


# Exploring Perceptions of Education for Central Venous Catheter Care at Home

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## Abstract

Pediatric oncology patients with an external central venous catheter (CVC) in situ can be discharged from the hospital. Caregivers are expected to learn how to care for the CVC prior to discharge while also dealing with their child's new cancer diagnosis. This study aimed to evaluate the perceptions of a CVC education program received by caregivers to identify opportunities for improvement. A qualitative study was conducted in 3 stages, using an evidence-based co-design approach, involving caregivers and one adolescent patient discharged from the British Columbia Children's Hospital Oncology/Hematology/BMT inpatient unit. Stage I involved semi-structured interviews to gain feedback on the existing CVC education program. In Stage II, educational resources were updated or developed and implemented. For Stage III, the revised CVC education program was evaluated through a focus group and semi-structured interviews. Interview transcripts were analyzed using QSR NVivo<sup>®</sup>. The original CVC education program was overall well received. Repeated instruction and support provided by nurses was reported to have increased confidence with performing CVC skills. Participants appreciated the multimodal approach to meet learning needs and expressed interest in additional visual aids. Inconsistencies in nurses' practice and offers of "tips and tricks" were identified to be challenging for caregivers while learning a new skill. Videos depicting CVC care were developed to provide an additional visual tool, decreased inconsistencies in care, and support to caregivers at home. Caring for a CVC at home is challenging and overwhelming for caregivers. A standardized multimodal education program is required to support caregivers at home.

## Keywords

central line care, education, evidence-based practice (EBP), oncology/hematology nursing

## Introduction

Continued advancements in pediatric cancer care have made it possible for some treatments to be provided in the ambulatory setting (Flury et al., 2011). Ambulatory treatment can have a significant positive social impact on families by facilitating care at home, or in a home-like environment, during cancer therapy (Flury et al., 2011). It can also reduce the separation between caregivers and siblings of children with cancer (Aburn & Gott, 2014). While reduced inpatient hospitalization can benefit families, it also increased the burden on caregivers to provide essential medical care outside of the hospital setting (Flury et al., 2011).

The majority of pediatric patients receiving cancer treatment require insertion of a central line for safe delivery of intensive chemotherapies, frequent blood transfusions, and supportive care medications (Rinke et al., 2013). A proportion of these patients have an external central venous catheter (CVC) which requires routine maintenance. Thus, caregivers are expected to learn how to care for CVCs at

home, or in a home-like environment. Caregivers receive the required education during their first inpatient admission and are expected to achieve skill mastery to prevent complications, including central line associated bloodstream infections (CLABSIs) (Altounji et al., 2020).

Bloodstream infections associated with the care of the CVC can be a significant source of morbidity and mortality for pediatric oncology patients and can result in readmission and/or prolonged hospitalization (Altounji et al., 2020). Wilson et al. (2014) estimated the cost of a CLABSI to be up to US\$70,000 for children with

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cancer and require 21 extra days in hospital per patient. Rinke et al. (2013) found that ambulatory CLABSI rates in pediatric oncology patients are almost 3 times higher than those in the inpatient setting, with 13% of these patients requiring intensive care support. Therefore, it is critical for caregivers to receive effective education to ensure mastery of CVC skills. Moreover, quality improvement efforts targeted at standardizing central line care and CVC education for caregivers can lead to a significant decrease in ambulatory CLABSI rates (Drews et al., 2017).

It is well documented that the diagnosis of childhood cancer is overwhelming (Aburn & Gott, 2011; Dobrozsi et al., 2019). Patients and caregivers receive complex information related to diagnosis and treatment while processing feelings of uncertainty, loss of hope and potential loss of life (Aburn & Gott, 2014). The first discharge to home after diagnosis is a step into uncertainty (Aburn & Gott, 2014; Flury et al., 2011). This milestone is characterized by families as both joyous and overwhelming (Flury et al., 2011). Caregivers are challenged with several new tasks including medication administration, management of side effects, and ongoing assessment of life-threatening complications such as fever (Flury et al., 2011; Haugen et al., 2016). A Delphi panel indicated that 97.7% of experts considered CVC education mandatory prior to the first discharge to home (Haugen et al., 2016).

