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The negative impact on patients when clinicians don’t learn their lines An international survey of people living with Central Venous Access Devices

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Full Title:	The negative impact on patients when clinicians don’t learn their lines An international survey of people living with Central Venous Access Devices
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Keywords:	Vascular access devices; Peripherally Inserted Central Catheters; Tunnelled Central Venous Catheters; Totally Implanted Central Venous Access Devices; Patient experience; Competence.
Abstract:	Background The literature on patient experience of living with a central venous access device (CVAD) is growing, but remains sparse. It suggests that patients accept CVADs as should reduce episodes of repeated cannulations. However, a recent doctoral study found the reality did not live up to the hope. Aim The aim of this study was to uncover the global, cross-disease experience of patients with CVADs. Methods An online survey was sent to an international sample of people living with CVADs. Findings Seventy-four people from eight countries responded. Respondents corroborated the PhD findings: painful cannulation attempts continued after CVAD insertion due to lack of clinical knowledge. Participants lost trust in clinicians and feared complications due to poor practice. Conclusion Clinicians often lack the necessary skills to care and maintain CVADs. This leads to a negative patient experience.

INTRODUCTION

Central venous access devices (CVADs) are necessary for the delivery of intravenous (IV) therapies that can be damaging to the inner layer (intima) of small peripheral veins (Al-Benna, O'Boyle and Holley, 2013). Technological advances have resulted in three main long-tern CVADs: peripherally inserted central catheters (PICCs) and tunnelled central venous catheters (TCVCs), which are both external devices; and totally implanted vascular access devices (TIVADs), which are implanted under the skin. Depending on the treatment, patients can have these devices in place for a few months to many years.

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). The literature on the experiences of patients living with a CVAD suggests that they are accepted, with the main attraction being a reduction of repeated painful cannulation (Yamada *et al.*, 2010; Sharp *et al.*, 2014; Alpenberg, Joelsson and Rosengren, 2015; Song and Oh, 2016; Parás-Bravo *et al.*, 2016). A recent doctoral study revealed that even when a device was inserted, it did not necessarily prevent challenging cannulation attempts.

With the aim of exploring the lived experience of patients with each of these devices, an Interpretive Phenomenological Analysis (IPA) study was conducted (Kelly, 2017). This study found that even after the insertion of a long-term vascular access device, patients recalled vivid memories of pain, distress, and anxiety experienced during the procedure of peripheral venous access. Once inserted, patients got used to having a CVAD in situ, regardless of type. They largely forgot they were there, and the device became embodied as part of them. However, most patients experienced instances where doctors and nurses lacked the knowledge of how to use their device. Variations in practice and lack of competence of healthcare professionals (HCP) left patients bewildered and dismayed. Clinician uncertainty resulted in peripheral veins being accessed once more, resulting in a 'return to violation' of cannulation (Kelly, 2017).

The findings from this study resonated with colleagues' experience at a number of conference presentations including National Infusion and Vascular Access Network NIVAS); World Congress for Vascular Access (WoCoVA), Association for Vascular Access (AVA) and the

IV forum of the Infection Prevention Society (IPS). A survey was subsequently designed to further explore if the findings were a global phenomena effecting patients with different disease processes.

AIM

The aim of the study was to establish the transferability of the findings of the IPA study. The main objectives were to establish whether the following experiences were generalisable:

1. Painful, repeated and frequent access of peripheral veins prior to having their long-term vascular access device inserted.
2. Nurses or doctors lacking the knowledge and competency and therefore being unable to use the device.
3. Having to have peripheral veins accessed because doctors and nurses were lacking in knowledge and competency with the devices.

METHODS

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 (FB) groups. The first FB group "*PICC Line Club 2.0"* records having 1.4 thousand members. Although set up specifically for people with PICC lines, membership now covers people with a range of different devices for various treatments. The second FB group "*IV's, Ports & PICCs & trades for PoTS*" records having two thousand 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 three thousand members across the groups, many members were involved in both groups and some were no longer active.

