

VOLUME 15, ISSUE 3 • FALL/WINTER 2021

VASCULAR ACCESS



JOURNAL OF THE CANADIAN VASCULAR ACCESS ASSOCIATION

IN THIS ISSUE / DANS CE NUMÉRO :

I-DECIDED® – A decision tool for assessment and management of invasive devices in the hospital setting

I-DECIDED® – Un outil d'aide à la décision pour l'évaluation et la prise en charge des dispositifs effractifs en milieu hospitalier

'Pinholes in my arms': The vicious cycle of vascular access

« Des trous d'aiguille dans les bras » : Le cercle vicieux de l'accès vasculaire

COLLABORATING FOR BEST PRACTICE

Learning from each other and our patients' experiences: Part one

Publication Mail Agreement 43332020 • ISSN (Print) 1913-6692 • ISSN (Online) 2563-7193



Canadian Vascular Access Association
Association Canadienne d'Accès Vasculaire

This article is reprinted with permission from the British Journal of Nursing, 2021, Vol. 30, No. 14 (IV and Vascular Access Supplement) © MA Healthcare Ltd.

Le Présent article est reproduit avec l'autorisation du British Journal of Nursing, 2021, vol. 30, n° 14 (IV and Vascular Access Supplement) © MA Healthcare Ltd.

'Pinholes in my arms': The vicious cycle of vascular access

Linda Kelly and Austyn Snowden

« Des trous d'aiguille dans les bras » : Le cercle vicieux de l'accès vasculaire

Linda Kelly et Austyn Snowden

Suggested Citation: Kelly, L., & Snowden, A. (2021). 'Pinholes in my arms': the vicious cycle of vascular access. *Vascular Access*, 15(3), 15–24. doi: 10.5737/cvaa-1531524 (Reprinted from "Vascular access device securement for oncology patients and those with chronic diseases," 2021, *British Journal of Nursing*, 30(14) [IV and Vascular Access Supplement])

This is an Open Journal Systems article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by-nc-nd/4.0>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Il s'agit d'un article d'Open Journal Systems distribué en vertu du contrat de la licence d'attribution Creative Commons (<https://creativecommons.org/licenses/by-sa/4.0>) qui permet d'utiliser, de distribuer et de reproduire sans restriction son contenu dans tout support, pourvu que l'œuvre originale soit adéquatement citée.

Abstract

Background: Vascular access devices (VADs) are essential for delivery of intravenous therapies. There are notable gaps in the literature regarding a focus on patient experience and meaning-making related to living with a VAD, specifically a central venous access device (CVAD).

Aims: To explore how patients make sense of living with a CVAD.

Methods: This study followed an interpretive phenomenological analysis (IPA) approach. Purposive sampling was used to identify 11 cancer patients who had a CVAD in situ. One-to-one semi-structured interviews were performed. Interviews were digitally recorded, transcribed and analysed by the lead author.

Findings: Four superordinate themes were identified: the self under attack; being rescued/being robbed; protection of others/protection of self; bewilderment and dismay at lack of staff competence.

Conclusion: Having a CVAD affects the psychological, social, and personal self and impacts on self-esteem and self-image. Despite this, CVADs are accepted by patients and are eventually 'embodied' by them.

Résumé

Contexte : Les dispositifs d'accès vasculaire (DAV) sont essentiels à l'administration des traitements intraveineux. Dans la documentation, on constate des lacunes concernant d'une part une approche qui se veut centrée sur l'expérience vécue par le patient et d'autre part la quête de sens pour un patient qui doit vivre au quotidien avec un DAV, en particulier un dispositif d'accès veineux central (DAVC).

Objectifs : Explorer la quête de sens des patients porteurs d'un DAVC.

Méthodologie : L'approche adoptée dans cette étude est celle d'une analyse phénoménologique interprétative. Les auteurs ont effectué un échantillonnage raisonné pour repérer 11 patients atteints de cancer porteurs d'un DAVC qu'ils ont rencontrés dans le cadre d'entrevues individuelles semi-structurées. Les entrevues ont été enregistrées électroniquement, transcrites et analysées par l'auteur principal.

Résultats : Quatre grands thèmes ont été dégagés : subir une attaque; être secouru/être volé; protéger les autres/se protéger; perplexité et désarroi face au manque de compétence du personnel.