Maintenance of CVCs at home can be a source of anxiety for caregivers if adequate education and support are not provided prior to discharge (Heiser Rosenberg et al., 2017). Caregivers have reported feeling unprepared to provide central line care at home and felt their readiness to perform the technical skills at home was overestimated by hospital providers (Heiser Rosenberg et al., 2017).

Recognizing that caregivers must be given high-quality, evidence-based, standardized CVC care education to decrease the patient's risk of a CLABSI, we wanted to gain better insight into the CVC education provided to caregivers. In order to make informed changes, we set out to evaluate patient and caregiver perceptions of our current CVC education program and identify opportunities for improvement.

There is evidence to support the approach of using registered nurses (RNs) for CVC education as a reasonable and practical method of educating families. In their literature review, Aburn & Gott (2011) identified that nurses involved in direct patient care are perfectly positioned to facilitate the discharge process. However, there are challenges with this approach as it can be difficult to maintain the consistency and quality of patient and caregiver education when involving multiple nurses. It is also recognized that a key worker involved in the discharge process is advantageous and avoids prolonging the discharge process (Aburn & Gott, 2011). Wolfe (1993) supported the idea of having one assigned role to provide education and recommended that specially

trained nurses, such as a discharge nurse, may be a more effective means of educating families. There are different philosophies on the most appropriate method of facilitating education at discharge for families (Aburn & Gott, 2011). Aburn and Gott (2011) have concluded that there is a lack of research into the practice of managing family education.

In British Columbia (BC), Canada, there is limited support for home care nursing to assist in CVC care for pediatric oncology patients. RNs working on the Oncology/Hematology/BMT inpatient unit at BC Children's Hospital (BCCH) provide caregivers with the training required to become skilled and competent in CVC care and maintenance. Caregivers must master these skills prior to discharge as they are required to perform these skills independently at home.

When a pediatric oncology patient is admitted for diagnosis and start of treatment, RNs deliver a multimodal CVC education program to the caregiver for each of the CVC maintenance procedures required at home. This includes dressing changes, cap changes, and heparin locking. The caregiver is taught each skill and observed by a nurse a minimum of three times. The caregiver utilizes a Chester Chest™ manikin for practice. The caregiver is then observed while performing these skills on the child. The RN is responsible for signing off that teaching has been completed using the CVC teaching flowsheet. Families are also given a booklet to take home with step-by-step instructions and pictures of each skill. Given the nature of shift work and fluctuating schedules in the nursing profession, caregivers may receive education from multiple RNs during their initial hospital admission. The discharge planning nurse reviews principles of CVC care with patients and caregivers before discharge to ensure all procedures have been taught and that all appropriate home care CVC supplies have been provided.

## **Study Objectives**

The aim of this study was to evaluate caregivers' perceptions of a CVC education program in order to improve education and enhance the provision of safe and competent CVC care at home.

## **Methodology**

This descriptive study design is based on experience-based co-design (EBCD). EBCD was developed as a participatory action research approach based on design theory, in an effort to improve healthcare services in the United Kingdom (Donetto et al., 2015). The EBCD approach is divided into stages involving patient, caregiver, and staff experiences and allows for rapid improvement over approximately 9-12 months (Donetto et al., 2015). This methodology allows caregivers and staff to reflect upon their

experiences and work together to identify areas requiring improvement, implement changes, and reflect upon the outcomes (Donetto et al., 2015). While EBCD traditionally involves 6 stages, this study was conducted in three stages:

### Stage I—Evaluation

An evaluation of the CVC education program provided to caregivers was initiated in Stage I. The goal of this stage was to determine how caregivers were being taught CVC care prior to discharge from hospital and explore caregivers' perceptions on what could be improved. Data were gathered via semi-structured interviews and analyzed to identify key themes. The questions posed are found in Table 1.

### Stage II—Implementing Changes to CVC Education

Based on participant feedback, a plan was developed to improve current educational resources and create additional modes of delivery. Over the course of 1 year, the content was created or revised, and the improved CVC education program was implemented.

### Stage III—Evaluation of Revised CVC Education

The goal of Stage III was to evaluate the revised CVC education program. Participants interviewed in Stage I were invited to take part in a focus group. The questions posed in the focus group are found in Table 1. Data were also gathered via semi-structured interviews from the second cohort of caregivers who had only received the new revised CVC education program.