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 can act as mutual support for others with similar ailments. Despite the public nature of social media, concerns about privacy and anonymity remain the same as with tradition research and therefore ethical rigor 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). Permission was also granted by the administrators of each FB group. Following ethical approval, an introductory post was uploaded to each FB sites. The post contained information on the study aims, objectives and purpose. If they met the inclusion criteria, group members were invited to participate in the study. If they chose to participate, they were directed to a link which took them to a patient information sheet. To reassure participants, a link to a privacy notice was provided. Members were advised that there was no obligation to complete the survey. Those who decided to continue where directed to a consent form. Once participants had agreed to the consent statements they began the survey in NOVI.

NOVI data base

This system is set hosted by Edinburgh Napier University. The database is only accessible by the principle investigator via double password protection. Both the system and the virtual private network required to access the software is password protected. Therefore, all data collected is securely stored. No personal data was collected and therefore it was unlikely that anyone could be unmasked by their responses to the questionnaires.

Questionnaire

The questionnaire was devised by the author using the themes that had been elicited from the doctoral study (Kelly, 2017). 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 they were living with. The main questions related to the objectives of the study (Kelly, 2017). The survey was available on the FB sites for a total of one month, with reminders posted a weekly basis.

RESULTS

Seventy-four people responded to the survey. All but two were female, with one male and one not declaring gender. The majority was 21 to 40 years old, with 55% having had their device for more than six months (Figure 1). The majority had a totally implanted port (table 2), and most respondents were from USA (n=62), with the remainder from 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.

The first question was: *Patients in my PhD study held vivid memories of painful, repeated and frequent access of their peripheral veins before they got their long-term vascular 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 and below is a 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-USA, 40-51 years)
>
> *'I have PTSD from this'.* (USA, 21-30 years)
>
> *'Has caused medical PTSD'.* (USA, 18-20 years)
>
> *'Doctors see you as a challenge when you say you have no veins. 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-USA, 21-30 years)

The second question was: *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 that said yes (n=46) two people said this had happened once, seventeen 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 comment, for example:

'*…had to teach everyone who thought about touching my line-how to protect it'.* (USA, 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'. (USA, 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-USA, 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-USA, 41-50 years)

The third question was: *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-USA, 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'. (USA, 18-20 years)

'It is not that they are unfamiliar with it, they don't WANT to use it'. (USA, 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-USA), 41-50 years)

DISCUSSION

The distress of peripheral cannulation

The results support the original doctoral finding that painful, repeated and frequent access of peripheral veins is experienced within this group; both before *and after* having a device inserted. The results also align with some of the existing literature on the patient experience of living with a vascular access device (Ritchie *et al.*, 2015; Song & Oh, 2016; Sharp, 2014;

Källenius Edström, Lindqvist and Rosengren, 2016). In these studies, participants experienced episodes of repeated peripheral cannulation prior to having a long – term device, which they found distressing. For example, the patients in the study by Song and Oh (2016) described becoming tired and stressed with the procedure of repeated cannulations, which was described as a significant cause of distress. In some case more than ten attempts were reported before successful access was obtained (Sharp, 2014). Two participants in this current study described cannulation as traumatic, in suggesting they had 'PTSD' (post-traumatic stress disorder). These powerful statements suggest that the patients have suffered very stressful, traumatic, frightening or distressing cannulation attempts.

As in Sharp (2014), there was repeated evidence of patients being ignored, with one describing clinicians carrying on and attempting cannulation 'long after [the patient had said] 'enough''. According to Bond *et al.*, (2015) the reasons for this could be that the cannulation procedure is given low priority and the pain of cannulation is underestimated by healthcare practitioners (Bond *et al.*, (2015). It is difficult to imagine any other context, outside health, where it would be deemed somehow acceptable to continue causing considerable pain to someone despite them asking for it to stop. At best this could be seen as an example of what Stratta, Riding and Baker (2016) term 'empathy erosion'. At worst, it is common assault. We suggest here that we should be honest with patients about the pain of the procedure of peripheral cannulation and encourage them to communicate during the procedure. It should be made acceptable for patients to voice their discomfort or distress and for them to be listened to.