Conclusion : *Le port d'un DAVC perturbe les aspects psychologique, social et personnel de la vie du patient, et est également préjudiciable à l'estime de soi et à l'image de soi. Malgré tout, les patients acceptent les DAVC et finissent par les voir comme une partie d'eux-mêmes.*

Keywords: central venous access devices, patient experience, peripherally inserted central catheter (PICC), tunneled central venous catheter, totally implanted vascular access device

Key Points

- Practitioners should be more aware of the negative impacts that repeated peripheral venous access can have on patients both emotionally and physically.
- A decision to move to a longer-term device could be considered at an early stage in the patient's vascular access journey.
- Education and training in the care and management of vascular access devices is crucial and should be offered to all staff responsible for looking after patients with central venous access devices (CVADs).
- Patients will generally accept and adapt to living with a long-term CVAD in a positive manner; however, it must be ensured that both body and mind are considered and discussed before a CVAD is placed.

Background

Central venous access devices (CVADs) are necessary for the delivery of intravenous (IV) therapies but are damaging to the inner layer (intima) of small peripheral veins (Al-Benna et al., 2013). They are typically used for vesicant chemotherapy agents, which can cause tissue necrosis if they extravasate out of the vein (Schulmeister, 2011). CVADs are also recommended for longer-term IV therapies as they can remain in place for prolonged periods of time. This reduces the need for continued, repeated cannulation, allowing preservation of peripheral vessels (Gorski et al., 2021).

Over the years, technological advances have resulted in three main device types for the delivery of drugs into the central venous system: peripherally inserted central catheters (PICCs) and tunneled central venous catheters (TCVCs),

which are both external devices, and totally implanted vascular access devices (TIVADs), which are inserted under the skin. Depending on the treatment, patients can have these devices in place for periods ranging from a few months to many years. Currently, there are limited studies that have explored, in depth, the lived experiences of patients with CVADs and how they make sense of their experiences. A review of the literature by the authors before the study discussed in this article highlighted that the meaning attributed to the experiences of living with a CVAD has not been explored.

Consequently, in the UK literature, evidence of how patients make sense of this experience is lacking. Although 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 improve understanding of the experience of living with a CVAD.

Aim

To gain insight and understanding of how patients make sense of living with a CVAD.

Methods

Methodology

The study employed interpretive phenomenological analysis (IPA) to explore how individuals ascribe meaning to their experiences of living with an external or implanted vascular access device (VAD). As a philosophy, phenomenology stresses the notion that only individuals who have experienced a phenomenon are able to communicate the experience to others (Smith et al., 2009). In addition to phenomenology, hermeneutics and ideography are major theories underpinning IPA. This approach was selected because it was deemed as appropriate to capture and explore the meanings that participants apportioned to their experiences (Smith et al., 2009).

Study population and sampling strategy

The study population was recruited from the West of Scotland Cancer Centre. Participants were recruited purposefully to reflect their expertise in the area of study. Individuals who had a CVAD in situ for longer than a 3-week period were eligible to participate. A research nurse from the cancer centre made initial contact with any patient who met the inclusion criteria (*Box 1*). Written information about the

Box 1*Inclusion and Exclusion Criteria***Inclusion**

- Patients who have had one of the three devices in situ for more than three weeks
- Patients aged 16 or over
- Patients with capacity to provide consent
- Male or female

Exclusion

- Patients without capacity to provide consent
- Diminished understanding or comprehension, or a language other than English spoken and an interpreter not available
- Patients aged below 16 years of age
- Patients deemed not well enough by clinical staff or researcher to participate

study was distributed to potential participants. Patients were invited to contact the first author if they required further information or if they decided to participate in the study. Six males and five females with ages ranging from 19 to 80 years responded to the participant call and all were recruited to the study. Five patients had a PICC, three patients had a TCVC and three had a TIVAD (*Table 1*). Smith et al. (2009) have emphasised that the main concern of IPA is with a detailed account of individual experience, and therefore they recommend including a small number of cases.