## Participants

Participants recruited to this study represented a convenience sample of caregivers who had been discharged home from BCCH Oncology/Hematology/BMT inpatient unit after receiving CVC education. Adolescent patients who performed their own CVC care were also eligible to participate. Participants were required to have received CVC education within the previous 2 months to enable accurate recall of their education experience. Participants were also required to have been discharged from the hospital for a minimum of 10 days to ensure there had been an opportunity for the caregiver to care for the CVC outside of the hospital. The discharge planning nurse assisted in identifying appropriate patients and caregivers for recruitment into this study. Caregivers were approached by a research nurse who explained the study and gained consent for participation.

All participants from Stage I were approached to be a part of the focus group in Stage III. A convenience sample of staff was also recruited to participate in the focus group. The second cohort of caregivers interviewed in Stage III met the same criteria as the Stage I cohort and had received the revised education model. Participant demographics are presented in Table 2.

This research protocol was approved by the University of British Columbia Children's and Women's Research Ethics Boards.

## Data Analysis

Interviews and focus groups were audio-recorded, reviewed, and transcribed by the principle investigator of this study. The transcripts were reviewed for accuracy against the audio recordings. To prevent researcher bias, the study team reviewed the transcripts independently to

**Table 1.** Questions Posed to Participants.

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#### Questions posed in Stage I interviews

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1. Can you tell me about the information you received to assist you to take care for your child's CVC at home?
2. Was enough information provided to you to care for a CVC at home?
3. Was there any other information or tools you believe might have made caring for a CVC at home easier?
4. What was the most helpful piece of information you received about caring for a CVC at home?
5. What was the least helpful piece of information you received about caring for a CVC at home?

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#### Questions posed in Stage III focus group

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1. What are your thoughts on the new process for CVC education?
  2. Do you feel your suggestions resulted in change?
  3. Was there anything you wish we would have included as part of this change?
  4. What would you see as further improvements?
  5. How did you feel about your involvement in the process?
  6. Any other comments?
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**Table 2.** Participant Demographics.

	Stage 1 interviews	Stage 3 focus group	Stage 3 interviews
Participants	8 mothers 1 father 1 patient	3 mothers 1 patient 2 registered nurses 1 media services	3 mothers 1 mother and father
Age of patient	5 months-18 years (Mean = 7.2 years)	(Data not obtained)	18 months-13 years (Mean = 6.6 years)
Type of central line	8 Hickman 2 PowerLine	(Data not obtained)	3 Hickman 1 MedComp

**Table 3.** Identified Themes.

Theme	Description of codes	Example quote
Demonstration	Reference to the demonstration portion of CVC education	"I don't know if it's just me but visual is the best way ...it's easier to see someone do it and then I can just do it." (Stage I—Participant 4)
Repeated practice	Reference to repeated practice or repetition of skills	"Overall it was pretty informative and just having someone go over the steps with me and watch me do it and tell me if I'm doing it right or wrong. The repetition really helped." (Stage I—Participant 10)
CVC booklet	Reference to use of education booklet depicting steps of CVC care	"Giving the booklet was the most helpful tool because it just had everything explained out. And often when you see it done, it's all well and good, but then when you get home and just blank. So the book was a key piece." (Stage I—Participant 9)
Video	Reference to use of a video	"There are TV's that are in the room so maybe a DVD or video to see it in demonstration might be possible." (Stage I—Participant 1)
Different steps/tips/tricks	Reference to nurses having different ways of doing CVC care or providing tips or tricks	"... that was confusing because I wasn't sure which way to do it from nurse 1 or nurse 2. It was slightly different every time." (Stage I—Participant 3)
Fear, stress, and anxiety	Reference to feelings of fear, stress, and anxiety	"I think that when you're getting the package on how to do it, it's quite overwhelming and scary." (Stage I—Participant 2)