The term DIVA (Difficult Intravenous Access) has recently been used to describe patients with veins that are non-palpable and non-visible resulting in challenging cannulation attempts (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 not as traumatic (Carr *et al.*, 2013; Loon *et al.*, 2016; Pagnutti *et al.*, 2016). The availability of DIVA tools could reduce these preventable traumatic experiences seen in this study (Sou *et al.*, 2017). In addition, there are many techniques available that would reduce the pain of cannulation. These include topical or local anaesthesia, vein visualisation technology and ultrasound guidance (Kelly, 2013). At present it appears that

these are not routinely utilised although they have been shown to improve cannulation success rates (Bahl *et al.*, 2016) .

Bewildering Incompetence

Like the participants in the original study (Kelly, 2017), many agreed that they had been bewildered by finding out that many doctors and nurses could not use their devices. Of those that stated that they could, a further proportion did not seem to use an aseptic technique, thereby putting participants at serious risk of infection. Patients with CVADs are often aware of the potential complication of catheter related bloodstream infections (CRBSIs) and subsequently live with this fear during the time the device is in situ (Ritchie,Kelly, Moss *et al.*, 2015).

Ritchie, Kelly, Moss *et al.*, (2015) showed that patients took a 'defensive stance' when HCPs working with their devices appeared incompetent. This was done as an act of self-preservation, with patients fearing that their device might become infected because of the actions of the HCPs. Similar findings were discovered in a study by Alpenberg, Joelsson and Rosengren, (2015). Patients in this study described feelings of insecurity and concern about potential complications resulting from incompetence of staff caring for their devices. Mutti *et al.*, (2016) also highlighted the lack of competence in staff managing TIVADs.

Perhaps for some this may have been the first time that trust in doctors and nurses was lost. Hall *et al.*, (2001p.615) characterise trust as '*the optimistic acceptance of a vulnerable situation in which the trustor believes the trustee will care for their interest*'. Rolfe, (2015) adds that trust is fundamental to doctor – patient relationships and Guffey and Yang, (2012) showed that patients who trust experience greater satisfaction with their treatment.

The participants here experienced the opposite of this, which led many of the participants in this survey taking matters into their own hands. To prevent anyone else from touching their device they learned to manage devices themselves. On the positive side, engendering personal accountability and ownership of health issues is entirely coherent with the current policy drive towards self-care and management (Calderwood, 2017). However, this agenda presumes partnership, collaboration and trust, not self-preservation born of necessity.

Recommendations for practice

To improve the experiences of patients with CVADs. Care and maintenance training should be mandatory and introduced into nursing and medical staff education programmes. We are aware that vascular access care and 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). This is further evidenced when coupled with an eLearning element (Hainey, Green, & Kelly, 2016). It is acknowledged that all HCPs may not be able to maintain competence and therefore the development of dedicated vascular access champions for clinical areas could also be considered.

The introduction of vascular access specialist teams for both device insertion and maintenance could also improve the experiences of patients living with a CVAD (Carr *et al.*, 2018). Herring (2017) suggests that healthcare facilities should consider dedicated specialist vascular access teams to insert, maintain and care for VADs. This strategy could potentially increase patient safety and reduce CRBSIs. In fact, Johnson et al (2017) reported a decrease in expenses and increased efficiency, quality of care, patient satisfaction, and improved patient outcomes when specialised registered respiratory therapist and line teams where employed to maintain VADs.

Finally, empowering patients to self-care should be encouraged. According to Møller and Adamsen, (2010), self – care of CVADs increases patients independence from HCPs and supports perceived self – efficiency and control.

Conclusion

Previous literature had suggested that participants accept having a CVAD, with the main attraction being a reduction in repeated painful cannulation (Sharp *et al.*, 2014; Alpenberg, Joelsson and Rosengren, 2015; Song and Oh, 2016; Parás-Bravo *et al.*, 2016). However, this study found the opposite to be the norm. Although it was true patients accept the device, it showed that painful, repeated attempts at cannulation persisted despite possession of a device designed to reduce it. It showed that the majority experienced incompetence in HCP, and led many to take matters into their own hands to prevent device complications. The findings of this study support and strengthen the original findings (Kelly, 2017) by showing consistency of experience across an international sample of patients living with CVADs

Limitations of Study

This was a small, self-selecting sample of vocal participants. We had hoped for more responses, given there were thousands of members of these online fora. However, of those that responded, the agreement with the findings was extremely strong. A related issue was that the majority of the respondents were from USA, a group 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. Nevertheless, it would be useful to repeat this study in a larger sample if possible. Finally, only a selection of the text responses was given here due to space restrictions, and so the authors could be criticised for selecting quotes consistent with their agenda. We can only assure readers that this was not the case, and we believe a representative selection of quotes was selected for publication.