Ethical considerations

Participants were given a detailed written information sheet. They were then allowed at least 72 hours to consider participating in the study. Participants were informed of the voluntary nature of taking part, in addition to their right to withdraw without prejudice. They were assured that all information collected would remain confidential and that anonymity would be assured by the removal of all identifying information. Recordings were securely stored throughout the study period. Ethical approval was sought and obtained from the University of the West of Scotland Ethics Committee,

Table 1*Participant characteristics*

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	4 months	Nurse
Alfred	66 years	Male	PICC	Chemotherapy for colorectal cancer	4 weeks	Nurse
Sam	84 years	Male	PICC	Chemotherapy for colorectal cancer	6 weeks	Nurse
Ruby	55 years	Female	TCVC	Chemotherapy for anal cancer	8 weeks	Nurse
Mary Rose	63 years	Female	TCVC	Chemotherapy for colorectal cancer	9 weeks	Interventional radiologist
Yasmin	19 years	Female	TCVC	Chemotherapy for non-Hodgkin's lymphoma	6 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	5 months	Interventional radiologist
John	80 years	Male	TIVAD	Chemotherapy for lung cancer	5 months	Interventional radiologist

PICC=peripherally inserted central catheter; TCVC=tunneled central venous catheter; TIVAD=totally implanted vascular access device

NHS Ethics committee and the Research and Development Committee. REC Reference number: 15/WS/0108.

Data collection

After providing information about the study and gaining written consent, one-to-one semi-structured interviews were undertaken by the first author within the hospital setting. Undertaking the interviews personally allowed the author to gain a sense of the whole experience from each participant. The interviews lasted between 20 and 70 minutes and were guided by the participant.

The semi-structured nature of the interviews allowed a natural unfolding of patient stories. An interview guide was used to ensure that all other relevant issues were covered.

Data analysis

Data analysis followed the IPA model (Smith et al., 2009).

- To gain an initial feel for the cases, each audio recording was listened to repeatedly by the first author. This helped gain an understanding and a feeling for the ideas and statements offered by each participant (Haase & Myers, 1988).
- Each transcript was then transcribed verbatim by the author. This enabled a deeper level of immersion in the data (Guba & Lincoln, 2005).
- Each transcript was then focused on individually and in depth. Exploratory and mostly descriptive comments reflecting initial thoughts about the claims, concerns and understandings of each participant were noted. This resulted in a vast amount of data. This was reduced by working closely with both the original transcript and the notes, and involved looking for connections, relationships and patterns observed between exploratory notes (Smith et al., 2009).
- Essential qualities of the account were captured, and emergent themes identified. This process was repeated for each account.
- Superordinate themes were generated using abstraction, which is a basic form of identifying patterns between emergent themes. A table was used as a graphic representation of the structure of the emergent themes and the development of the superordinate themes and subthemes (Smith and Osborn, 2015).

Throughout this process, diary entries were made by the same author. Feelings and thoughts that submerged while working through the transcripts were detailed. This process aided in the reflective process and allowed the acknowledgement of previously held beliefs and biases to be considered. During data analysis, the author attempted to make sense of the

statements and stories the participants shared. This type of interpretation involved the author trying to understand what this was like from each participant's point of view.

Validity and quality

The assessment of the quality of qualitative research is challenging, however, the first author followed guidance offered by Yardley (2000), which includes issues of sensitivity to context; commitment and rigor; transparency and coherence; and impact and importance. Sensitivity to the data was ensured during the interview process. In addition, the use of verbatim statements ensured that the words of the participants were not altered or influenced by the preconceptions and beliefs of the author. The use of a reflective diary also enabled the author to be open and honest throughout the analysis period.

Findings

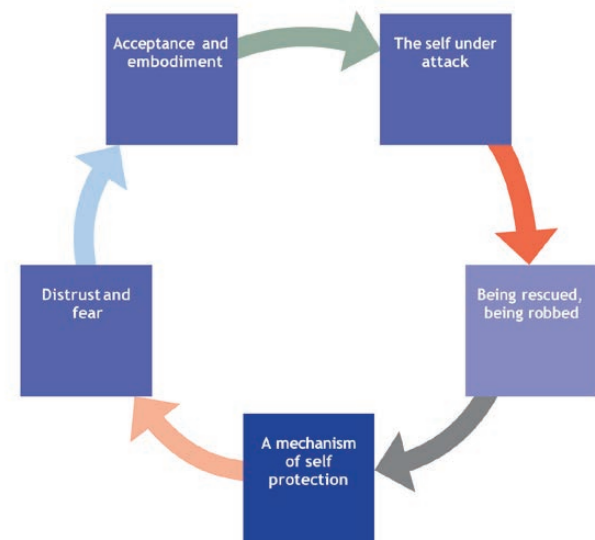
Four superordinate themes, some with related subthemes emerged from the study.