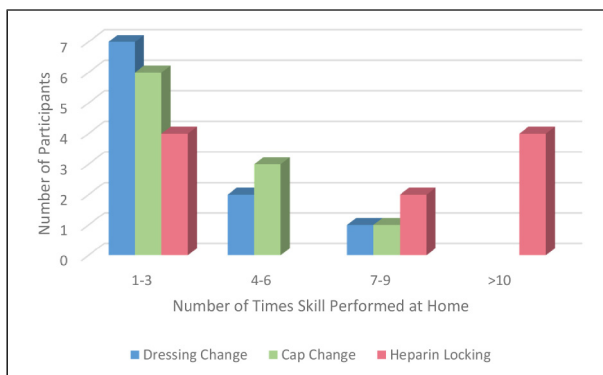
analyze the data and identify key themes. The team then came together to validate initial findings, discuss themes, and ensure that an accurate representation of participants' views were being presented. Transcripts were then uploaded into the QSR NVivo<sup>®</sup> qualitative analysis software. QSR NVivo<sup>®</sup> enabled the identification and application of keywords, known as codes, following an inductive coding process. This process expanded understanding of the data and refined the themes. A summary of the themes with descriptors and associated quotes are included in Table 3.

Data collection and analysis occurred on an ongoing basis throughout the project.

## Results

### Stage I—Evaluation

Participants in Stage I ( $n=10$ ) included 9 caregivers (8 mothers, 1 father) of pediatric oncology patients between



**Figure 1.** The number of CVC skills performed by the participants prior to the interview.

5 months and 19 years of age and one adolescent who performed their own CVC care. The CVCs accessed at home were the BARD HICKMAN<sup>®</sup> (80%) or BARD POWERLINE<sup>®</sup> (20%). The number of CVC skills

performed by the participants prior to the interview is presented in Figure 1.

**Themes: Demonstration and Repeated Practice.** All participants who accessed CVCs had been educated by BCCH RNs. The majority of participants reported that nurses followed the current hospital CVC education program. All participants described the RN providing demonstration of CVC skills and spoke to the value of demonstration and the hands-on training aspect of the CVC education program. Demonstration of skills on a Chester Chest™ was reported by 90% of the participants, while 50% noted performing skills on the patient with the nurse present. Repetition of education and skills, along with the hands-on practice, was reported to have increased confidence when performing CVC care. Having the nurse present to guide and support the learner allowed for the individual to gain mastery and confidence in performing the required skills.

... the most helpful was the detailed lesson from a nurse where she had lots of time and we were able to ask lots of questions. Also, doing it in the hospital under the nurses supervision gives you confidence as well because they're checking to make sure you're doing it right.—Stage I Participant 8

**Themes: CVC Booklet and Video.** Most of the participants (80%) mentioned the CVC booklet during their interview. While some found it helpful, others reported it did not meet their learning needs for a visual representation of skills. Many of the participants suggested more encompassing visual aids to enhance the educational program. Having a video accessible at home was specifically mentioned by 40% of the participants.

The pamphlet was pretty good. There are TV's that are in the room so maybe a DVD or video to see it in demonstration might be possible ...—Stage I Participant 1

A how-to video with a nurse and parent doing it together and explaining it ... less words and more visual would help a lot of parents.—Stage I Participant 4

**Theme: Fear, Stress, and Anxiety.** A common theme that emerged during our data analysis phase was the fear and anxiety surrounding caring for a child's CVC at home. Participants expressed that learning how to care for a CVC at home was stressful and overwhelming.

... when you're getting the package on how to do it, it's quite overwhelming and scary. When I went home I was worried that I didn't get it in the right order and I felt in those first few weeks it was quite frightening.—Stage I Participant 4

**Theme: Different Steps/Tips/Tricks.** In total, 60% of participants discussed how nurses provided different approaches to care for CVCs. Of those, most described the different approaches as confusing and not helpful as it was difficult to know which was the "right way" to care for the CVC. Participants suggested that it would be less stressful and complicated if all the nurses followed the same guidelines and teaching strategies.

If the nurses were all on the same guideline it would have been easier. They all did it different. They all had their own ways, "it's easier to do it this way" or "I find it easier to do that" but if you're not a nurse it's not easier by any means ...—Stage I Participant 5

Overall, caregivers were satisfied with the education received but identified gaps in our CVC education program, which we aimed to address in Stage II.

### Stage II—Implementing Changes to CVC Education

Strengths and challenges of the CVC education program were acknowledged by the study team. A plan was put in place to revise the education materials and create additional content based on participant feedback. Central to the development of a revised education program was the creation of videos depicting care of the CVC. Two sets of videos were developed, one series intended for caregivers and another series for RNs. The videos for caregivers were created to provide an additional visual aid and an accurate, standardized depiction of the skills they were expected to perform at home. The aim of creating videos for nurses was to provide consistent CVC education to RNs, standardize the in-hospital care provided by RNs, and decrease the inconsistencies that caregivers would witness. Video scripts were written based on updated, evidence-based procedures and were reviewed by a health literacy specialist to ensure they were at an appropriate literacy level.