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We would like to thank all participant who gave up their time to share their experiences of living with a vascular access device. PoTS is a dysfunction of the autonomic nervous system that primarily affects heart rate and blood pressure. The abnormal increase in heart rate happens after sitting or standing up. Typically, the sufferer experiences dizziness, fainting and other symptoms (Low, 2014). Other members of the have Myalgic encephalomyelitis / chronic fatigue syndrome (ME / CFS), fibromyalgia, Ehlers-Danlos syndrome (EDS) (a group of genetic connective tissue disorders) and Medium – chain acyl-CoA dehydrogenase (MCAD) deficiency. These syndromes are often treated with IV fluid administration hence the requirement for long – term venous access.

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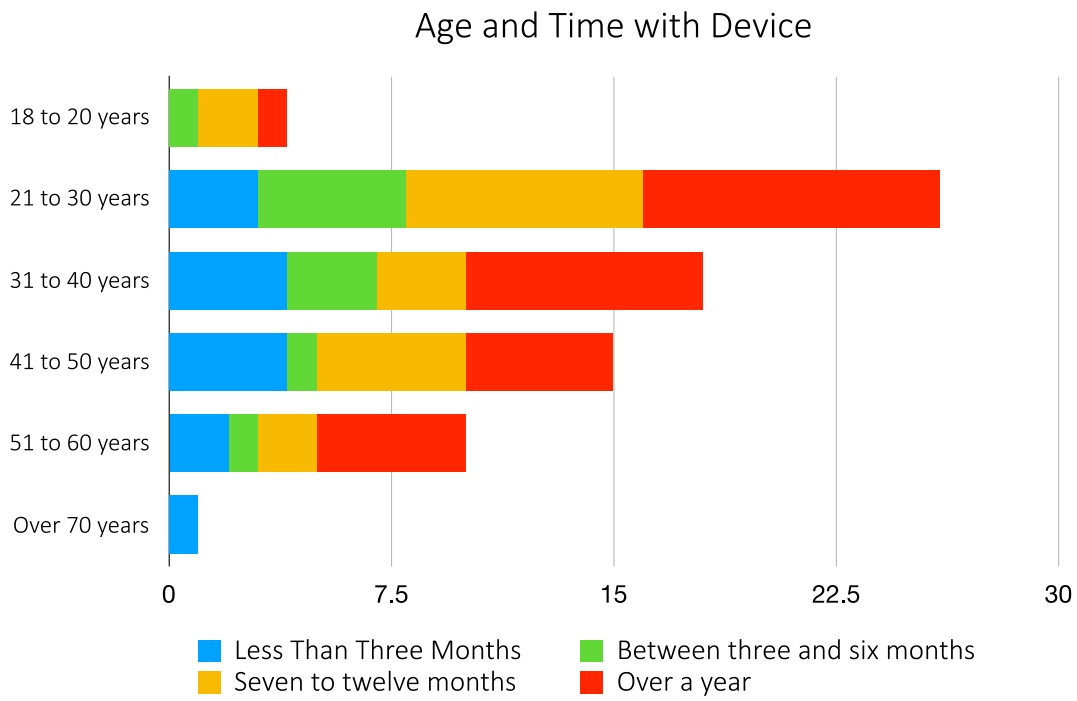

Figure 1. Age group and time with device

Inclusion Criteria	*Exclusion criteria*
• Adults aged 18 or over • Currently has a PICC, TCVC ***or*** TIVAD in place ***or*** • Has had a PICC, TCVC ***or*** TIVAD within the past three months • Device in place for any type of treatment • Patients with the capacity to provide consent	• Children under the age of 18 years • Inability to read the English language • Patients without the capacity to provide consent

Table 1: Inclusion / exclusion criteria

Peripherally Inserted Central Catheter (PICC)	19
Totally Implanted Port (Port, Portacath, Implanted port)	45
Tunnelled Catheter (Hickman type, Broviac type)	10

Table 2. Type of device reported by respondents