- The self under attack
 - The violation of vascular access
 - Accepting the ordeals of vascular access
- Being rescued/being robbed Being thrown a lifeline
 - Device as part of self
 - Better than the rest
- Protection of others/protection of self
- Bewilderment and dismay at lack of staff competence.

These themes resulted in a conceptual framework of the 'vicious cycle of vascular access' (Figure 1).

Figure 1

The vicious cycle of vascular access



The self under attack

Participants shared vivid, detailed accounts and memories of repeated, painful cannulation. These descriptions included the physical, as well as physiological, impacts of the procedure. Interpretation of the statements suggests that there was a degree of distress and violation associated with frequent repeated peripheral cannulation, which the participants faced before having a long-term device inserted:

'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

The extent of distress was captured when participants described the procedure of peripheral cannulation as you would an act of violence. Ruby described the procedure as 'being attacked by a needle' and went on to say:

'It felt like they were stabbing me to death.'

Ruby, TCVC

It appeared that the longer it took to find suitable veins to cannulate, the greater the suffering became for the patients. One patient recalled the use of the strategy of heating her hands in warm water to increase the success of cannulation:

'You just sat there with your hands in the water praying that it would work.'

Tina, PICC

This theme conceptualises the lived experience in the period before having a long-term CVAD inserted. This experience impacted on self-esteem and resulted in a reduced sense of agency.

Being rescued/being robbed

Because of the negative experiences participants had had with cannulas they were grateful to have been offered a long-term device. This was captured in accounts from both Norman and Mary Rose.

'It's really a wonderful thing and it's so nonintrusive that you just carry on with your life and ... you know, it's actually a real medically helpful device.'

Norman, PICC

'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 ... I have absolutely none of those side effects so the TCVC to me has been a life saver 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

Despite the acceptance of CVADs, the devices resulted in the need for adaptations to daily life for some participants. Those 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.

'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

Alfred also discussed adjustments that he made to his typical sleep routine to accommodate his PICC:

'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

This was not such an issue for participants living with other devices. However, the presence of a TIVAD caused an issue for Amaya because it prevented her from undertaking an activity that she had always wanted to do:

'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 suggests that Amaya has lost control of herself and the decisions she could make. Although 'the guys' that she refers to are unlikely to be medical professionals, they have taken it upon themselves to make this decision for her. It could be suggested that this demonstrates that Amaya has experienced a loss of self-control.

Another participant with a terminal diagnosis described how he felt when told that he would have to give up his sports if he had a TCVC inserted. 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 him 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 sports 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 while doing the things he had done 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.

This theme conceptualises the experience of and relief at getting a device that could 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

The patients in this study described concealing their devices to protect others from seeing them. One reason was because they believed that their device portrayed them as someone who was sick:

'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 prefer to ... I do wear a top that will cover it.'

Mary Rose, TCVC

The other reason was to protect others from having to see the device:

'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.'

Sam, PICC

This concealment appeared to be done to protect others from potentially becoming distressed on seeing the device. Participants believed that others might be alarmed at the sight of their devices and therefore they went out of their way to conceal it from them. This was a perception held by many of the participants and is suggestive of anticipated

stigma. Mary Rose described one of the advantages of her device as the 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

It is interesting to note that two of the patients who mentioned being conscious of their devices were the patients with the TIVADs in situ. This was a surprise finding as the TIVAD is the device viewed by clinicians as the least noticeable and one that 'allows a patient to have minimal body image changes' (Blanco-Guzman, 2018). This description has the potential to mislead patients, as highlighted by John:

'At first I thought it was worse, it's a wee bit of a bump—when you see the diagram, there's nothing, it's flat there.'

John, TIVAD

This theme conceptualises the experience of perceived and self-stigma, as well as the need to maintain a positive self-image. It is also concerned with the need to protect others from having to see the device.