Caregiver videos were posted on a hospital television system available in each patient room for ease of access throughout the patient's hospital admission. They were also uploaded to YouTube to ensure they were accessible outside the hospital setting. The videos for nurses were posted as an unlisted playlist on YouTube, linked in hospital central line procedures and incorporated into the central line education workshop required for nurses upon hire to the hospital.

To further improve the CVC education program, updates were made to the CVC booklet to add clarity to steps required for each skill. Weblinks and quick response codes were also added to the booklet to provide easy access to the videos on YouTube. An existing CVC teaching flowsheet used for tracking the progress of CVC education was updated to incorporate the videos as the first step for all caregiver teaching.

Once all the educational content and videos had been developed, the findings from Stage I and the revised CVC education program were shared with nurses. The rationale was provided for the changes and development of new content. We provided education to nurses on the new education program with an emphasis on supporting nurses with how to best teach CVC care to patients and caregivers, including minimizing the “tips and tricks” they offered during CVC education. Education was delivered through daily staff huddles, formal electronic communication via email and demonstration of how to access the videos on the patient televisions. Nurses were encouraged to provide teaching in conjunction with the booklet and videos to ensure caregivers witnessed consistent practice. The importance of repetition was highlighted and reflected in our revised CVC teaching flowsheet documentation. Nurses responded by expressing their understanding and commitment to discontinue the practice of offering “tips and tricks,” and to use the caregiver videos to promote consistency in teaching. All staff members were shown the nursing videos and a separate YouTube playlist was created for ease of access outside the hospital. In addition, the nursing videos for CVC care were added to online policies and procedures, which made them readily available for reference and ensure consistency in practice not only in oncology but throughout the hospital.

### Stage III—Evaluation of Revised CVC Education

Following the implementation of the revised CVC education program, participants were recruited for the focus group and semi-structured interviews to evaluate the new and updated materials.

The focus group ( $n=7$ ) included 4 participants from Stage I, 2 RNs, 1 member of Media Services, and a moderator. Two of the study investigators were observers of the session. Semi-structured interviews were also conducted with the second cohort of participants ( $n=4$ ) who had only received the revised CVC education program. Participants were introduced to the revised CVC education program prior to providing feedback.

**Theme: Video.** All of the caregivers reported a high degree of satisfaction with the videos stating they believed it would be, especially, helpful to have access at home and have the ability to stop, start, rewind, or play in slow motion. One participant mentioned that the video helped to create a “gold standard” for what CVC care ought to look like.

[The video] will be especially helpful for new parents ... I know there are a lot of parents that go home really quickly and I can see having the video but I can see how this would be really helpful at home for parents. Kind of like a safety net .... I can see this video being very useful. The fact that you can stop and start it when you want to ...—Stage III Focus Group Caregiver 2

The RNs participating in the focus group described how they found the videos to be a valuable tool for CVC teaching.

I think it is brilliant to have [videos], we all go to nursing school in different places, and while we do get an orientation and teaching here, we may have been taught how do things a little bit differently ... to have a streamline approach and to be able to watch it and to have it all consistent I think is helpful ....—Stage III Focus Group Nurse 1

**Theme: Different Steps, Tips, and Tricks.** Participants also reported that nurses tried to help caregivers with CVC care by sharing their “tips and tricks.” While the participants recognized the nurses did this in an effort to share their expertise, participants expressed that it was overwhelming when trying to learn a new skill.

... the thought of caring for your child, because you are already so vulnerable in the spot that you are in ... the whole process in the beginning to so overwhelming too so then to add on this is my little tricks it is like, I don't need any of the tricks right now.—Stage III Focus Group Caregiver 2

The RNs in the focus group mentioned how valuable it was to learn that caregivers found the different approaches and “tips and tricks” confusing rather than helpful.

