain questions about the experience of living with a long - term vascular access device. The survey is hosted in NOVI, and this database is controlled by ENU. The names and location of participants will be kept securely by NES. No identifying information is requested in the survey.

Data Controller	Edinburgh Napier University
Purposes for collection/processing	The aim of the study is to explore the experiences of people living with a long - term vascular access device.
Legal basis	Under Article 6(1) of the General Data Protection Regulation (as the legal basis for processing data) Edinburgh Napier University is the data controller and the legal basis for this study is that you have given explicit consent to take part. You have been advised of your right to withdraw consent at any time and how to do this.
Whose information is being collected	Members of the vascular access Facebook groups who have formally consented to participate in the study
What type/classes/fields of information are collected	Your age, your gender and the country that you live in is the only personal data that will be collected by the principal investigator. These data will all be stored securely, electronically at Edinburgh Napier University. No other identifying information will be held by Napier.
Who is the information being collected from	Data is being collected directly from you.
How is the information being collected	You will complete the online survey. Your responses will then be held in an electronic survey database called NOVI.
Is personal data shared externally	No

<p>How secure is the information</p>	<p>Data will be stored on the University’s secure data centres. These data centres are resilient and feature access controls, environmental monitoring, backup power supplies and redundant hardware. Information on these servers is backed up regularly. The University has various data protection and information security policies and procedures to ensure that appropriate organisational and technical measures are in place to protect the privacy of your personal data.</p>
<p>Who keeps the information updated</p>	<p>The principal investigator (Linda J Kelly) is responsible for keeping the study information updated.</p>
<p>How long is the information kept for</p>	<p>At the end of the research, electronic data will be kept securely for ten years and then will be destroyed as per Edinburgh Napier University guidance. All electronic files containing data will be deleted from the secure university server where the data is held.</p>
<p>Will the data be used for any automated decision making</p>	<p>No</p>
<p>Is information transferred to a third country? Outside the EEA and not included in the adequate countries list.</p>	<p>No</p>