Distrust and fear

The participants highlighted issues regarding the competence and confidence of the health professionals caring for their long-term VAD. At the time they would have either voiced their fears and concerns to the health professional, refused the professional access to their devices or chosen to have treatment delivered through peripheral veins rather than risking potential complications if the device were to be used incorrectly.

The participants appeared to be bewildered that nurses and doctors were either not competent or not confident and therefore were, at times, unwilling to use the devices. One relative discussing her husband's experience (this was the only interview where a relative was also present) explained how he refused to let staff touch his TIVAD:

'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

This issue was highlighted when the participants or their relatives were successfully taught to access and care for devices themselves:

'It didn't take long to train him, I said to the nurses my husband learnt in 10 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

The lack of staff competence led to anxiety for patients because they were aware of the potential complication of having a CVAD. This anxiety was fuelled when care of the device varied across healthcare settings. Participants became aware of variations in practices between primary and secondary care settings. Since they received care both within and outside hospital settings this variation became obvious to them. They could not understand why care would be different from one setting to another. This led to them feeling vulnerable, anxious and disloyal for questioning or highlighting the issues they faced.

'[Care] is different in the community, yes, you try to be loyal and you try not to be critical ... you shouldn't be caught in the middle like that.'

Tina, PICC

'The staff in here [hospital] are more familiar with PICC lines than the district nurses are.'

Garud, PICC

This theme conceptualises the experience of living with fear of device complications—this being increased due to the inability of health professionals to use the CVAD. In addition, it conceptualises the loss of trust in healthcare services and the experience of fear of a return to the violation of painful and repeated peripheral cannulation.

Acceptance and embodiment

Patients in this study appeared to eventually 'embody' their device irrespective of whether it was visible or implanted under the skin. The device became part of them and at times they even became unaware of it. This suggests that CVADs become embodied. This was captured in some of the accounts:

'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

This final theme conceptualises that, despite the negative aspects of CVADs, the devices are eventually accepted and embodied.

Discussion

This study demonstrates the effects of painful challenging peripheral cannulation on patients' self-esteem and worth. Similarly, previous studies also highlighted that adult patients are often negatively affected by the pain

of repeated peripheral venous access (Robinson–Reilly et al., 2016; Larsen et al., 2017). The findings from the current study would suggest that patients feel that the pain of peripheral venous access is something that has to be endured. Subsequently, once a long-term device (PICC, TCVC or TIVAD) is inserted, patients describe relief at no longer having to endure challenging peripheral cannulation procedures. They accept and adapt to the devices readily. It appears that patients in this study accepted the negative aspects of their devices because the alternatives would be a return to painful peripheral cannulation or the inability to have treatment.

The findings from this study are in accordance with previous studies. An early study focusing on PICCs reported that patients found them to be comfortable and that they did not adversely affect lifestyle (Gabriel et al., 2000). All of the patients in that study viewed the PICC as a solution to their difficult venous access problems and they felt the device improved their quality of life (Gabriel et al., 2000). Similarly, a descriptive study by Molloy et al. (2008), based in a West of Scotland cancer care centre, concluded that the positive aspects of having treatment through a PICC outweighed the negatives and the patients felt that they had adapted to and accepted their device. More recently, Sharp et al. (2014) discovered that patients adapted to their PICC and came to accept the device because it allowed convenient access for treatment. Studies focusing on TIVADs gleaned similar findings (Chernecky, 2001; Minichsdorfer et al., 2016; Yagi et al., 2016).

What this study adds is that these positive feelings applied regardless of device, a finding that has not been uncovered in previous studies. In fact, a prominent phenomenon in the findings here was that the patients not only accepted their devices, but even appeared to embody them and view them as part of themselves. In other words, the patients seemed to go beyond mere acceptance of the device as an instrument to allow them to receive treatment. Despite this, it was highlighted in the study that the presence of a long-term VAD led to the need to adjust how patients lived their everyday lives. Adaptations had to be made to activities of daily living, particularly for patients with PICCs, who had to adjust how they bathed or showered. In addition, patients had to refrain from certain leisure activities such as swimming or playing contact sports. This is an important finding because, although these devices are a necessity for sometimes curative treatments, they are also part of life-

prolonging treatment. This could result in patients living the end of their lives unable to participate in activities that aid their mental health and wellbeing.