I remember hearing that parents found it confusing when the nurse would teach their little tricks so I can [understand] if every nurse did that, it would be confusing. And you think you are being helpful but ... hearing that feedback it is so nice to hear and be able to think about it and realize yes of course that is going to be confusing when every nurse tells you something different. It was great to get that feedback.—Stage III Focus Group Nurse 1

**Further Improvements.** Interestingly, all participants in Stage III suggested the creation of troubleshooting videos, in addition to the new videos they were shown. Participants expressed that it would be helpful to have a video that describes what to do when something does not go according to plan when caring for a CVC. This may suggest that caregivers may be too overwhelmed to receive “tips and tricks” with initial education, but also require guidance on troubleshooting CVC care when at home.

One caregiver also shared their challenges with demonstrations and practice on Chester Chest™ as their child had a different line than the one represented on the manikin.

When asked what was most helpful about CVC education, 30% of participants mentioned the instruction on

maintaining aseptic technique. It was evident that these caregivers understood the importance of maintaining aseptic technique in caring for their child's CVC.

Participants in this study also reported that they were happy to provide feedback to the study team and that their participation was worthwhile as their suggestions were heard and taken into consideration.

Yes well you have the videos now ... So yes, I think listening to our feedback and making these videos is so much better. I mean we are done with it now but I know it will be helpful [for future caregivers].—Stage III Focus Group Caregiver 1

## Discussion

The CVC education provided to caregivers was overall well received. Participants reported satisfaction with the multimodal CVC education program. There were discrepancies in the preferred approach which highlights the need for differentiated instruction and the importance of learning through multiple modalities. Providing caregivers with various ways to access content can improve learning, as being exposed to multiple modalities is an effective way to boost memory and understanding (Hattie, 2011). Based on the feedback and qualitative data received, all existing elements of the CVC education program were deemed to be relevant; thus, the focus of the intervention was to enhance current content, maintain consistency, and develop additional modalities that would support caregivers beyond their hospital stay.

The videos created a clear standard of care and provided a visual representation of what was required from the caregivers. Making the videos easy to understand and access was key in supporting caregivers' learning. By posting the videos on the hospital television system, patients and caregivers could review the skills throughout their hospital admission at a time that was convenient to them, not only the time that was convenient for the RN. Accessibility of the videos outside of the hospital was also crucial to supporting caregivers who may want to review the videos prior to performing a skill for the first time at home.

While patients with a BARD POWERLINE<sup>®</sup> represented 20% of our study population, it was recognized that it was not adequately visually represented in the CVC education materials provided to caregivers. Some of the CVC care for the BARD POWERLINE<sup>®</sup>, such as heparin locking and cap changes is the same; however, dressing changes are different. We are unable to easily adjust Chester Chest<sup>™</sup> manikin to demonstrate a BARD POWERLINE<sup>®</sup>, which led to the creation of a separate dressing change video for this specific central line. Adding a visual representation of care required for this specific type of CVC may help caregivers to perform the skills they are not able to simulate on the manikin.

Given the feedback on the varied CVC practices by RNs, it was essential to create separate CVC videos for the nurses, both to provide a visual representation to support various learning styles and to standardize CVC care in-hospital. It is important to highlight that at BCCH, CVC care in hospital differs from CVC care at home, hence there is a need for a separate set of videos for health care providers. The videos are now the first tool used for CVC education with new hires. It is hoped that the creation of step-by-step videos representing evidence-based practice for in-hospital CVC care will limit the variations in practice, lead to less confusion, and more consistent caregiver education. In addition, the use of direct feedback from participants was a key driver for change when appealing to nurses to provide consistent CVC care and education.

The key role that nurses play in providing CVC education to caregivers and patients was recognized, as there was the need for consistency, repetition, and caregiver support. The support from nurses was also crucial in assisting caregivers during a time after diagnosis, that is particularly stressful and overwhelming. The fear and anxiety when learning to care for a child's CVC at home was evident in the interviews and focus group. Participants articulated the overwhelming nature of the early days in treatment following a diagnosis of cancer. While nurses may be aware of how overwhelming a new diagnosis of cancer is, acknowledgement of the extra burden placed on caregivers to provide medical care to their child is important. Moreover, the provision of adequate resources and educational resources is necessary, with the recognition of the difficulty caregivers might have in absorbing the information under stressful conditions.