Although the participants in this study said that they accepted their devices, they also mentioned the attempts they made to conceal them. Previous studies have suggested that there may be a potential social stigma attached to an externally placed device. A study by Ritchie et al. (2015) gathering views about participation in a randomised controlled trial also found that patients adapted to the devices by using strategies such as hiding, covering or concealing the device. However, the findings from the in-depth interviews carried out in this study suggest that the reason for device concealment was to either reduce the perceived seriousness of their illness or to shelter and protect others from it. Concealment was done to maintain privacy about illness and to avoid having to share information with others.

According to Charmaz (1983), sick people frequently experience a fragmentation of their former self-image. Over time this can build up to a loss of a formerly sustaining self-image and result in a lower self-value (Charmaz, 1983). The presence of a device that is external and visible may act to lower a patient's self-image. A device that remains visible may change the patient's identity and place them in an illness role or assign them a sick role status (Parsons, 1951). This may not be the impression that the patient wishes to portray. Therefore, concealment limits the social impact on the individual's identity and allows them to be viewed in a positive way by others.

Vascular access devices have many advantages but they also carry a risk of complications, including potentially fatal catheter-related bloodstream infections (CRBSIs), chemical or mechanical phlebitis and catheter-related vein thrombosis (Moureau, 2019). Within this study, patients were concerned about the lack of competence of some health professionals responsible for using their devices. This led to feelings of anxiety, vulnerability and lack of trust in health professionals. The care often varied, which resulted in a distrust of staff caring for their devices, and anxiety and fear about potential device complications.

Healthcare workers' lack of knowledge has been described in previous studies (Chernecky, 2001; Goossens et al., 2005; Molloy et al., 2008; Alpenberg et al., 2015; Ritchie et al., 2015; Ryan et al., 2019). Gabriel et al. (2000) described how participants who had previously had a long-term CVAD

in place were concerned about 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. Goossens et al. (2005) also highlighted a lack of experience and knowledge of staff regarding TIVADs. Furthermore, Alpenberg et al. (2015) and Ryan et al. (2019) described feelings of insecurity and concerns about potential complications resulting from nurses' uncertainty and doubt when handling devices, performing dressing changes, and variations in practice. Finally, Alpenberg et al. (2015) went on to 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.

Most disturbingly, this lack of knowledge about how to use long-term CVADs often leads to patients having to return to repeated peripheral cannulations, a situation they thought they had escaped.

Implications for clinical practice

The findings from this study have provided an insight into the deep-rooted feelings and emotions of patients living with a device. As more and more people undergo long-term treatment through a VAD, this knowledge is important because it will enable a more sophisticated approach to caring for patients in the lead up to and during life with a CVAD. It is possible to break the vicious cycle of vascular access with strategies to improve the experiences of patients.

First, the practitioner should be more aware of the negative impacts that repeated peripheral venous access can have on patients both emotionally and physically. This could be addressed with the use of anaesthesia, vein visualisation technology or ultrasound guidance. Additionally, a decision to move to a longer-term device could be considered at an early stage in the patient's vascular access journey.

It should be noted that patients may wish to conceal external devices to maintain a certain body image. If possible, the choice of device should be made available to patients and counselling offered to explain and deal with potential issues with self-esteem. It might be that a patient would be more comfortable with a totally implanted device rather than an externally situated device. A buddy system would also be a positive way to help individuals manage the changes that will occur once a device is inserted. Images of devices in place would help patients visualise and prepare them for the changes that will happen to their bodies once their devices

are in situ. Written information about aspects of living with the device, including continuation of everyday activities such as showering, bathing and sleeping, would also be useful for patients. In addition to activities of daily life, patients might partake in certain leisure activities or have life dreams that they would wish to achieve. If the device that has been selected is likely to take away aspects of a patient's life or dreams, an alternative device should be considered, whenever possible.

Education and training in the care and management of VADs is crucial and should be offered to all staff responsible for looking after patients with CVADs. An alternative would be dedicated vascular access teams who could provide necessary care and offer training to others, if required (Moureau, 2019).

Finally, if a long-term device is used, patients will generally accept and adapt to these in a positive manner. However, it must be ensured that both body and mind are considered when a CVAD is placed.

Limitations

The themes identified in this 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 patient experience of living with a CVAD. Participants were recruited from a single centre and were all oncology patients receiving chemotherapy because oncology is one of the only specialties to use all three CVADs. However, the 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 those reported in the previous literature, as outlined in a separate qualitative study by the authors (Kelly et al., 2019). Moreover, the method was consistent with the state of knowledge on the topic, and the evidence obtained allows for larger, hypothesis-driven studies.

Conclusion

The findings of the current study show that the experience of living with a VAD involves a number of negative processes. This includes changes to self-esteem, self-control and self-image. Despite this, CVADs appear to eventually be accepted and embodied by patients who learn to live life with a changed self. This study shows that the body and mind are not equally considered when a CVAD is inserted, and to break the vicious cycle of vascular access, consideration to how a CVAD impacts on the self must be a priority.

CPD reflective questions

In your place of work, are discussions held with patients ahead of the insertion of long-term central venous access devices (CVADs)? If so, do they address issues related to self-image, self-stigma and potential changes to activities of daily life?

In your institution, is the patient's lifestyle considered when a long-term vascular access device is inserted? Do you involve patients in device selection?

Do you have an adequate system in place for teaching clinicians to care for long-term CVADs? Are there systems in place to direct patients to staff who are competent in the care and maintenance of these devices?

About the authors

Linda J. Kelly, *International Clinical Educator, Vygon, Swindon, Wiltshire, UK*

Austyn Snowden,* *Chair in Mental Health, School of Health and Social Care, Edinburgh Napier University, Edinburgh, Scotland*

*Corresponding author: Austyn Snowden, a.snowden@napier.ac.uk

À propos des auteurs

Linda J. Kelly, *formatrice clinique à l'échelle internationale de Vygon, Swindon, Wiltshire, Royaume-Uni*

Austyn Snowden*, *chaire de santé mentale, School of Health and Social Care, université Napier d'Édimbourg, Édimbourg, Écosse*

* Coordonnées de correspondance : Austyn Snowden, a.snowden@napier.ac.uk

Declaration of interest

None

Funding

The study was funded via PhD scholarship by Vygon Ltd

Acknowledgments

The authors would like to thank the 11 people who agreed to be interviewed for this study, for giving their time, being open, and expressing their willingness to help other further patients was a

selfless act. The authors would also like to thank the members of the Cancer and Venous Access (CAVA) study group for their support and help in the recruitment for this study.