While caregiver confidence in performing CVC skills was not measured pre- and post-intervention in this study, it would be worthwhile to do in future studies aimed at improving caregiver education. Moreover, increased caregiver competence in performing CVC skills could theoretically assist in decreasing CLABSIs associated with central line care provided in the home. As discovered in this study, many of the participants mentioned how the education about maintaining aseptic technique was crucial to CVC care. These caregivers clearly recognized the importance of aseptic techniques in caring for their child. This speaks to the significant opportunity nurses have to teach and enforce effective CVC care in an effort to reduce CLABSIs. As such, it would be of benefit to measure outpatient CLABSI rates pre- and post-intervention in the future.

Critical to the success of this project was the feedback provided by the patient and caregivers. Their input was valued, guided revisions of the CVC education program, and provided a rationale for changes. Use of the EBCD participatory action research approach ensured that patients and caregivers would be included as partners in this quality

improvement initiative. As previously mentioned, a true EBCD cycle would have included 6 stages: (1) project set-up; (2) obtaining staff experience; (3) obtaining patient and caregiver experience; (4) focus group with patients, caregivers, and staff to review an edited film of patient narratives; (5) co-design of changes to process; and (6) event to review and celebrate (Donetto et al., 2015). A modified EBCD approach was used for this study, with focus placed on project set-up, obtaining patient and caregiver experience, making changes to the CVC education program, and conducting a focus group with patients, caregivers, and staff. The focus group also served as a celebratory event for participants, staff, and investigators to recognize participants' contributions to the revised CVC education program. These stages were selected to emphasize caregiver input while expediting changes. Use of all 6 stages of the EBCD approach would be of value in the future to capture additional staff experience and to engage participants in co-designing changes to the process being improved.

## Limitations

We recognize that this project has several limitations. It was conducted on a single unit of an academically affiliated tertiary hospital using a convenience sample of participants, which limits generalizability. Our participant population was quite homogeneous with an over-representation of mothers and English-speaking caregivers. We must also highlight the cost and staffing resources associated with the creation of videos. Production of the videos including editing, voice-over recording, and paid actors totalled approximately US\$9,000. Access to funds may be an obstacle for the integration of video resources in caregiver education in other settings.

Currently, there is no standard data collection on ambulatory CLABSI rates as it is difficult to determine what is acquired during line care at home or acquired during an encounter in the ambulatory setting. Our institution also underwent a change in our blood culture collection guidelines during this study. The change in blood culture collection guidelines was successful in increasing test sensitivity; however, it also contributed to a higher CLABSI rate recognized within our patient population. Comparison of pre- and post-intervention CLABSI rates would have been confounded.

## Future Research

An important avenue for future research is the importance of assessing the capacity of patients and caregivers to receive CVC education. Typically, education materials have been aimed at caregivers, missing the opportunity to empower patients in their central line care. Effective patient and caregiver education must include an assessment

of patient and caregiver literacy, preferred language, learning style readiness to learn as well as physical and psychological health (Rodgers et al., 2016). This should be included in future research.

Discharge teaching varies based on the teaching abilities of direct care nurses (Tang et al., 2019). Future research should also look at the teaching skills of nurses providing CVC education, including their ability to assess learning needs and health literacy levels of patients and caregivers. In order to provide culturally competent care, we would like to translate these videos into several other languages. We would also like to develop an evidence-based education pathway for newly diagnosed hematology/oncology patients by streamlining resources and ensuring role clarity among the multidisciplinary team. It is our hope to have all facets of new diagnosis teaching consistently documented and eventually captured in the online health record.

## Conclusion

Exploring perceptions of CVC education programs allows for tangible improvements in the education provided and the provision of safe care. It is possible to take steps to streamline the education received by caregivers and patients and improve the consistency of information provided while in hospital. By incorporating caregiver feedback, creating visual aids, and a consistent teaching approach, it is possible that caregivers can feel more confident and less overwhelmed when performing CVC procedures after discharge from the hospital.

This project also empowered patients, caregivers, and nurses to be involved in research and to recognize the direct impact research has on patient care. In future, we hope that this will continue to have a positive impact on the consistent safe and competent CVC care provided by both nurses in the hospital setting and caregivers at home. We hope that this improved care will translate into a reduction in our CLABSI rates in our pediatric hematology/oncology patients.

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## Declaration of Conflicting Interests

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