Accepted for publication: April 2021

References

- Al-Benna, S., O'Boyle, C., & Holley, J. (2013). Extravasation injuries in adults. *ISRN Dermatology*, 2013: 856541. <https://doi.org/10.1155/2013/856541>
- Alpenberg, S., Joelsson, G., & Rosengren, K. (2015). Feeling confident in using PICC lines: Patients' experiences of living with a PICC line during chemotherapy treatment. *Home Health Care Management and Practice*, 27(3), 119–125. <https://doi.org/10.1177/1084822314566300>
- Blanco-Guzman, M. O. (2018). Implanted vascular access device options: A focused review on safety and outcomes. *Transfusion*, 58(Suppl 1), 558–568. <https://doi.org/10.1111/trf.14503>
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness*, 5(2), 168–195. <https://doi.org/10.1111/1467-9566.ep10491512>
- Chernecky, C. (2001). Satisfaction versus dissatisfaction with venous access devices in outpatient oncology: A pilot study. *Oncology Nursing Forum*, 28(10), 1613–1616.
- Gabriel, J. (2000). What patients think of a PICC. *Journal of Vascular Access Devices*, 5(4), 26–29. <https://doi.org/10.2309/108300800775891454>
- Goossens, G. A., Vreboz, M., Stas, M., De Wever, I., & Frederickx, L. (2005). Central vascular access devices in oncology and hematology considered from a different point of view: how do patients experience their vascular access ports? *Journal of Infusion Nursing*, 28(1), 61–77. <https://doi.org/10.1097/00129804-200501000-00008>
- Gorski, L. A., Hadaway, L., Hagle, M. E., McGoldrick, M., Orr, M., & Doellman, D. (2021). Infusion therapy standards of practice. *Journal of Infusion Nursing*, 44(Suppl 1), S1–S224
- Guba, E., & Lincoln, Y. (2005). Competing paradigms in qualitative research. In: Denzin NK, Lincoln YS (eds). *The SAGE handbook of qualitative research* (3rd ed.). Sage.
- Haase, J. E., & Myers, S.T. (1988). Reconciling paradigm assumptions of qualitative and quantitative research. *Western Journal of Nursing Research*, 10(2), 128–137. <https://doi.org/10.1177%2F019394598801000202>
- Kelly, L. J., Snowden, A., Paterson, R., & Campbell, C. (2019). Health professionals' lack of knowledge of central venous access devices: The impact on patients. *British Journal of Nursing*, 28(14), S4–S14. <https://doi.org/10.12968/bjon.2019.28.14.S4>
- Larsen, E., Keogh, S., Marsh, N., & Rickard, C. Experiences of peripheral IV insertion in hospital: A qualitative study. *British Journal of Nursing*, 26(19), S18–S25. <https://doi.org/10.12968/bjon.2017.26.19.S18>
- Minichsdorfer, C., Füreder, T., Mähr, B., Berghoff, A. S., Heynar, H., Dressler, A., Gnant, M., Zielinski, C., & Bartsch, R. (2016). A cross-sectional study of patients' satisfaction with totally implanted access ports. *Clinical Journal of Oncology Nursing*, 20(2), 175–80. <https://doi.org/10.1188/16.CJON.175-180>
- Molloy, D., Smith, L. N., & Aitchison, T. Cytotoxic chemotherapy for incurable colorectal cancer: Living with a PICC-line. *Journal of Clinical Nursing*, 17(18), 2398–2407. <https://doi.org/10.1111/j.1365-2702.2008.02359.x>
- Moureau, N. L. (2019). The VHP model. In: Moureau, N. L. (ed). *Vessel health and preservation: The right approach for vascular access*. Springer International Publishing, 3–8 (online). https://doi.org/10.1007/978-3-030-03149-7_1
- Parsons, T. (1951). Illness and the role of the physician: A sociological perspective. *American Journal of Orthopsychiatry*, 21(3), 452–460. doi: 10.1111/j.1939-0025.1951.tb00003.x <https://doi.org/10.1111/j.1939-0025.1951.tb00003.x>
- Ritchie, M., Kelly, L. J., Moss, J., Paul, J., & Shaw, R. (2015). Exploring attitudes towards a randomised controlled trial of venous access devices—a nested pre-trial qualitative study. *The Journal of Vascular Access*, 16(5), 407–412. <https://doi.org/10.5301/jva.5000447>
- Robinson-Reilly, M., Paliadelis, P., & Cruickshank, M. (2016). Venous access: The patient experience. *Supportive Care in Cancer*, 24(3), 1181–1187. <https://doi.org/10.1007/s00520-015-2900-9>
- Ryan, C., Hesselgreaves, H., Wu, O., Moss, J., Paul, J., Dixon-Hughes, J., & Germeni, E. (2019). Patient acceptability of three different central venous access devices for the delivery of systemic anticancer therapy: A qualitative study. *BMJ Open*, 9(7), e026077. <https://doi.org/10.1136/bmjopen-2018-026077>
- Schulmeister, L. (2011). Extravasation management: clinical update. *Seminars in Oncology Nursing*, 27(1), 82–90. <https://doi.org/10.1016/j.soncn.2010.11.010>
- Sharp, R., Grech, C., Fielder, A., Mikocka-Walus, A., Cummings, M., & Esterman, A. (2014). The patient experience of a peripherally inserted central catheter (PICC): A qualitative descriptive study. *Contemporary Nurse*, 48(1), 5066–5091. <https://doi.org/10.5172/conu.2014.48.1.26>
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method, and research*. SAGE.
- Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain*, 9(1), 41–42. <https://doi.org/10.1177/2049463714541642>
- Yagi, T., Sakamoto, T., Nakai, K., Tanizawa, M., Okabe, T., Hoshikawa, N., Kohatada, M., Kitagawa, F., Hanya, R., & Kotani, M. (2016). A questionnaire-based assessment of the anxiety, satisfaction and discomfort experienced by Japanese cancer patients during the use of central venous ports. *Internal Medicine*, 55(17), 2393–2399. <https://doi.org/10.2169/internalmedicine.55.6032>
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15(2), 215–228. <https://doi.org/10.1080/08870440008400302>